Accompanying Them Home: The Ethics of Hospice Palliative Care

Monika Anne Wilson
BSocSc BAHons MCouns

Humanities Research Program
Queensland University of Technology
Brisbane, Queensland
Australia

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To Margo, whose courage and tolerance inspired me,
To Reg, whose kindness and bright blue eyes I remember.

To Lyn, whose self changes in the face of death give new meaning to the
concept of self transformation,
To Chris, whose concern for others will serve as a constant reminder.

To my father, Clive, for his gifts and his quietness,
To Lainie, who reconfirmed the power of story for me.

Watching, being with, and witnessing your deaths have humbled me,
Your stories show that leaving can be painful and miraculous too.
Abstract

This inquiry, which employed a narrative research approach, critically explored the ethical dimension of hospice palliative care. Hospice palliative care is the profession specifically developed to care for the dying. The development of this practice has grown significantly since the 1980s in Australia, yet ethical inquiry into this professional practice has largely focused on particular issues, problems or dilemmas, such as euthanasia. Although particular ethical issues are important considerations, a broader investigation of the ethics of hospice palliative care practice has not been given sufficient consideration in the growing accumulation of the research literature in Australia. Jennings (1997) surmises that “systematic reflection on ethics in the hospice field is curiously underdeveloped” (p. 2). This study goes someway towards filling this gap. In building upon the Pallium research by European scholars and integrating a social practice framework (Isaacs, 1998) this inquiry provides an alternative account of the ethical agenda and one which has privileged an internal exploration, rather than assume that the ethics would be the same as any other health care modality or to simply adopt a dominant, principles-based approach. These internal explorations were located in the storied accounts of thirty interdisciplinary hospice palliative care professionals.

This thesis provides a thorough, textual conversation into the realm of ethical caregiving at the end of life. Several key insights were illuminated. Firstly, total care must be central to the philosophy underpinning hospice palliative care practice, but this concept and practice of total care was being eroded and contested. Secondly, a predominantly modernist account of personhood was located in the narrative accounts. This modernist account of personhood was thought to be insufficient for the practice of total care and needed to be reconceptualised. An embedded ontological account was provided which would assist with the understanding and practice of total care. Thirdly, initially it was thought that there was no common, shared understanding of the purpose of the practice. It was suggested that the profession was “wandering in the wilderness” when it came to the aim of its practice. However, the professionals did share a common telos (aim towards a good) and it was overwhelmingly relational. This led to the proposal of a new
telos for hospice palliative care practice centered on the creation and maintenance of unique relationships which would assist people in their final stage of life. Lastly, the ethical frameworks which guided practice for the professionals were presented. In these frameworks it was significant values (acceptance of human mortality, total care and honest and open communication) and relationships (how we treat each other) which played the main role in what constituted hospice palliative care ethics. An account of a hospice palliative care ethical relationship was provided which included a proximity stance of in-between. Overall, any ethic for hospice palliative care must have at the heart the relationship between professional caregiver and living-dying person. The relationships in this social practice, between each other, accompanying one another, are our ethical compass.

This thesis concluded that hospice palliative care, as a social practice, has a rich ethical dimension as understood and articulated by its professional members. These insights have resulted in the construction of a new ethical framework reflecting, formalising and adapting the ethical dimension as understood by its professional members. This ethical framework - A Relational Ethic of Accompanying - is needed to help maintain, sustain and protect the unique identity of this profession. This framework adds to the “moral vocabulary” (Jennings, 1997) and “moral specificity” (ten Have & Clark, 2002) of hospice palliative care practice. In addition, it would provide important guidance to palliateurs reflecting on how best to provide quality, compassionate and ethical care at the end of life.

Keywords: Ethics, moral, narrative, story, social practice, hospice palliative care, dying, death, personhood, ontology, living-dying person and end of life care.
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Appendix One: Statement of consent

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Abbreviations

AGDHA  Australian Government Department of Health and Ageing  
HPC   Hospice Palliative Care  
PBE   Principles-Based Ethics  
PCA   Palliative Care Australia  
REA   Relational Ethic of Accompanying  
SPF   Social Practice Framework  
WHO  World Health Organization

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Authors Declaration

The work contained in this thesis has not been previously submitted to meet requirements for an award at this or any other higher education institution. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made.

Signed:

Date:
The Living-Dying Person

Prior to getting cancer it was an ordinary, everyday life with family and working. I worked full time and cared for a family full time too. It was very busy. Everything was going along fine and then whammo! All of a sudden I was terminally ill and just not very happy about the whole affair. When I was in hospital I didn’t feel like a person. I felt like a non-event or a nuisance more than anything. Because I was in a single room and nobody wanted to come in, because of the infection. It was so severe I couldn’t wear any clothes. I was stuck in this room and I was very alone. It was the loneliest time I have ever spent in my entire life. The staff couldn’t have cared less. I was semi-naked all the time and nobody wanted to come in. I was very vulnerable. Now I just get fed up. Fed up with the fact that I’m sedentary and I think quite often about what I should be doing. Or what I want to be doing. I think a lot about the fact that I was a mum, with children to care for. And now I’m just incapable of caring for my daughter. And she needs me. I felt I did a good job as a mum and a wife, and then all of a sudden, this horrible thing happened and I couldn’t do the things that I wanted to do. Now I’m just stuck in a chair. I’d love to be able to go back to work again. To go back to work and be a whole person again, because I don’t feel like a whole person. Not a bit (Mary, cited in Wilson, 2002, p. 60).

There is no other way for me to commence this thesis, but with the voice of the living-dying person. Mary, who I interviewed in 2002, explained to me the changes in her life and self. These changes, which are encompassed in the living-dying process, are so poignantly captured in her story above. In the inquiry, Re-storying the dying self: A narrative investigation of self-identity complexities at the end of life (Wilson, 2002), I sought to understand what happens to a person’s sense of self (identity) when they found out that they were dying. It was discovered that people who are living their dying experience multiple and complex assaults, disruptions and changes to their sense of self. Mary’s words stay with me, especially the use of her descriptors; non-person and whole person. The experience of dying, and how we care for living-dying people, is at the core of this research inquiry. Even though the professional caregiver’s voice is privileged in this thesis, and the living-dying voice is not tangibly as present, the reader must understand that within each word, sentence, paragraph and chapter the concerns, experiences and respect for living-dying people are foremost. Living-dying people are the reason for this thesis. For any word that I wrote in this thesis, I think firstly of Mary or Chris or any of the number of people that I have been with as they were living their dying. This thesis is for them, and for all the people, including you and me, who will die in the future. The living-dying voice is not absent from this thesis, but rather is the silent glue, connecting and guiding each word of this thesis.
Reading this Thesis (Story)

The writer’s object is, or should be, to hold the reader’s attention. I want the reader to turn the page and keep on turning to the end (Tuchman, 1989, cited in Richardson, 2004, p. 473).

In preparation for the reading of this thesis, I would like to explain that there are some differences in this thesis, perhaps, in comparison to others. Firstly, inline with postmodern research methodologies I consider myself an integral part of this research and so I have used the pronoun ‘I’ throughout. I do not claim to be a neutral or invisible part of this body of work. As noted by Denzin (2004) the postmodern approach to research “encourages writers to put themselves into their texts” (p. 453). This is what I have done.

Secondly, the stories from the hospice palliative care professionals, perhaps known as ‘data’ in other research projects, and the hospice palliative care literature are interwoven into each chapter, rather than having a traditional literature review and findings section. Richardson (2004) encourages this “transgression of the boundaries of social science writing genres, [through] the violation of prescribed conventions” (p. 480). I have transgressed in how I have presented and constructed this thesis.

Thirdly, as I am using the concepts of narrative and story throughout this thesis, there are elements of creativity taken with this aspect. This thesis is a large story, which has been constructed with and through other smaller stories. As Reissman (1993) suggests, “in the end, the analyst creates a metastory about what happened by telling what the interview narratives signify, editing and reshaping what was told and turning it into a hybrid story” (p. 57). With this, I recognise that when people talk, whether in the spoken or written sense, their words are “closer to poetry than to sociological prose” (Richardson, 2004, p. 482). Poetry and creativity are included and valued in this inquiry.
Lastly, rather than suggesting factual, generalised findings, I offer insights and reflective statements and questions, so that there is an open ended nature about this thesis. The intention of this critical inquiry is to articulate, understand and illuminate, rather than to make grand generalisations and provide fixed conclusions. Important insights have been highlighted, as is the case with any good conversation. Like Bond (2002) declares “as a researcher I am not claiming any universal findings or ability to predict what would happen again if the same circumstances were to happen again. This research is local in every sense to the people involved” (p. 136). This ‘local’ ethics research inquiry, rather than being argumentative in tone, as traditional Western moral philosophical studies tend to be, is reflective in tone and exploratory in nature.

The creativity involved in this thesis, including the intention of illumination, makes this quote below an apt one to commence the reading of this thesis

> The experience of art makes concrete the process of the fusion of horizons. When we understand a work of art, we experience that our horizon is broadened, not by giving up our own viewpoint, nor by overpowering that of others, but by opening ourselves towards the view of others and thereby acquiring a new and richer view (Widdershoven, 2002, p. 45).

I hope you find the reading of this thesis an enjoyable and enlightening one, and one that broadens your horizon!
Monika as author, researcher, professional, human being

It is important to me to recount a small part of my own story and the stories I hold about dying, caring for the dying, and my passion about this topic. Stories, for me, are central to my understanding of self, of life and of the living-dying process. They not only provide a way of understanding the world and a way of understanding personhood, but have also provided the pragmatic requirements of structure, methodology and conceptual underpinnings for this thesis. It is through the flexibility, fluidity and power of stories that understandings of life, and life’s endings, are gained.

Story also necessarily includes the notions of voice and conversation and the purpose of articulation and illumination that this inquiry sought to achieve. I had always wanted, from the beginning of my involvement with the hospice palliative care profession, to have meaningful conversations about the changes that I perceived to be occurring within the profession, the important ethical underpinnings of the practice, and what it all meant to the people involved in this caring practice. This is what I have sought through interviewing hospice palliative care professionals and putting these conversations on paper. I have brought together the voices and stories of hospice palliative care professionals, my voice, the articulations of authors and, importantly, the voice of the living-dying person, to construct this exploratory conversation.

The program of ethics in which I am situated acknowledges the importance of, and promotes, voice (the dialogical voice, the storied voice, the historical voice, the medical voice) as being at the heart of ethical inquiry and ethical engagement (Isaacs, 2005a). In collecting and holding these voices together as conversation I have been mindful from the start about how it is that I present them in this thesis and how precious they are. I wanted to make sure that I presented them in honorable and respectful ways. Ideally, I would have liked to present the professionals’ stories in a complete format, with all the wondrous articulations included in them. That is, to be able to maintain the integrity of their stories as a whole. Unfortunately, that is not possible in an academic work such as
this. My word count would be way over! Yet, I can still honour them, but not include all of the words from their stories. So, to make up for this and to include their poetic nature, I decided to put together a poem of their words that I believe captures the nature of hospice palliative care practice as they described it to me. It is through the words and sentiments in this poem (page xxv) that hospice palliative care professionals practice each day. This is how they described their work to me; in caring the way that they do for and with living-dying people. The many understandings of home, too, have been incorporated into this thesis. This was mainly aided by the reflections of Dekkers (2001) who initially provided the reflections on the metaphor of ‘coming home’ as the goal of palliative care. I am very grateful to him for this. This was further reinforced by Kellehear (2000c) who wrote about the four houses of total care which forms the basis of hospice palliative care practice. Finally, during the period of conducting this study, I was imagining, creating and building my own home – Emsland – in which I now sit. Hence, the concept and lived reality of home became a living and breathing metaphor for this thesis.

Next I would like to provide a brief background to my interest and involvement in the hospice palliative care profession. I have had an interest in end of life care for many years now. When I tell people of this interest, many assume that I must have experienced the death of someone close, or even had a near-death experience myself, and that this has prompted my investigations. Certainly, I have met many people where this is their story – their mother or father or friend has died and this experience has caused an awakening in them, perhaps a curiosity about death or possibly a new commitment to make a difference to someone else’s dying. But this was not my story.

For me, my interest in dying and death commenced in 1996 when I attended my first in-sight meditation retreat and experienced for the first time the ‘truth’ of my being; that I was dying every second inside and that my physical body will die one day, even one day soon! Or, in other words, because I was breathing that meant that one day I would stop breathing. Once this had occurred (not in a moment, but over a period of time) I was then hungry to understand more about the process of dying, whilst we are still living;
what happens during this process and how it is that we care for living-dying people. I had not seen much of death in my life, which was amazing for a then 28 years old woman, but not really surprising as our Western society tends to hide the old, and the living-dying away from our healthy and young eyes.

What commenced from that time onward was a process of reading and gathering knowledge and insights, and learning about the process of living and dying. This is what I have done for many years now. Often, people that come to my house and see my book collection are fascinated by the number of death and dying books that I have. I have been labeled, at times, as overly obsessed with the topic, and perhaps at times I have been. But if a person in this society had that same preoccupation with birth, I don’t believe they would’ve been looked at and judged in the way that I have been.

During my undergraduate studies I commenced volunteer work in two hospice palliative care organisations and started to learn about how this team of professionals attempted to be responsive to the needs of the living-dying person and his or her family. Dame Cicely Saunders and Elisabeth Kubler-Ross both became my heroines, as well as many of the practitioners that I observed. My first volunteer shift saw me going into the home of an Australian-Asian family. The husband was dying, in a more immediate sense, and the wife and I sat together; talked, cried, and massaged his feet in the naïve hope of keeping him alive until his two sons arrived from Sydney; as if we had any control over that! Once this man took his last breath, and the family had left the room, it was just his dog and I being overawed by the whole event – the mystery, the spirituality, the subtlety and the reverence of this moment. I had been offered an experience that forever changed my life.

As I continued to be immersed in the hospice palliative care community in Brisbane through attending meetings, education sessions and so forth, my ideas grew and changed, but my commitment to studying, researching, teaching and counselling in this area grew. Parallel to this growth was my concern about the changes and direction of the hospice palliative care profession and what I believed to be the moving away from
what Dame Cicely Saunders originally intended in her concept of total care articulated in
the modern hospice movement, to what amounted to a medicalisation of the profession.

An incident with a male patient in a hospice unit, when I was a volunteer there,
prompted my first research inquiry in 2002. A dying man indicated to me that what he
most wanted was for someone to hear his account of his life. I was honored to be a
witness to this man’s story about his life and his self, and then to learn that he died a few
hours later. The research I undertook as a response to this experience was an
exploration of the identity changes and challenges for living-dying people and the
importance of stories at the end of life (Wilson, 2002). I was blessed with the
opportunity to get to know three courageous women, and one in particular who was
‘dying’ for around seven years! The findings of this research inquiry, when presented
and discussed with various groups of people in Brisbane, met with interest and
enthusiasm.

As with my previous research inquiry, this thesis, too, was prompted by an experience. I
was at an annual palliative care conference in Queensland. It was evident that the
coordinators had not gained the attendance that they had hoped for and many of the
speakers and topics were not new to our ears. There was an air of disappointment at the
event. Towards the end of the conference, in a sum up speech, one of the senior people
of Palliative Care Queensland said “Isn’t it great to see the palliative care philosophy
being practiced in so many different places!” And I simply sat there and thought to
myself - ‘Is the philosophy really being understood in a common way by everyone and
practiced this way in different settings?’ This question prompted this thesis.

Yet, with all of these wondrous experiences, of volunteering, teaching, and researching,
I still did not feel as if I was an actual hospice palliative care professional. I saw myself
as being on the outside looking in, almost the ‘objective’ researcher! That was until
2005 when I commenced the position of counsellor and education coordinator for a
small community based hospice service. This employment opportunity has certainly
affected me greatly and assisted me in the writing of this thesis. I have ‘become’ the
hospice palliative care professional that I have been writing about and so my voice has
legitimately been incorporated with the voices of the other hospice palliative care professionals.

I have documented my journey of the last seven years so that anyone reading this thesis gets a sense of who I am in relation to this research inquiry. I am not, and never could be, an invisible or objective researcher in this topic, although as mentioned above, I naively thought so at times. I am, and most likely always will be, passionate about the needs of the living-dying and the direction of the profession. To this end it is important for me to outline some of my values and personal biases in the research, so as to make my stance as a person, a researcher, and a hospice palliative care professional as transparent as possible.

Firstly, I do tend to be idealistic at times about the process of living and dying, and definitely see it as a time of opportunity and possibility – a spiritual experience which can be transformative and healing for all involved. Having this view lends itself towards a perceived glossing over of the negative and painful aspects of dying. Although the reader may perceive this in my writing, it is far from the truth. I do acknowledge the ‘messy-ness’, the tremendous loss and anguish and suffering in the dying process. My intention, however, is to attempt to balance the scales in our society about our stories of dying; that, yes, it can be horrible (the dominant story), but also it can be incredible (the silent story).

Secondly, I have intentionally omitted the ethical issue of euthanasia in this thesis. This was a concern of the faculty academics until I explained my reasoning for it. When I first started researching the ethics of hospice palliative care all I could find were articles and book chapters on euthanasia. It is the dominant issue discussed in this area. It was so dominant it was difficult to find anything other than this topic. So, for this reason alone, I wanted to offer an ethics research inquiry that did not explore issues of euthanasia, as this had already been sufficiently done. Certainly, I understand it is an important issue in the ethics of hospice palliative care, but so many other enlightening
authors have covered this topic. I wanted to offer something that was missing in the research.

Finally, I value the approach to caring for the dying as articulated by the modern hospice movement, with the original values of open and honest communication of dying, the acknowledgement of the finality of our physical existence and care that is directed towards the whole person; including the physical, social, psychological and spiritual domains. With this preference I fervently believe that hospice palliative care practice needs to be kept distinctive from medical care, but that it still needs to work side by side with medicine in our health care system. I do not hold back in my opinions about the problems that have, and still do occur, in regard to the medicalisation of dying. These problems are what prompted the hospice movement in the first place and I hear about them often from people being over-treated for a disease that cannot be cured. I am disappointed that hospice palliative care is becoming more clinically orientated, including the fact that when I go to conferences these days it is all about drug trials, symptom control and assessment tools. It is not possible to hide my concern about this. A further concern surrounds the noticeable omission of the words death and dying from the Palliative Care Australia Standards for Practice (2005). Indeed, it is concerns such as these that have assisted me in my perseverance in finishing this thesis. I do not intend to pretend otherwise in this work; as I mentioned above, I do not believe it is possible for me to be neutral in this research inquiry. But with this awareness I hope to lessen any negative effects of having these biases. I do believe that hospice palliative care practice and the experience of living and dying has been enhanced by the advancements in medical knowledge, especially when it comes to pain and symptom relief. However, my concern, like Randall and Downie (2006), is with the direction of the practice.

With these experiences, motivations, preferences and concerns all outlined, all that is left to say is that I sincerely hope that in some small way this research inquiry assists in providing a valuable conversation about the direction of the practice. The words herein have genuinely and well-intentionally incorporated the stories of the hospice palliative
care professionals in a respectful way to articulate their understanding of the ethical
dimension of hospice palliative care practice. In doing so, I hope that the insights that
have been gained by this ethical conversation can help the profession to better serve
those who are in the throes of the end of life.
Accompanying Them Home

The end of life
The final thing
An opportunity
To stay as witness
Marking what’s valuable.

Following their unfolding
And being alongside
Giving of yourself
To make precious, these final days.

Being with
Supporting and guiding
Holding and enabling
Noticing and witnessing.

Staying with
What you bring of yourself
To be responsive
To their uncovering.

Be a mirror
Nurturing as like birth
Willing and open
Intimately involved.

A state of grace
A deeply spiritual journey
Accompanying them home.

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Acknowledgements (Gratitude)

I am deeply, socially embedded. What this means is that what I do, who I am being and who I am be-coming is influenced by my connections with people. This translates into a recognition that the voices and ideas of many significant people have influenced and impacted upon this body of work. Two significant bodies of work acted as the platform for this thesis. The first one is the work and insights of David Massey and Peter Isaacs. Their assistance, through ideas, writings, feedback and support has helped me enormously. Their articulation of an alternative approach to ethics (engaged ethics) has always resonated with my preferred way of viewing the ethics of daily life.

The second is the work of a collaboration of European scholars who have explored the ethics of palliative care. Their work in the Pallium project served as a further platform from which to build this research. When making contact with these scholars, who reside on the other side of the world, two in particular showed considerable support and kindness in sending me their theses, and offering thoughts and conversations via electronic mail. I sincerely thank you, Maaike and Gert. Your generosity meant so much to me at a time of confusion and isolation. Other scholars, who have proven to be inspiring and influential include Bruce Rumbold, Arthur Frank, Howard Brody, Beverley McNamara and, most especially, Allan Kellehear. In addition, I would like to acknowledge Pam McGrath who originally provided the inspiration to become a researcher in this field.

I am also in significant relationships with the hospice palliative care men and women whose words, motivations and qualities have continued to sustain me throughout this project. These incredible men and women, who stand face to face with the concrete reality of the finality of our physical being, sustained over a period of time with continued love and compassion, have inspired me. Often when I thought I could read and write no longer, that I could not sit in front of a computer ever again, I found that it was their words that kept me going. I am so grateful for their willingness to be a part of this research project and for their honest, reflective responses. I hope, with all sincerity, that I have represented their words, thoughts and sentiments in an honorable way.
I have also been sustained over time by the memories and qualities of the people who I have accompanied on their dying journey. Their words and images, too, sustain me. When I see their grace and courage, their tears and their joy; when they touch me and I touch them, this is what keeps me going. The love and courage of family, friends and living-dying people continue to overawe me. Also, my friends and family, although often mystified by the work and processes of this thesis, have continued to love me and forgive me when I’ve cancelled outings, or not been as present for them as they, or I, would’ve liked. For all of the inspirational conversations, unconditional support and understanding, I thank you Vik, Fiona, Jen, Marie, Jai, Athena and Ros. Aside from my connections and relationships with wonderful people, I am also deeply embedded in the natural world. What this means is that my home, my beautiful sanctuary of trees, sustains me. So I thank the trees, the birds, the fungi, the sun (for providing the electricity) and rain. This haven I have, and the gifts She gives me; the interconnectedness of my spirit with nature, has helped me in times of great isolation. My animals have also played a significant role in the continuing work that is this thesis. I thank them (Mash, Midget and Mouse) for providing that special kind of companionship, during the lonely hours of writing up this thesis, which only an animal can give.

Finally, and definitely not least of all, I would like to acknowledge (acknowledge seems like an inadequate word!), my incredible partner in life, Michael, who stood beside me through this mystifying process that is a PhD. He gave of himself through ideas, often contrary, to prompt my thinking further. He tirelessly helped me with my grammar and structure, something, fortunately for me, that he is a master of. His jokes about numbers (how many words today?) both annoyed and motivated me. His meaning of support was exemplified by standing and cleaning my ideas white board for several hours so that new ideas and structures could go up. My love, my life, my husband, I thank you. I know, without any doubt, that without our conversations and your enduring love and support I couldn’t have finished this task. From the depths of my heart and spirit, I thank you all and hope that when your time comes to die you will be cared for with all the love, compassion and peacefulness that you deserve.
Part One
The Floorboards

Coming Home: To One’s Own Home
To lie in my own bed
Familiar smelling pillows
To see the wondrous and ever-changing trees
My families’ hands all around me
Their gift of love
As I drift off to a never ending sleep.

Coming Home: To Hospice
A haven of peace and safety
Welcoming people all around
Colour and gardens abound
Let us hold you till the end
And watch over your family too.
CHAPTER ONE
Introduction: Setting the Scene

The care of the dying has remained a kind of open moral wound in our health care system, bedeviling us for decades now, full of hopeful initiatives that do not quite work out (Callahan, 1995, p. 231).

Your heart is beating faster, almost visibly thumping through your chest. You can feel your hands getting wet. You feel as though someone or something is preventing you from being able to breath. The doctor in front of you is mouthing words, but no sound is reaching your ears. The only words you can hear are the ones that announced, only moments ago, that you have only a certain time left to live. Nothing else is reaching your ears anymore as you try to digest the meaning of this. Time now seems to stand still, as you look up and expect that the clock on the wall has stopped. ‘I am dying’ is the one thought that keeps spinning through your head, over and over again. How could this possibly be happening to me? Yet happen it does, everyday, for people all over Australia. Silently, and often out of the public gaze, people are dying, whether it be from a disease like cancer or a slower process of physical deterioration through aging. Dying and death are a part of life.

1. Introduction
This thesis is concerned with dying: “the life we live in that urgent space created by the awareness that death is soon to engulf us … Dying as a self-conscious anticipation of impending death and the social alternations in one’s lifestyle prompted by ourselves and others that are based upon that awareness” (Kellehear, 2007, p. 2, original italics). Specifically, this thesis is concerned with how people are cared for during this ‘space’ of living and dying, for living-dying people require compassionate and responsive care. The worth of a society is often measured by how it is that it cares for those entering life, and those who are ill, but often neglects how it is that it cares for people who are leaving life. Callahan (1995), quoted above, expresses his concern that in Western societies not enough has been done to care for people who are facing the end of their life. There is still an open moral wound in the care of the dying.
Although many of us in Western societies will turn our gaze away from the dying, and the care of the dying, there is one professional group whose commitment is to care for the dying. This professional group is hospice palliative care (HPC). This study turns the spotlight on the ethical dimension of the caring practices\(^1\) of this profession. The specialised professionals, who make up the hospice palliative care profession in Australia, have been specifically educated to care for people in the end stage of life. This inquiry asks the central question: How is the ethical dimension of HPC practice articulated and understood by its professional members? This ethical dimension is understood through the conceptual foundation of an engaged ethics approach (Isaacs & Massey, 1994) and the lens of a social practice framework (Isaacs, 1998; MacIntyre, 1981/1984, Langford, 1991). This introductory chapter provides explanations about what is hospice palliative care and the viewpoint of ethics taken in this thesis. It outlines the rationale, literature and research question and objectives for this study, including the clarification of some key terms. Finally, this chapter offers some reflections on the limitations of the inquiry and sets out the structure of the overall thesis by way of chapter summaries.

1.2 What is hospice palliative care?

I am constantly reminded when I give lectures to doctors, nurses or other professionals and discuss my work with lay members of the public, that there is still much confusion, or at least uncertainty, about what palliative care is and does. The usual questions posed are: what does it do, who does it treat, when is it used and where is it done? (Ahmedzai, 1994, p. 1).

A study into Community attitudes towards palliative care (Australian Government Department of Health and Ageing (AGDHA), 2006) found that eight in ten Australians were aware of HPC at some level, but generally did not understand it well enough to be able to explain the concept or practice to someone else (p. 1). Generally, there has been some increase in awareness of hospice palliative care since a previous study in community awareness of HPC, and that it is available, however, this increasing awareness did not equate to an increase of understanding about the end of life caring

\(^1\) This thesis consistently spells practice with a ‘c’ whether it is used as a noun or a verb.
services being offered. This introductory chapter assumes that the reader is aware of HPC, but that he or she requires some further explanations about what constitutes HPC.

People who fall ill to a disease, such as cancer\textsuperscript{2}, may commence a regime of treatments designed to assist in curing the disease. The advancements made in Western medicine mean that curative measures are often successful. Modern medicine will, in every way it can, assist a person back to a healthy physical status. If a cure for the disease is no longer possible, thus making further treatments futile, your disease could then be recognised as ‘terminal’ and HPC may be offered to assist you in the living-dying process – the last stage of your life. This is, of course, a rather simplistic understanding, as many of the definitions and ideals of HPC emphasise that this caring service can, and should be introduced much earlier in the disease process, side by side with chemotherapy and radiation therapies. That is, these treatments are often promoted to provide palliation: the easing or alleviation of symptoms and sufferings\textsuperscript{3}. The World Health Organization (WHO) (2002) definition below makes this point. This negotiation point of the when of HPC is often a complex issue. Most often, though, an ill person will be referred to a HPC service, if one is available, when they are given a six month prognosis of life left to live.

1.2.1 The definitions of hospice palliative care
Defining hospice palliative care has long been, and continues to be, a challenge. It seems, however, as though the most common definition now being utilised is the WHO (2002) definition, which states that

\textsuperscript{2} Please note that palliative care has been criticised for overly providing services to, and focusing upon, people who have cancer, rather than a broader application for people experiencing other life-limiting illnesses and those who are dying of aging.

\textsuperscript{3} The definition of palliate (palliation) has changed over the years. In its original sense palliate meant to cover with a cloak; to clothe; and to shelter. Later, it was understood as to conceal; to having its real nature concealed. This could translate into the concealment of imminent death. The contemporary definition includes the alleviation (of a disease or its symptoms) without effecting a cure; to relieve or ease (physical or emotional suffering) temporarily or superficially; to mitigate the sufferings. Palliative can nowadays be understood simply as the response of easing or alleviation of a person’s symptoms and suffering (OED, 2007).
Palliative care is 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 (p. 1).

As a further explanation, the WHO (2002) definition provides some supplementary details

Palliative care provides relief from pain and other distressing symptoms, affirms life and regards dying as a normal process, and intends neither to hasten nor postpone death. Palliative care integrates the psychological and spiritual aspects of patient care, and offers a support system to help patients live as actively as possible until death. It also offers a support system to help the family cope during the patient’s illness and in their own bereavement. Using a team approach, palliative care addresses the needs of patients and their families, including bereavement counselling if necessary. It enhances quality of life, and may positively influence the course of the illness. It is applicable early in the course of the illness with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (p. 1).

Randall and Downie (2006) suggest that the words of this WHO definition “express the deeply-rooted attitudes [and beliefs] which palliative care professionals adopt and which determine their practice; the words distil the philosophy and the philosophy directs the practice” (p. 2). Hence, this definition is taken to be the philosophy that underpins the practice and that guides practitioners in the ‘goods’ of the practice.

It can be noted that there are key points in this definition of what HPC is about, which are then common in most definitions of HPC. These key points are

- The intention to improve quality of life. The WHO statement, however, includes that it will improve quality of life, not only for patients, but for families as well. The family is the ‘unit of care’ in HPC practice;
- The terminology of a life-threatening illness is included. Interestingly, the language of ‘terminal’ and ‘dying’ has largely been omitted in many of the recent definitions;
- The prevention and/or relief of suffering. This is a consistent aspect in most definitions. However, it is sometimes written as minimising, rather than preventing or relieving;
The treatment of pain and other symptoms. This recognises the concept of total pain - physical, psychological, social and spiritual;

The understanding that dying and death are a normal and natural part of life;

The intention neither to hasten nor to postpone death. This has always been a part of the concept of HPC and forms the anti-euthanasia stance that is adopted by the profession;

The approach to care is one offered by an interdisciplinary team. This emphasises the importance of a team approach to caring for the dying;

The suggestion that HPC can positively influence the course of an illness. This is the first time that a definition has included this viewpoint;

The attempt to integrate HPC practice early in the course of illness.

These above key points make up the core aspects of the professional practice of hospice palliative care.

In Australia there are several definitions of HPC that are worth noting. These include the AGDHA (2000) and Palliative Care Australia (PCA) (2005) definitions. In 2000 the AGDHA developed a National Palliative Care Strategy: A National Framework for Palliative Care Service Development. This framework, and the corresponding funding from the government, has assisted in the development of HPC and access to services for more people. The expression of the nature of HPC as stated by the Department of Health and Ageing is

Palliative care is the specialised care of people who are dying. A person receiving palliative care will have an active, progressive and far-advanced disease, with little or no prospect of cure. The central aim of palliative care is to achieve the best possible quality of life, both for the person who is dying and for their family. Palliative care respects the dignity of the person who is dying, and is based on the person’s needs and wishes, with attention to the specific needs of different cultural and religious groups. Care is provided, where possible, in the environment of the person’s choice, and is delivered by coordinated medical, nursing, allied health and volunteer services, including both specialist and generalist providers.

Palliative care affirms life and regards dying as a normal process, where death is neither hastened nor postponed. Palliative care provides relief from pain and other distressing symptoms by integrating the physical, psychological, social, emotional and spiritual aspects of care, including coordinated assessment and management of each person’s needs. This care offers a support system to help people live as actively as possible until death and continues to help the family cope during the person’s illness and in their own bereavement.
The values inherent in palliative care, and some of the services provided, are relevant across many areas of health care delivery. Procedures, including radiotherapy, chemotherapy and surgery, have a place in palliative care to achieve symptom relief, provided that the benefits of treatment clearly outweigh the disadvantages (Commonwealth Department of Health and Ageing, 2000, p. 3).

As can be seen, this definition is very similar to the one offered by WHO. They each have an emphasis on quality of life, total care and that dying is normal and should not be hastened or prolonged. These are standard in most definitions. It can be noted, however, that there are also some differences. The Government definition is clearer on the nature of the illness; it stresses the importance of cultural and religious considerations; it includes the make up of the care team and, finally, it acknowledges the importance of dying in one’s environment of choice, another recent addition that points out that people will have a preference for where they wish to die.

Palliative Care Australia (PCA), the peak body for HPC practice in Australia, has developed its Standards for Providing Quality Palliative Care for all Australians (2005). In the Standard’s booklet it defines HPC as

Care provided for people of all ages who have a life-limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life (p. 10).

This definition then goes on to utilise the WHO key points by way of further explanation. Of note in this definition is the preferred terminology of ‘life-limiting’ illness. PCA (2005) explain that

The term life-limiting illness is used here to describe illnesses where it is expected that death will be a direct consequence of the specified illness (p. 11).

The use of this term, ‘life-limiting illness’, throughout the standard guidelines has meant that the words death and dying have been largely omitted. The implication of this change of language is considered in this thesis, with an exploration of changing societal values and the importance of an acceptance of human mortality. In addition, the concept of quality of life as the central goal of HPC practice is critically explored in chapter five.
1.2.2 The values of hospice palliative care

It is also pertinent for the intentions of this study to note the stated values outlined by PCA in its standards guidelines (2005) as these values play a crucial role in the ethical dimension of HPC practice. PCA (2005) writes that “These core values were articulated in consultation with the palliative care community that resulted in the 3rd Edition of the Standards for the Provision of Palliative Care” (PCA, 1999, p. 3). In 2004 I made inquiries to PCA as to what these consultancy processes included and what methodology or questions were asked to discover these important values; I received no reply. In addition, since the 1999 process of investigating and articulating these core values of the practice, PCA has changed some of these values. In 2005, at an awareness workshop for the new standards, I was informed that these values had been changed by the members of the Standards and Quality Committee. PCA (2005) states that quality end of life care is provided by health care workers who

- Endeavour to maintain the dignity of the patient, their caregiver/s and family;
- Work with the strengths and limitations of the patient and their caregiver/s and family to empower them in managing their own situation;
- Act with compassion towards the patient and their caregiver/s and family;
- Consider equity in the accessibility of services and in the allocation of resources;
- Demonstrate respect for the patient, their caregiver/s and family;
- Advocate on behalf of the expressed wishes of patients, caregiver/s, families, and communities;
- Are committed to the pursuit of excellence in the provision of care and support; and
- Are accountable to patients, caregiver/s, families and the community (p. 5).

The stated values of compassion, dignity and respect have certainly been a part of HPC since its inception. However, recent changes that reflect dominant Western ideals in health care have now been included in this list of core values. These include notions of empowerment, advocacy and equity. This ethical inquiry examined what values underpin the practice of HPC from the professionals standpoint and these are outlined in chapter six and compared with this list of core values from PCA.
1.2.3 The demarcation of hospice palliative care

The demarcation of hospice palliative care is something that, like its definition, is diverse and oft debated. “The concept of palliative care has become ambiguous”, writes ten Have and Clark (2002, p. 6). One element of this ambiguity includes the question of whether hospice palliative care is a practice that is distinctive from health care itself, or a practice within the mainstream health care system. This debate includes the consideration of whether all health care professionals can do hospice palliative care practice, or whether it requires specialist professionals. Hermsen (2005) identifies this important question in her study into the ethics of palliative care practice. Hermsen (2005) writes

> It has been argued … that palliative care should not be considered as a separate discipline apart from the formal health care systems, but to be intrinsically related to it. The integration of palliative care in this system means that palliative care has to be practiced in various settings, instead of in separate institutions (p. 13).

Certainly the hospice and palliative care mandate, since its inception, has emphasised that care and compassion in end of life care “cannot be the monopoly of any one individual setting, but needs to be a basic component of all health care” (ten Have & Clark, 2002, p. 2). The narratives that form the basis of this research inquiry included these important considerations of separation (distinctive) or integration (similar) at times, even going so far as to call for a separation between our understandings and practices of palliative care and hospice care.

This thesis does not overly focus on this debate about the demarcation of hospice palliative care. What is simply important to note is that at present several terms are utilised in describing this particular kind of professional care provided for those at the end of their life. These terms include supportive care, “which is part of palliative care aiming at the support of patients undergoing chemotherapy or radiotherapy” (Olthuis, 2007, p. 6). Certainly, palliative medicine is now recognised as a common term to refer to the medical specialist area of end of life care, such that a text book that guides practice is evident – *Oxford Textbook of Palliative Medicine* (Doyle, Hanks, Cherny & Calman, 2004), now in its third edition. Next there is the terminology of hospice care,
which has long denoted a specific setting or building, except that the services included in this study, which referred to themselves as hospice, did not denote a building or in-bed service, but rather an adherence to this name for the reason that they thought it different, and often better, than palliative care. Rumbold (1998, p. 16) provides a useful table explaining the differences, as he understands them, between hospice care and palliative care.

Table One: Differences between hospice care and palliative care

<table>
<thead>
<tr>
<th>Hospice Care</th>
<th>Palliative Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Holistic care</td>
<td>Symptom control</td>
</tr>
<tr>
<td>Systemic perspective</td>
<td>Service delivery perspective</td>
</tr>
<tr>
<td>Nursing the core discipline</td>
<td>Medicine the core discipline</td>
</tr>
<tr>
<td>Egalitarian organisation</td>
<td>Hierarchical organisation</td>
</tr>
<tr>
<td>Patient active in directing care</td>
<td>Patient increasingly a consumer of medical expertise</td>
</tr>
<tr>
<td>‘Bottom-up’ development of care in small unit, reflecting community context</td>
<td>‘Top-down’ direction of care in large institution, reflecting large-scale political and managerial priorities</td>
</tr>
</tbody>
</table>

In addition to the terms palliative and hospice, there are other terms utilised, such as terminal care and end of life care. Recently, there is the formulation of what is known as the palliative approach: “This is a much broader term and refers to the philosophy of care that underlies palliative care practices” (Olthuis, 2007, p. 6). A palliative approach is understood to be able to be practiced by all health care professionals, including general practitioners. Olthuis (2007) appreciates that with the palliative approach, the demarcation of hospice palliative care is problematic. This, of course, leads right back into the debate about whether HPC is considered a separate and distinctive practice, or an integral part of all health care practices. For the purposes of this inquiry, HPC is understood as a specialty; something different from medicine or health care, with its own sets of practices, educational processes and a unique ethical dimension. I have adopted the term hospice palliative care to describe and explore this social practice.
1.2.4 Current critiques in hospice palliative care

Hospice palliative care is, like any social practice, a critiqued phenomenon. Several authors, especially since the 1980s, reflect on, and argue certain concerns about the changing nature of the profession. Kellehear (2005) indicates that “a number of social observations … that appear to be critical of recent developments” have been generated (p. 7). The first, and often loudest, critique is the assertion that HPC practice is becoming highly medicalised.

1.2.4.1 The medicalisation thesis: Selling our soul

It is noted that the hospice movement was initiated out of the concern that the care of the dying was not being met by Western medicine. “Hospice leaders argued that hospitals have proved inadequate to the task of caring for the dying. They over-treated the terminally ill, isolated them from their families, and abandoned them when they were most needy” (Abel, 1986, p. 72; James & Field, 1992). The hospice movement of the 1960s included the intention “to start afresh, unencumbered by the practices, traditions, and regulations of the traditional health care system” (Abel, 1986, p. 76). However, now contemporary practices of hospice palliative care are being medicalised.

‘Medicalise’ simply means to make medical and the emergence of medical ways of thinking and practicing (Clark & Seymour, 1999).

The medicalisation thesis argues that HPC practice, which includes sets of values, beliefs and goals which are distinctive from those of medicine, has now become medicalised, and, therefore, lost its original intentions and practices (McNamara, 2001; Kearney, 1992; Bradshaw, 1996; Abel, 1986; Clark & Seymour, 1999; Manima, 2003; Kellehear, 2001/2003; Janssens, ten Have, Broeckaert, Clark, Gracia, Illhardt, Lantz, Privitera & Schotsmans, 2002; Biswas, cited in Clark, 1993; James & Field, 1992). The medicalisation of hospice palliative care poses a very real threat to the fundamental principles and values of this caring profession, or the proposed danger of the re-emergence of the medical model. This argument highlights the uneasy relationship between HPC and medicine, a relationship that continues to change with the advent and growth of palliative medicine. Ten Have and Janssens (2001) suggest that HPC and its
relationship with mainstream medicine has reached “an ideological stalemate” (p. 4). Crucially, Kearney (1996) emotively suggests that with the development of palliative medicine

   my concern is that our need to belong and fear of the unknown, coupled with the expressed aim of integrating our expertise back into general medical care and the now wide open arms of the medical establishment towards us, may lead to our not continuing to develop as a specialty and to our not fulfilling a potential I sense this specialty may have. In essence, I am afraid we may be in the process of selling our soul to the very medical model whose excesses have created the needs our specialty sets out to meet (p. 41).

What this statement by Kearney is referring to is that the motivation and establishment of hospice care came about as a result of needing something different from medicine, but that it has come full circle and is now becoming more like medical care. With these changes, so it is argued, the domains of care that do not pertain to the physical are delegated to the ‘not necessary’ basket. Hence, we have a changing type of HPC practice that emphasises pain management and symptom control, forgetting that this was one of the reasons why hospice care was developed in the first place: an understanding that people who were dying were getting adequate medical care in the hospital settings, but that simply was not enough for this important passage from life. A palliative care nurse sums up this concern about the medicalisation of end of life care

   The shift from terminal care to the much wider area of palliative care is a shift in emphasis which alters the original concept of improving care of dying people. Palliative care shifts the focus of attention away from death and there is a real danger that, by talking about and focusing upon palliation, people may stop talking about and confronting the fact that the individual is going to die (cited in McNamara, 2001, p. 125).

With this shift of emphasis comes the corresponding devaluing of the social, psychological and spiritual aspects of care, a hierarchical team approach, the omission of the language of dying and death, and an emphasis “from dying people to issues of symptom control and ‘palliation’, or the masking of the symptoms of dying” (McNamara, 2001, p. 125). Furthermore, “it privileges an understanding of illness in terms of disease, valuing outcomes in terms of cure or remission, promoting a reductionist view in which care is expressed through a series of modular services”

1.2.4.2 The professionalisation thesis: Too precious

Another critique, more recently offered by Randall and Downie (2006), is that the profession has become over professionalised. Randall and Downie (2006) in their critique and reconstruction of palliative care write

> We shall criticize the practice of palliative care for becoming too elaborate, too intrusive, and too precious, in effect over professionalised. What we shall recommend is a return to the original simplicity of palliative care and its philosophy as it was first formulated in the twentieth century by Cicely Saunders (p. 5).

As palliative care in the past has been viewed as “soft and lacking in intellectual rigor” it has sought to establish its credibility through a professionalisation process (McNamara, 2001, p. 131). By and large, however, this professionalisation process has resulted in the formation of palliative medicine. Thus, medicine now takes the central place in the development of the discipline (McNamara, 2001). Field (1994; cited in Clark & Seymour, 1999) is not sold on the professionalisation of palliative care arguing that

- there is a lack of clarity about the remit of palliative medicine;
- there is a lack of emphasis on dying;
- there is a tendency towards the ‘inappropriate’ use of technology;
- there is a threat to the autonomy of other health care professionals;
- the role of hospices is threatened by the expansion of palliative medicine (p. 121).

These points alert us to the fundamental changes that are currently occurring in the foundations, ideals, practice and definitions of HPC.
1.2.4.3 The mainstreaming thesis: Wholly absorbed

A further critique that is linked with the medicalisation thesis is that of the mainstreaming of hospice palliative care. This mainstreaming thesis argues either for or against the call for HPC to be integrated into all health care settings, and being able to be practiced by all health care professionals, with hospice palliative care specialists being called upon only if needed (Corner & Dunlop, 1997; Kearney, 1996; McNamara, 2001; Rumbold, 1998).

Allbrook (cited in Rumbold, 1998) hoped that “palliative care will be a transient phenomenon of the 1990s, and that by the time the 2000s begin, it will have been absorbed wholly into the mainstream of medicine” (p. 16). This process of the mainstreaming of hospice palliative care could occur, and would not be problematic, if it were simply specialist information and a transferable set of strategies, but it is much more than this. It is the founding ideals, the unique values, and the attitude and commitment to make dying and death an accepted part of living that is not so easily transferred into curative settings. McNamara (2001) recognises this when she writes, “there is a very real possibility that the founding ideals of the hospice movement may be lost in the process” (p. 129). This concern fundamentally involves this sense of something being lost with the movement into the mainstream health care arena.

A further concern is that with a shift from emphasising its distinctiveness, to focusing on integration into health care generally, this will mean that hospice palliative care “increasingly [needs to be] …accountable according to mainstream criteria of effectiveness, efficiency and competitiveness” (Rumbold, 1998, p. 3). Certainly there was the original hope, articulated by Saunders (the recognised founder of the modern hospice movement), that hospice values would influence mainstream health care. Saunders (cited in Rumbold, 1998) said that “we moved out [of the National Health Service] so that attitudes and knowledge could move back in” (p. 7). This statement by Saunders emphasised the hope that the particular way of caring for the dying according to the hospice movement would influence mainstream health care. The potential pitfalls of the mainstreaming of HPC include the call to conform to a management approach,
which deemphasises values which have been at the heart of the hospice movement (Rumbold, 1998). This, in turn, could mean that attention to the quality of relationships between professional and clients is minimal (Rumbold, 1998). As well as these types of concerns about mainstreaming is the understanding that “our experience is that the philosophy of palliative care isn’t transferring that well, as a complete package” (palliative care nurse, cited in McNamara, 2001, p. 130). It would seem, however, that “current political wisdom is that hospice care should be integrated with mainstream services” (Rumbold, 1998, p. 16). Rumbold (1998) ultimately argues for an independent identity of the practice.

With the increasing medicalisation and mainstreaming of HPC practice further critiques arise. It has been argued that HPC is now being routinised, bureaucratised and institutionalised (Abel, 1986; Byock, 1994a; James & Field, 1992; Clark & Seymour, 1999). Corner and Dunlop (1997) and James and Field (1992) argue that what was once a radical, innovative, alternative model of care is losing this radicalism and becoming routinised. Practices have become bureaucratised with “increasingly rigid hierarchies and management practice … the principles of biomedical care are re-emerging, and certain practices are at risk of being controlled by policy and procedure” (Corner & Dunlop, 1997, p. 289). Abel (1986) was the first author to suggest that institutionalisation might be taking place “with the effect of curbing hospice innovation” (p. 72). Abel (1986) asserts that HPC has “lost its uniqueness; that the critical force of the movement has been blunted; that there is now a new reliance on an established order for resources, personnel, and acceptance … [and that this] has undermined their ability to offer a true alternative [from health care]” (Abel, 1986, p. 81). These processes also include health care accreditation processes which further accelerate bureaucratic formulations. The original innovation of the hospice movement that included a “nostalgia for simple, old fashioned ways, dissatisfaction with bureaucratic and authoritarian institutions, faith in the power of nature, a determination to avoid domination by experts, and a desire to improve the quality of personal relationships” is slowly drifting away (Abel, 1986, p. 71).
1.2.4.4 The secularisation thesis: Danger of losing the heart and soul

A further dominant critique of the direction of hospice palliative care is offered by Bradshaw (1996) who argues that the practice has now become secularised. This author postulates that the very spiritual values that provided for the foundation of this caring practice are now lost (Bradshaw, 1996). It was the core spiritual values, or spiritual calling, that formed the traditional basis for the care of the dying. Furthermore, Bradshaw (1996) argues that the spiritual dimension of hospice palliative care “holds the key to the development and changes” in the practice (Bradshaw, 1996, p. 410). Bradshaw (1996) poignantly asks the questions

What happens if the original charismatic ethic, which we might describe as the Christian conscience, is marginalised from the care of the dying? Which other ethic will replace it? As the original spiritual values diminish so the values become those of the ‘expert’. The tragedy and awfulness of death is ‘managed’ away. The relationship of genuine ‘real care’ gives way to the application of ‘palliative care’ techniques. Unarticulated love in action is replaced by the articulated propositions of the various experts, whose values are those of aesthetics, therapeutics and managerialism. Death is no longer a truth to be confronted, but a process to be managed. We may conclude that we are in danger of losing the heart and soul of care precisely because its originating ethic is being marginalised (p. 418).

These questions that Bradshaw reflected on are pertinent for this research inquiry, especially the question of ‘which other ethic will replace it?’ Could it be that a biomedical, principles-based ethic has replaced the original Christian foundations? Is this a helpful or problematic ethic or is there some other ethic that can emerge? This inquiry explored these important questions through an examination of the ethical dimension of this practice.

1.3 Buffeted by external forces

Linking in with these above critiques are the broad considerations of the influence by external forces. McNamara (2001) claims that “social movements like hospice and palliative care are subject to the forces of social change” (p. 8). This means that like any other social practice, HPC practice is being influenced by external forces which may take the shape of values, concepts, or dominant ways of thinking. The three dominant external forces considered in this thesis include
• Individualism, the valuing of choice and the patients rights movement;
• Biomedical frameworks, biomedical ethics (principlism) and the prominence of the principle of respect for autonomy;
• The denial and devaluing of dying and death in contemporary Western societies.

Each of these external forces is reflected upon at various stages throughout this thesis. The influence of biomedicine is considered in chapter three with the contestation and erosion of the philosophy of (total) care and in chapter six with the considerations of the role of biomedical ethics (principlism) and the principle of respect for autonomy. The influence of individualism is explored in chapter four in considerations of ontology. Individualism and choice are also considered in light of the goal of the practice in chapter five where largely this external force has played a role in dismantling the overarching goals of HPC. Finally, the denial and devaluing of dying and death is considered at various points throughout the thesis, but particularly in chapter six which considers the value of the acceptance of human mortality as the number one value listed by the hospice palliative care professionals.

1.4 The standpoint of ethics

With these understandings of hospice palliative care now outlined, it is also important to consider the understanding of ethics adopted in this thesis. Ethics is concerned with “both questions about what it is right to do [in caring for the dying person] and questions about what it is good to be or to be-come [the professional caregiver]” (Isaacs, 2005a, p. 1). As this is an applied ethics inquiry, which includes these fundamental questions and explorations, the particular viewpoint of ethics that this research adopts requires further explanation. This can be termed a humanistic approach to the doing of ethics (Isaacs, 2005a). This research is based on the ‘Mapping the Applied Ethics Agenda’, which “enables us to think more deeply and more fully about the applied ethics agenda” (Isaacs & Massey, 1994, p. 13). There has been notable dissatisfaction with the Western moral philosophical tradition when understanding the ethics of practice, and for this reason an
engaged ethics\(^4\) approach has been adopted for this critical inquiry. Engaged ethics, as outlined by Isaacs (2005a); Massey (2002); and Isaacs and Massey (1994) understands the ‘doing’ and ‘seeing’ of ethics as something that is much broader and practically-oriented. An engaged ethics approach understands ethics to be about

Creating and sustaining relationships which mutually recognise the needs, interests and aspirations of all participants as ‘ends in themselves’. The focus is on the continuing enhancing of the other and the self within the human social condition as it is actualised within specific situations, roles, practices, institutions and cultures. In short, applied ethics seeks to enhance the ethical form of life (Isaacs & Massey, 1994, p. 2).

It is the enhancing of the self and other, in relationships, via situations, roles, practices, institutions and cultures that require our ethical attention. In enhancing this ethical form of life, it can be seen that the doing of ethics is not simply at the point of a decision, problem or issue, but rather is something that takes place on a moment to moment, daily basis throughout one’s “life-worlds” in different contexts and relationships (Massey, personal communication, 2004). This is certainly a distinctive departure from the Western moral philosophical tradition that views the doing of ethics at the point of dilemmas, problems or issues, which requires a choice or decision.

Ten Have and Clark (2002) have made this distinction as well when they write about HPC ethics. These authors suggest two different approaches: the ethics in palliative care and the ethics of palliative care (ten Have & Clark, 2002)\(^5\). They explain that the ethics in palliative care “is the application of the tools of ethics to the problems of palliative care” (p. 235, original italics). This indeed has been the focus of HPC ethics literature and research for many years now, as particular ethical issues and problems make up the bulk of the work in this area. This reflects the Western moral philosophical tradition that posits the ‘doing’ of ethics as “a decisional morality” revolving around choices and problems of the practice (Isaacs, 1998, p. 14). The second approach is the ethics of palliative care. Ten Have and Clark (2002) explain that the ethics of palliative care is a

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\(^4\) Isaacs & Massey first entitled this approach ‘Mapping the Applied Ethics Agenda’ in 1994. Since then Isaacs has termed it a Transformative Approach (2001) to ethics and Massey has coined the term an Engaged Ethics approach (2002). This thesis adopts the term Engaged Ethics.

\(^5\) Please note that this concept was originally drawn from Pellegrino (1976) in Philosophy of medicine: problematic and potential. Pellegrino introduced two models of engagement: philosophy in medicine, and philosophy of medicine (ten Have & Clark, 2002).
somewhat broader concept and approach to the investigation of the purposes and values that make up this practice. Ten Have and Clark (2002) write that the ethics of palliative care can be regarded as the “crucial examination of the meaning of palliative care, its nature, concepts, purposes and value to society … this assumes that palliative care [is] a practical human activity” (p. 236).

Isaacs (1994) has also articulated a similar distinction when responding to an understanding of ethics in business. Isaacs (1994) wrote that, certainly, we can see ethics about “individuals grappling with vexatious problems, issues and dilemmas (ethics in business)” (p. 16). On the other hand, we could also reflect on the ethics of business by exploring the nature of business as a social practice and “seek to understand better how that practice is woven into the social fabric of a broader community life” (Isaacs, 1994, p. 16). This study assumes the second approach - the ethics of HPC and thereby offers a broad exploration of this practice and, most importantly, acknowledges and values the significance of the social in understanding ethics.

Aside from this much broader lens for the understanding and the doing of ethics, other important features set it apart from the understandings of a Western moral philosophical approach. These important features of the engaged ethics framework include an understanding of personhood (ontology) as being one that is embodied and embedded in relationships, the social world, time and language (Isaacs, 2001). This re-examination of the ontological is outlined in chapter four. This ethics approach tends to focus on the site of relationships and on the context or particularities of engagement and people (and institutions), and the acknowledgement that people (and practices) are shaped by a past and confront a future (Isaacs, 2001; Isaacs &Massey, 1994). One implication of understanding the doing of ethics in this way is that this inquiry has challenged the assumptions held about what it means to be a person, about how we die, and how others care for us when we are dying, and has paid much closer attention to the particularities of HPC professionals’ stories of practice.
Furthermore, in adopting an engaged ethics framework I have aimed towards practical responses for enhancing the ethical dimension of HPC practice. In presenting this conversation of the understandings of the ethical domain of HPC practice I am carrying out the fundamental role of ethics inquiry, which is the intention to “understand and transform human actions and practices” (Isaacs, 2002, p. 2). With this alternative understanding of ethics, as presented here briefly, and further explained in chapter two, I have been able to construct the approach I have taken in developing, conducting and presenting this inquiry; that is, as a foundation for this thesis. Whilst at the same time, I have been receptive to the HPC professionals’ storied accounts of what the ethics of HPC means to them, understanding that there are many articulations and understandings of ethics.

1.5 Clarification of terms

1.5.1 Ethics (ethical) and morals (morality)

It needs to be clarified that this thesis prefers to utilise the term ‘ethics’. The definition of ethics was provided above and denotes an engaged ethics approach. Isaacs and Massey, however, do use the terms ‘ethics’ and ‘morality’ interchangeably. This means that they do not make an obvious distinction between these two terms. In this thesis the term moral is most often aligned to the dominant approach to ethics: a Western moral philosophical tradition. Thereby, this thesis utilises the term moral when referring to the moral philosophical tradition. What further complicates this, though, is that the European scholars largely incorporated into this thesis prefer the term moral, and have an understanding of it that aligns itself with the engaged ethics understandings. An example of this is seen in the following section. In summary, I have referred to the term ethic in exploring this topic; I use the term moral to describe the dominant Western moral philosophical tradition; and I have endeavored to be consistent with any author’s use of either of these terms, and have provided any required explanations about what way they are using these terms throughout.
1.5.2 Living-dying person
A further term that requires explanation is that of living-dying person (and living-dying process). This term was articulated by Balber (1995). Balber does not clearly explain why she adopts this term as she discusses the importance of storytelling for people who are dying, except to say “their lives are never quite the same, each becomes the living-dying, a marginal being” (p. 96). It seems that she is referring to this liminal state where people are both living and dying. Morrie Schwartz describes it well when he said: “People see me as a bridge. I’m not as alive as I used to be, but I’m not yet dead. I’m sort of … in-between” (Albom, 1997, p. 33). I have adopted this term to acknowledge that there is no clear separation between living and dying, that people enter into a time of their life that is about both living and dying, and that there is value in the recognition and processes of both.

1.5.3 Patient identity
I do not use the term patient. The notion of patient is a label and role placed upon people who are in institutional settings. Frank (2000) makes the distinction between patient and ill person, suggesting that “being a patient – entering a clinic to be treated by medical professionals – was only one part of a life in which illness remained present” (p. 359). Someone who is dying is not necessarily a patient. The adherence to this term patient exemplifies a further medicalisation of HPC practice. Where patient is included in this thesis it will be because it has come from the HPC professional’s stories or the literature. I prefer to understand and language them as people who are experiencing a terminal illness and who are both simultaneously living and dying.

1.5.4 Stories
The final key term used in this thesis is that of story or narrative. At this point I would like the reader to understand that I tend to use the words story and narrative interchangeably. Narrative is perhaps used more in its academic sense and story in a ‘local’ or personal sense. Certainly you would not hear someone say ‘let me tell you a narrative’. People tell stories, not narratives. Narrative suggests “a structure underpinning the story”, and narrative inquiry “locates structures that storytellers rely on
but are not fully aware of” (Frank, 2000, p. 354). By and large, however, the reader can understand that these two terms are meant as the same thing. Story, for me, is both a meaning making and articulation process, in either one’s mind or spoken to another. A story or narrative is an account where someone describes or explains an experience or an event (or multiple experiences and events), linked in sequence, across time, according to some type of theme or plot (or multiple themes or plots). This understanding of story is understood from the work of Michael White⁶ (2001), the founder of narrative therapy. It is a broad understanding of narrative, as many others suggest that there needs to be other key components to stories that I have not mentioned. The concepts of narrative are further outlined in chapter two.

1.6 The purpose of the inquiry

This introduction has so far included an explanation of hospice palliative care, the viewpoint of ethics taken in this thesis and provided explanations on some of the key terms used in this thesis. This next section outlines the purpose and rationale for this research. The purpose of this inquiry is to critically explore the ethical dimension of HPC practice. As mentioned above, the viewpoint of ethics utilised to guide this research inquiry is that of an engaged ethics approach. In addition, a further ethical conceptual framework has been utilised in this thesis: a social practice framework (SPF) (Isaacs, 1998). It is suggested in this framework that any understanding of the ethics of a practice requires an internal inquiry, stemming from the practice itself, rather than external, moral philosophical theories being placed ‘upon’ the practice to gain understanding. Other features included in this SPF are considerations of the tradition of the practice, what constitutes personhood (ontology) within the practice, and the teleological features internal to the practice (aims, goals, purpose, ends). These features of the SPF have then become the guiding notions and structure for this critical exploration. This SPF is further explained in chapter two.

⁶ I would like to acknowledge the death of Michael White on the 5th April, 2008. He will be dearly missed by so many.
1.6.1 Taylorian articulation

This research project not only sought understanding, but also had the intention of facilitating articulation. Articulation or ‘telling’ is an important process in ethics. Taylor (1989) explains this notion of articulation (and unarticulation) in *Sources of the self: The making of modern identity*. Articulation is the process whereby the “tacit background” or what is unsaid about the ethical domain is expressed and acknowledged. Certainly, this expression can take different forms, but for the purpose of this inquiry articulation takes the form of language (spoken and written) (Abbey, 2000). The telling of the HPC professionals’ stories was of primary importance, with the understandings gained from them secondary. This articulation is required as many of our strongly held values and ethical frameworks go unacknowledged and unarticulated. Often, Taylor suggests, it is not until “times of conflict or crisis that one is forced to spell out and defend the assumptions and presuppositions that underlie one’s moral values and practices” (Abbey, 2000, p. 41). I am not suggesting that HPC is at a time of crisis; however, as noted in the rationale for this inquiry, the ethical frameworks and values of HPC largely go unarticulated.

This articulation offered in this inquiry, then “bring[s] into the light of awareness that which is unspoken” (Abbey, 2000, p. 41). Greater awareness is just one outcome of ethical articulation. Another function, Taylor explains, is the possible strengthening of an ethical framework.

Taylor proposes that because the articulation of a moral framework or source identifies what is moving about it, this can strengthen commitment to it. [This means] that articulation empowers: bringing a good to light, raising awareness of what usually remains tacit, brings its adherents into closer contact with this good and its ideals, which can invigorate their allegiance to it (Abbey, 2000, p. 44). Arguably, this would mean that the failure to articulate “these underlying goods can contribute to their attrition” (Abbey, 2000, p. 44). This could be an important point for the continued development of HPC, for it could be suggested that it is the lack of articulation of the ethical dimension of HPC that may have contributed to the proposed confusion and lack of common, shared understandings of the values and purpose of this professional practice. By extension, articulation of the ethical goods of HPC practice
could strengthen the profession as a whole. This is what was intended in this research investigation.

A further function of articulation is that of “immanent critique” (Abbey, 2000, p. 46). As this inquiry seeks to address perceived problems within HPC it is inherently a critique. Abbey (2000), in explaining Taylor’s thoughts about this function of articulation, writes

[E]thical debate and change involves not simply repudiating some of the modern goods like individualism and technological control over nature but reconfiguring them. By making contact with the vision of the good that originally inspired them, it is possible to appreciate either how current practices or values have distorted this vision or that there are other possibilities that this vision could nourish (p. 46).

This function has a direct link with the original questions posited in this research inquiry, as I was interested to understand whether the original values of the hospice movement have been eroded. A Taylorian (1989) approach to ethical articulation assisted with the understanding of this. Overall, it could be argued that articulation, in and of itself, is a vitally important process for the development and cohesiveness of the profession of HPC. PCA most likely would agree, as when it published its recent standards for practice (2005) it included in these standards that each service needed to have an articulated philosophy, values and culture for the provision of competent and compassionate care (Standard Seven) and that staff and volunteers reflect on their practice (Standard Thirteen). This study, in the first instance, addressed this aim of articulation in the narrative interviews. HPC professionals mentioned how helpful these interviews were and how they had not had the opportunity to discuss these important matters before

It’s not until you start talking about these things, that you think, yeah, how do I do all this? What are my values? This has been really helpful (Martha)

These are really interesting questions. It’s been really interesting to think about my replies to these questions. Great interview (Jackie)

It’s not until you try and answer these types of questions, that you realise, yeah, that’s why I do this the way I do it (Emma)
The philosophy of I’m not sure. I haven’t really ever put it into words. That’s funny isn’t it? And now I can’t find the words. [Later] I realise that it’s been so helpful to speak about these things. I think we should do more of it (David).

Thus, even before the stories were collated and compiled into this thesis, this study has reached its objective of articulation.

The HPC professionals who offered to take part in this study are located in the specialist HPC services in the greater Brisbane area, including the Sunshine Coast, Gold Coast, Toowoomba and Gympie areas. A variety of HPC contexts was gained, including a range of HPC professionals who make up the HPC team. Overall, this thesis explores, articulates, interprets and appraises these HPC contexts through the storied accounts of HPC professionals practice and understandings. What is offered in this conversation on the ethics of HPC practice contributes to the continuing development and identity of the profession and, hopefully, the enhancement of the quality of care that dying people receive.

1.7 The rationale of the inquiry

1.7.1 Significant developments

Aside from providing an important contribution to the development of this profession, there are further reasons to support the ‘why’ of this research inquiry. HPC in Australia has undergone many changes since its humble beginnings and continues to grow as a specialised field (McNamara, 1998b). Notably, this growth has accelerated in Australia since the 1980s (McNamara, 1998b). Indeed, hospice palliative care is thought to be “in a crucial phase of development in many countries” (ten Have & Clark, 2002, p. 6). Reflecting this development in Australia has been the involvement of the Commonwealth Government which has played its first major role in the development and funding of HPC via the National Strategy for Palliative Care: A National Framework for Palliative Care Service Development (AGDHA, 2000). The main objective for this strategy is to secure the place of HPC as an integral part of health care across Australia (AGDHA, 2000). With this objective has come increased Commonwealth and State government funding, a greater recognition of the role of HPC.

A table of the HPC professionals and contexts is provided in chapter two.
in our health care system and a wider array of ways in which this specialised service is carried out (PCA, 2003). Thus, this rapid growth of HPC in Australia provides an important opportunity to examine the ethics of its practice.

1.7.2 Eroding values?
Specifically, the broader ethical dimension of the practice of HPC was chosen to be of significance for this research endeavor. There are several reasons for this. With what is known as the philosophy of (total) care, which is outlined in chapter three, came a coherent set of values and purpose for this caring practice. Such values included the importance of open communication, the awareness of death and a gradual acceptance of dying (McNamara, 1998b). These three values were internal to the practice and provided it with substance and identity (Isaacs, 1998). They also provided for a shared and agreed ethical framework that underpinned and guided the end of life caring practices at that time. However, any social practice is embedded within a broader social context and is influenced by external value sets (Isaacs, 1998). Isaacs (1998) suggests that these external values can either positively or negatively impact upon a social practice. In the case of HPC, McNamara (1998b) suggests the latter. Her research found that these original values of HPC have been lost (McNamara, 1998b). They have been eroded over time, mainly because of the cultural value placed upon autonomy and individualisation (McNamara, 1998b). In other words, external, societal values such as individualism and freedom of choice have radically altered the ethical underpinnings and purposes of this social practice. This inquiry wanted to explore this further; whether the original values were lost and if there is greater emphasis placed upon individualisation and autonomy. Chapter six of this thesis presents the significant findings of the articulated values in HPC in Queensland.

1.7.3 The place of biomedical ethics
Thirdly, a further cultural shift has meant that contemporary HPC in Australia can be viewed as being increasingly integrated into mainstream health care. This transition into health care settings was alluded to in the medicalisation thesis. To further explain, when hospice was established in the 1960s it was set up as distinctive from hospitals and the
medical system. This includes specific, physical locations for people to come to die. Nowadays the majority of new HPC services are either attached to, or a part of, acute care hospitals. This can further be recognised by the growth of HPC consultative services in major hospitals. With greater integration into mainstream health care the adoption of an ethical framework for practice stemming from biomedical ethics is evident in the literature on HPC ethics (Beauchamp & Childress, 2001).

This biomedical approach to HPC ethics provides professionals with four ethical principles to understand and guide HPC practice; beneficence (to do good), nonmaleficence (to do no harm), justice and respect for autonomy. Unfortunately, what doing good entails and of what the good consists, specifically in hospice palliative care practice, is often not articulated or specified. This principles-based way of seeing the ethical agenda in health care stems from a Western moral philosophical paradigm. Furthermore, it has been argued that it is the principle of respect for autonomy that now plays the greatest role in guiding the ethics of HPC practice (McNamara, 1998b; 2004). Janssens et al. (2002) concur when they state “the notion of autonomy is adopted uncritically from its use in curative practices” (p. 73). This investigation has critically explored the nature of this adoption of biomedical ethics as a framework of HPC ethics and sought to understand the meanings of ethics from the HPC professionals. The significant findings of these understandings of ethics are outlined in chapter six.

1.7.4 Missing broader ethical investigations
A fourth reason for this research inquiry is that there are few studies that look into the values, purposes, and overall ethical frameworks of HPC practice. Most of the HPC ethics literature and research focuses on particular ethical issues, dilemmas or problems, especially that of euthanasia. In other words, there is inadequate attention being paid to a broader ethical inquiry of HPC as it has developed over time. Jennings (1997) considers that this is perhaps due to the accepted nature of the “value-based heritage of hospice” (p. 2). Jennings (1997) surmises that for this reason “systematic reflection on ethics in the hospice field is curiously underdeveloped” (p. 2). What this means is that for many years hospice care practice had a strong and coherent value basis that guided
the overall purpose and practice of the care of the dying, and that further investigation into this was simply not needed. However, HPC practice has changed over the years and this coherent value base is no longer apparent. This means that an investigation of this type now, more than ever, requires our attention.

What is known is that there is insufficient research into this topic. I certainly concur with Jennings (1997) and Hermsen and ten Have (2003) who believe that systematic analysis of the moral notions\(^8\) in the context of HPC is “relatively scarce [and that] not much has been known about the specific moral dimension of palliative care” (p. 97). Critical analysis of the moral notions of HPC largely remains absent (Janssens et al., 2002). Hermsen and ten Have (2003) also assert that “not much has been known about this specific moral dimension of palliative care” (p. 97). The body of European scholars that make up the Pallium project conclude that “the ethics of palliative care is not at the moment an object of research for many ethicists, [yet] many important questions are awaiting thorough scholarly analysis” (ten Have & Clark, 2002, p. 11). Both Schotsman (2002) and Olthuis and Dekkers (2003a) believe that it is this missing investigation of the ethical foundations of HPC practice that will enhance the “ethical culture” of HPC (p. 126; p. 193).

It is for these reasons that “support for hospice [and palliative care] in the future will require finding the right moral vocabulary for appraising the ‘good’ that hospice serves” (Jennings, 1997, p. 7). This thesis presents one such ‘conversation’\(^9\) for this moral vocabulary which can aid in providing direction towards a fuller and richer articulation of the ethical specificity of HPC (Janssens et al., 2002). With this conversation and articulation, a clearer, shared sense of the ethical dimension of this social practice which cares for the dying can be gained. For through conversations and articulations, HPC

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\(^8\) Here can be seen the first example of the European authors utilising the term moral. What these authors are referring to when they use the term moral are the values, the goals and so forth of HPC. They set out this moral dimension in the book *The ethics of palliative care: European perspectives* which covers values, principles, goals, tradition of hospice, and a relational and contextual approach to ethics. Thus, they are using the term moral in the same way as I am using the term ethic. You can also notice in this section that these European authors use ethic and moral interchangeably as well.

\(^9\) This conversation includes my voice, the voice of HPC professional’s and the voice of the literature combined together to provide an overall conversation of the ethics of practice.
professionals can enhance their shared understanding of the values, purposes and philosophy of (total) care. Thus, understandings of the purpose, values and ethics of HPC practice could, not only guide development into the future, but also orientate HPC practitioners to the ethical practice of end of life care.

1.8 Research questions

This ethics vocabulary that is largely missing from HPC ethics required exploration, articulation and interpretation. Inquiry into the key ethical influences on contemporary HPC practice in Australia is timely and required, for as MacLeod (2003) explains, “it is up to palliative care practitioners to protect the moral framework of how we provide care to people who are dying” (p. 125). This research investigation reflected on the questions

- How is the philosophy underpinning HPC caring practices understood? Does this philosophy still resemble the original hospice philosophy or has it changed?
- How do HPC professionals understand and articulate the purpose of their work and the profession? What do they hope to achieve in their work?
- What are some of the ethical values that underpin HPC practice for HPC professionals? Are the values of the original hospice movement still evident in HPC professionals’ stories?
- What role does the biomedical ethics approach (principlism) play in HPC practice? How important is the principle of respect for autonomy in guiding HPC practice?
- What sort of future for the profession do HPC professionals hope for?

What these above questions form is a critical exploration of the ethical dimension of HPC. The overall guiding research question is

How is the ethical dimension of HPC practice articulated and understood by its professional members?

Certainly, this is a broad research question, yet the main themes of the tradition, ontology, ethics frameworks, and the teleological features of HPC practice provide for the central aspects of this inquiry.
1.9 Current literature

As mentioned above, the domain of HPC ethics is curiously underdeveloped. At present only a hand full of texts explore this topic and many of these are not research based. They are also often ‘issue or problem-based’ ethical explorations. This next section provides a brief presentation of the key HPC ethics texts. What is important to note is that the main texts adopt a Western moral philosophical, biomedical, and sometimes quasi-legal perspective of ethics. They include the assumption that HPC practice is a part of health care, thereby viewing it as the same as other health care practices. This adoption of a Western moral philosophical approach to ethics, and a corresponding biomedical, principles-based understanding of ethics, may or may not be helpful for HPC professionals, but it is only one way of understanding the ethics agenda. It is a partial view of ethics. Therefore, this thesis was curious to understand whether HPC professionals do view this ethics framework, based on moral philosophy and biomedical ethics, as helpful and applicable.

Currently, the dominant texts for HPC ethics are *Palliative care ethics: A good companion* and *Palliative care ethics: A companion for all specialties* (2nd ed.), offered by Fiona Randall, a palliative medical specialist, and Robin Downie, a professor of moral philosophy (1996; 1999). These texts have come out of the United Kingdom context. This means that they are situated in a biomedical, moral philosophical and Western context. Randall and Downie position HPC practice as firmly situated within a health care domain and adopt a biomedical approach to ethics. This necessarily includes the application of principles to clinical issues. Here are some examples of how Randall and Downie (1996) express their viewpoint of ethics

First, ethics can refer to that branch of philosophy called moral philosophy. Ethics in this sense is a theoretical study of practical morality and its aim is to discover, analyse, and relate to each other the fundamental concepts and principles of ordinary practical morality (p. 2).

The second main sense of ethics is ordinary morality or value judgments as they are found in a professional context. Morality or ethics must be seen broadly as including the whole area of value judgments about good and harm (p. 2).
These explanations provide examples of the features of the Western moral philosophical tradition that largely dominates the applied ethics agenda. It is an agenda that views the doing of ethics as a theoretical task and an analytical endeavor, coupled with the importance of learning knowledge of principles to apply to practice. It focuses on the role of appraisal or that of value judgments. Isaacs (2001) writes that the teaching of this Western moral philosophical approach includes

- A mastery of the techniques of analysis and clarification in order to establish clearly the nature of the issue or dilemma being faced;
- A sound understanding of philosophical theories of the good – one cannot pursue the good unless one rationally knows what the good is;
- A sound grasp of the rational normative principles which serve to guide practical ethical decision-making;
- An established competency in the careful and skillful application of these techniques, understandings and principles to practical problems, issues and dilemmas (p. 6).

Isaacs’ (2001) description of the teaching of this philosophical tradition mirrors the approach that Randall and Downie (1996; 1999) adopt in the two HPC ethics texts. It focuses on the role of value judgment and helping the HPC professional become more aware of one’s values and how they make their judgments.

With this viewpoint of ethics, stemming from the Western moral philosophical tradition, these authors do not acknowledge that there are other understandings of, and approaches to, ethics. Randall and Downie (1996) discuss “a range of specific clinical issues” and the ethical concerns inherent in these issues (p. xiii). This includes processes of clinical decision making; giving information; confidentiality; clinical treatment decisions; research and resource allocation (equity). This equates to one version of understanding the ethical in HPC practice, aligned with ten Have and Clark’s (2002) distinction of the ethics in palliative care. This biomedical, moral philosophical approach is not the only way of understanding the ethics agenda of HPC practice. Randall and Downie do not make transparent the socially constructed nature of their work or acknowledge that there can be a diversity of approaches to ethics. Furthermore, they do not clarify that they are positioning HPC practice as a part of the health care arena. This is simply assumed.
Randall and Downies’ second edition includes some notable additions including chapters on the patient-carer relationship and the relative-professional relationship. These chapters discuss the complexities involved in these relationships; including issues of power and vulnerability. Yet, these relational aspects are still viewed through a dominant clinical and moral philosophical lens, as it focuses on the issue of consent. What was of interest for this thesis is Randall and Downies’ (1999) response to their critics about the problematic nature of placing the principle of respect for autonomy foremost. These critiques have provided a pertinent inclusion for this thesis.

Randall and Downie (2006) have recently published a critique and reconstruction of the philosophy of palliative care. Their intention in this text is to cast a critical eye over the philosophy, which they have assumed to be outlined in the WHO (2002) definition of HPC. In this text, Randall and Downie have challenged HPC’s most cherished tenets, such as the importance of the family as the unit of care, our intention to attend to the spiritual and psychosocial care and the problematic nature of attempting to impact the quality of life of each living-dying person and their family. Furthermore, in this latest text Randall and Downie have seemingly altered their viewpoint of ethics, from a Western moral philosophical tradition with its reliance on principles to a case-based approach that attends to the individual and his or her ‘case’. This alteration reflects a current trend in the ethics arena, especially in health care ethics, to attend to the individual case. This approach is often referred to as casuistry: a case-based approach to ethical decision-making (Randall & Downie, 2006, p. 12). Randall and Downie (2006) now suggest that “the practical difficulty with applying ethical theories and principles is that ordinary people pay little attention to theories when they make their moral decisions” (p. 13) and that “professionals do not seem to use the principles in the resolution of cases” (p. 13). Therefore, Randall and Downie (2006) maintain that “we must always come down to the individual case” (p. 12).
Certainly, Randall and Downies’ (2006) new text provides a timely inclusion for this thesis. In summary, what is important to note about the Randall and Downie texts overall is that, by and large, they do adopt a Western moral philosophical tradition, without acknowledging that this approach to understanding ethics comes out of a particular context and time, and is simply one way of seeing the ethics agenda, albeit a dominant one. In addition, they do not make transparent the fact that they are positioning HPC practice firmly within a biomedical realm. These are two key differences between their articulation of the ethical dimension of HPC practice and the one offered in this thesis. First and foremost, this thesis acknowledges that there are several ways of understanding ethics in practice and incorporates some of them in this exploration. Secondly, it is made obvious in this thesis that I am positioning HPC practice as a distinctive social practice.

Webb (2000; 2005), a scholar from the United Kingdom, has produced two edited books on Ethical issues in palliative care. Webb’s contribution is one, like Randall and Downies’, which stems from the Western moral philosophical tradition. Webb’s (2005) approach is a problem-based one, that focuses on decision making, because “it does not take long for anyone in clinical practice to face their first ethical dilemma about which they are called upon to make a judgment or have a view” (p. 1) and so represents a “choice morality”, which Kekes (1990) explains is a morality about making rational choices when faced with novel problems, issues and dilemmas. This is also a highly individualistic approach to ethics (Isaacs, 1998; 2001). Ethics, for Webb, is about “applying moral philosophy to the real world of work with patients in health services” (p. 2). This knowledge base of the theories of philosophy is simply one basis for attending to ethical problems in clinical settings. Importantly, it is the focus on the individual, in studying ethics, who is “encouraged in logical, reasoned thinking” (p. 2) where “any or all of the four ethical principles considered appropriate to health care may need to be considered or debated” (p. 5). Webb has taken the Western moral philosophical approach, as applied to the biomedical world generally, and superimposed it upon HPC practice. Indeed, Webb, Randall and Downie seemed to have forgotten some of the distinctive features of HPC practice and viewed the ethics of HPC as the
ethics of health care generally. In adopting this moral philosophical tradition and biomedical approach, Webb’s book then provides considerations of ethical decision making, informed consent and euthanasia.

Other literature on HPC ethics includes one small chapter in the *Oxford textbook of palliative medicine* (Doyle et al., 2004) which focuses on issues of euthanasia and the principle of futility. Futility refers to the question of how pointless some medical interventions are in terminal illness. As mentioned earlier, euthanasia seems to be synonymous with HPC ethics and a major concern that many worthy writers have explored. It certainly concerns me, however, that a major text such as this does not include anything other than considerations of euthanasia and futility in its consideration of the ethics of HPC practice.

Jennings (1997) has included a short chapter entitled *Individual rights and the human good in hospice* in the text *Ethics in hospice care: Challenges to hospice values in a changing health care environment*. This text mostly focuses on issues of equity and justice, however, Jenning’s chapter offers an interesting reflection on what he believes are the three values or ‘goods’ of hospice care: palliation and the relief of suffering; enhancing individual control and autonomy; and the value of healing or maintaining meaning and person integrity in the dying process (p. 1). Jennings’ reflections are incorporated in chapter six of this thesis. This article reinforces the notion that HPC reflects a distinctive set of values, but that these values have been viewed as “self-evident, noncontroversial, and in need of little explicit analysis and examination” (Jennings, 1997, p. 2). Like Bradshaw (1996) Jennings is concerned with the question of “what source will hospice draw a moral vocabulary rich enough to articulate the profession’s proper sense of social and ethical purpose?” (p. 6). This author expresses his frustrations with the adoption of a biomedical ethical approach, and the underlying social ethos of a liberal individualistic culture, citing such notions of autonomy, independence, and the like which tend to produce “conflict and frustration rather than empowerment and respect” (Jennings, 1997, p. 6). Ultimately, Jennings (1997) argues that “the notion of healing or making whole provides the richest and most adequate
concept upon which to ground the social and ethical case for [palliative] hospice care in the future” (p. 1) and that finding the right “moral vocabulary for appraising the good that hospice serves” is needed (p. 7).

The most influential HPC ethics text for this inquiry has been *The ethics of palliative care: European perspectives* (2002). From 1998 until 2001 a group of European scholars\(^\text{10}\) carried out an international research project entitled Palliative Care Ethics (The Pallium project) (ten Have & Clark, 2002; ten Have & Janssens, 2001). This research project focused on the ethics of palliative care. It incorporated seven European countries: Belgium, Germany, Italy, the Netherlands, Spain, Sweden and the United Kingdom. The ethical analysis of this project started from the standpoint where

The underlying assumption of this project from the outset was that what is considered as palliative care is frequently related to specific moral values (for example, dying as a normal human process; life as an intrinsic good; acceptance of unavoidable death; a focus on quality of life; the significance of interpersonal relations; integrated care of the ‘total’ person). We therefore made an explicit examination of the moral values implied in the various concepts of palliative care (ten Have & Clark, 2002, p. 4).

As can be understood from this quote, unlike the aforementioned texts, these authors viewed HPC practice as distinctive from other health care practices, rather than being fully integrated into the health care system

Palliative care differs from curative and preventive medicine because it not only has specific goals, but also specific underlying moral values. Clarifying these underlying goals and values is therefore important for the future development of palliative care (ten Have & Clark, 2002, p. 2).

This does not mean that curative and preventive medicine does not have its own goals and values, but rather that palliative care has unique and differing goals and values. Ten Have and Janssens (2001) concluded that “it was clear that palliative care is related to a specific set of moral values” (p. 8) that are different from other health care practices. This was certainly an exciting discovery. This thesis, similarly, discovered what unique values were central as underpinning the practice of HPC. These distinctive values are set out in chapter six.

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\(^{10}\) I refer to the authors and researchers of this Pallium project as simply ‘European scholars’, rather than naming them all. There are twenty-six of them.
Aside from this viewpoint of HPC being distinctive from other health care practices, this European perspective also presented an alternative standpoint to ethics. Ten Have and Clark (2002) write that “there is much here to take the reader beyond the four principles of biomedical ethics” (p. xii). This book offers some alternative perspectives to the view of bioethics which prevails in the Anglo-American tradition and which is summed up in the notion that a given number of ‘principles’ can be identified as central to all problems of health care ethics (p. 2).

Certainly, the alternative perspective of ethics offered in ten Have and Clark’s book, which includes a greater focus on values, goals, and relationships in the practice of HPC, differs from the overt focus on problematic, ethical, clinical issues. The European approach to ethics resonates with that of the approach utilised for this thesis: an engaged ethics approach. With these similarities I understand that I am building from the Pallium project and continuing the European scholars’ intent of focusing on this broad, and often missing, dimension of the ethics of HPC practice. The intention of both the Pallium study and this ethical investigation is “to provide direction towards an articulation of the moral specificity of palliative care” (Janssens et al., 2002, p. 73).

Another European scholar, Hermsen (2005), conducted a literature-based study into the ethics of palliative care. In her thesis, Hermsen investigates the specific moral problems that have been included in hospice palliative care journals, with the intent on understanding whether HPC practice has a specific moral dimension. Hermsen (2005) concluded that the moral problems mentioned did not arise exclusively in the practice of hospice palliative care, yet the “virtuousness” required in the care of the dying meant that there was a “value surplus” that is an “expression of the specific moral dimension of hospice palliative care” (p. 169). Hermsen’s reflections and discoveries, especially the notion of virtuousness and a value surplus, have been insightful in the ethical conversation provided in this thesis.
Olthuis (2007) has provided another insightful ethics text for the hospice palliative care profession which came out of the European context. Olthuis’ (2007) text, entitled *Who cares? An ethical study of the moral attitude of professionals in palliative care practice*, posits that HPC professionals practice on a daily basis from a specific moral attitude, defined in general terms as “the motivation and commitment to act in the interest of other people” (p. 3). Specifically, Olthuis focuses on the nature of this moral attitude, and how it can be maintained and further developed. This research text links into chapter six of this thesis when considering the ethical frameworks of HPC professionals, and particularly a virtue-based understanding of ethics. In conclusion, Olthuis states that the practice of HPC is “closely interwoven” with the self-identity of the person who cares. In his summary chapter, Olthuis offers some reflections about three moral notions: phronesis (practical wisdom), the caring conversation and the covenantal relationship. Each of these three notions, and the general discussions, reflections and findings of Olthuis’ research, have been incorporated into the explorations of this thesis and provided for another timely platform from which to enhance the significant insights of this investigation.

Finally, the research of an Australian author, McNamara (1998a/b; 2001; 2004), a Western Australian anthropologist, have provided helpful directions and incorporations for this thesis. McNamara conducted extensive research into the moral notion of the good death. Her thesis “*Good enough*” death: *An ethnography of hospice and palliative care* (1998b) and her follow up book entitled *Fragile Lives: Death, dying and care* (2001) also parallel aspects of this research project. Although McNamara’s analysis of the good death plays the central role in her research, it is much more her writings on how palliative care has been changed by the values and concepts of autonomy, individualism and choice that are critical for this inquiry. McNamara also provides an important critique of the medicalisation of palliative care, which has been incorporated into this thesis.
These key texts mentioned above make up the bulk of the HPC ethics literature in the world today. Certainly, there are smaller journal articles available, but often they are non-research based, and generally they are about particular ethical issues, and most likely, the key ethical issue, that of euthanasia. To reiterate, this research inquiry provides a different way of viewing the ethics agenda, is a research based inquiry, and one that does not simply focus on one particular issue, but takes a broad sweep across the underlying ethics of practice that influence everyday HPC.

1.10 Limitations of the inquiry

In maintaining a stance of transparency in postmodern research it is important to mention some of the limitations of this investigation. There are always limitations in any research inquiry. Indeed, limitations are an important component in any academic work, to set up the boundaries of an inquiry. This thesis is not exempt from these.

One limitation that can be recognised in this study concerns the nature of stories. It is recognised by narrative theorists that stories are always unfinished, embellished upon and have parts omitted. Parry (1991) reports that “in a story there is, of necessity, more left out than included” (p. 41). Stories are inherently incomplete. Furthermore, the stories that people tell do not necessarily equate with actual practice; what people do. Thus, this is a limitation of any study utilising a narrative approach to research. Then, in turn, the meta-story that has been created from the multiple voices of the storied accounts of professionals, the literature and my voice is also unfinished, constructed by one writer who has chosen and omitted. The nature of this thesis means that it is viewed as an important part of a continuing conversation about the ethics of HPC practice. Further considerations of limitations include the primary focus on the living-dying person, the HPC professional and the relationship between the two. This means that the family and friends of the living-dying person, who are also important in the practice of HPC, are largely missing from this study. I also acknowledge that a Western perspective has been taken in this study which precludes considerations of cultural diversity. These are some of the elements that make up the limitations of this thesis.
Finally, something that it not necessarily a limitation of the research, but rather a complexity that simply needs to be pointed out to the reader, is that I have, through necessity, imposed a separation and structure on such concepts as philosophy, beliefs, attitudes, principles, values, morals, ethics, telos, and goods. This separation and structure was necessary for the explorations and structures in this study. However, the author appreciates that many of these concepts do overlap and intertwine with each other in meaning.

1.11 Chapter summary
This introduction has set the scene for this thesis by presenting an explanation of hospice palliative care, including the demarcation of this practice, the differing terms utilised and some current critiques concerning the practice, including the important considerations of the external influences on the practice. An articulation of the viewpoint of applied ethics – an engaged ethics approach - was then briefly explained and is further clarified in chapter two. The important purpose, rationale and questions of this inquiry were set out and the pertinent HPC ethics literature reviewed. Finally, some limitations for the inquiry have been mentioned. The contents of this introductory chapter have provided an explanation of hospice palliative care practice and the format for this critical inquiry.

1.12 Contents of this thesis
Part one of this inquiry, which is entitled The Floorboards, sets out the foundations of this thesis. This has included the crucial underpinnings of this research inquiry, as outlined in this introduction. Next, chapter two provides an outline of the conceptual foundations and methodological approach of this thesis. It includes a comprehensive account of the engaged ethics approach, an articulation of a social practice framework and an exploration of the basis and role of narrative inquiry. In addition, it includes the pragmatic research processes undertaken in this investigation. This includes the important contexts and HPC professionals who took part in this inquiry.
Part two of this inquiry, which is entitled The Walls, sets out the explorations of the three chosen components of the social practice framework. Chapter three thoroughly explores the tradition of hospice palliative care, looking back to the modern origins of this practice and the importance of the philosophy of (total) care. Important insights and arguments of the erosion of this central philosophy are contained in this chapter. Chapter four critically explores ontology: what it understood of personhood, or what it means to be a human being. This chapter incorporates the subtle understandings of personhood articulated by the HPC professionals and the literature that reinforces a particular type of modernist self. Considerations of an embedded account of personhood, which align with the philosophy of (total) care, are also presented. Chapter five investigates the purpose or teleological features of HPC practice. This chapter outlines the central, overarching goals of the practice and includes critical insights into the importance of relationship as a goal. This chapter articulates a new telos for HPC practice.

Part three of this inquiry, which is entitled The Roof, tops off this thesis with chapter six which includes an outline of the ethical frameworks articulated by the HPC professionals. This includes the explorations about the role of principlism and the centrality of the principle of respect for autonomy in HPC practice. This chapter also contains the important presentation of the values which underpin practice and an argument for a unique ethical dimension for HPC. Importantly, this chapter provides a distinctive ethical framework for the profession: A Relational Ethic of Accompanying (REA). Finally, chapter seven concludes this thesis by reiterating the key insights that have been illuminated in this critical exploration of the ethics of hospice palliative care, some suggestions for ways forward, and the poignant expressions of hopes for the future from the HPC professionals.
CHAPTER TWO
Methodology: Foundations of Thought and Processes of Research

Confronted with a mountain of impressions, documents, and field notes, the qualitative researcher faces the difficult and challenging task of making sense of what has been learned. I call making sense of what has been learned the art of interpretation (Denzin, 2004, p. 447).

2. Introduction

The research processes for this inquiry are multi-faceted. By research processes I am alluding to more than the interviewing and data collection phase of a study. I include all such processes of research involved in this inquiry; the conceptual underpinnings, the analysis method, the writing process and the concrete activities such as recruitment and interviewing. Therefore, these are the elements of this chapter. This research is underpinned by three conceptual foundations; an engaged ethics approach to understanding and doing ethics (Isaacs & Massey, 1994; Massey, 2002); a social practice framework for understanding the ethics of a professional practice (Isaacs, 1998); and the theories and methods of narrative inquiry. Each of these three conceptual foundations is crucial throughout this research inquiry and deserves full attention in this chapter.

Although a brief outline of the engaged ethics approach was offered in the introduction, it requires further examination. To better understand the engaged ethics approach it is juxtaposed to the current, dominant approach to ethics, that of principles-based ethics (PBE), which stems from the Western moral philosophical tradition, a tradition that is firmly situated in modernity. A brief description of the PBE approach is included in this chapter. This principles-based approach has been critiqued over recent times and some of those criticisms are mentioned in this chapter. However, this is not the overt focus of this chapter. Rather, attention is paid to outlining the engaged ethics framework which, arguably, is a fuller conceptual framework for engaging in ethics. A social practice framework, as articulated by Isaacs (1998), is then described, including how the features of this framework have influenced this inquiry. Both the engaged ethics and social
practice framework have provided a significant foundation for the development of this research; of assistance with the conduct of the research processes; and with the interpretation and structuring of the written task of this thesis. Once these significant foundations are presented, other research processes are examined. This includes the initial ethics clearance applications, consent processes and the methods employed for locating interested HPC professionals. A profile of these HPC professionals is provided which includes their roles and the contexts they work from. Finally, the narrative research methods of interviewing, transcribing, interpreting and evaluating are detailed.

2.1 A dominant approach to ethics: Principles-based ethics (PBE)\textsuperscript{11}

To understand the engaged ethics approach, it is juxtaposed to the dominant approach of understanding ethics - principles-based ethics (PBE). The ethics of health care practice, and more recently, the ethics of HPC practice, are predominantly understood by a modernist, moral philosophical tradition, of which PBE is a part. This moral philosophical gaze, as Isaacs (2001) refers to it, has several key components, each displaying typical characteristics of modern Western thought. Moral philosophy emphasises the making of decisions about ethical problems. This is why this approach is also sometimes known as decisional or choice morality: focusing on making choices when faced with issues, problems or dilemmas (Kekes, 1990). Here there is a direct linkage between philosophical theories and principles to the problems of practice (Isaacs, 2001). Moral philosophy is an approach to ethics that is individualistic in nature, focusing on the moral agent as the one to decide (‘what ought one to do?’), thereby emphasising a personhood that is atomistic in nature. This individual also requires a stance of rational, objective detachment (Gadow, 1999). There is a reverence of human reason or rationality in the moral philosophical tradition (Isaacs, 2001). The work of moral philosophy requires the application of universal, abstract principles to ethical considerations. Thus, it usually encompasses the realm of moral or ethical theories, principles, codes and laws. It is universalism which is at the heart of the moral philosophical tradition, whereby “this modern turn in ethics aims at overcoming the

\textsuperscript{11} Principles-based ethics is often referred to as principilism. These two terms are used interchangeably in this thesis.
relativity of competing parochial certainties by producing one incontestable system of universal principles” (Gadow, 1999, p. 61). Each of these features are characteristics of modern Western thought (Isaacs, 2001). Callahan (cited in Randall & Downie, 2006) advises us that

Good ethical theory, it was believed, should be objective, rational, internally coherent and consistent, universally applicable, detached from individual self-interest, and impersonal in its capacity to transcend the particularities of time and culture (p. 15).

This modernist approach to ethics then translates into the well known approach which is referred to as either the principlist approach, or principlism, or principles-based ethics (PBE). This approach to ethics was championed by Beauchamp and Childress in their book, *Principles of Biomedical Ethics*, which made its first appearance in 1979 and has been refined since then. Now in its fifth edition (2001), this understanding and articulation of an ethical framework for practice has dominated health care ethics for many years (Cimino, 2003; McCarthy, 2003). The PBE approach concerns the “application of general ethical theories, principles and rules to problems of therapeutic practice, health care delivery, and medical and biological research” (Beauchamp & Childress, cited in ten Have & Clark, 2002, p. 237). Similarly, Randall and Downie (2006) explain the PBE approach as one of seeking “general theories, principles and rules, or most famously ‘oaths’ and ‘codes’, which can be universally applied to the work of health care” (p. 16). Widdershoven (2002) explains that “[ethical] problems can be rationally solved, by considering the pros and cons of the application of the principles” (p. 42). As understood by these explanations, it is the application of universal principles that are to assist in the ethical practice of health care, including HPC.

To summarise how the PBE model is understood, McCarthy (2003) writes that “the PBE approach is an ethical decision making process which negotiates between fundamental principles, on the one hand, and the nature of moral situations on the other” (McCarthy, 2003, p. 66). To utilise this ethical approach, it is understood that

1. There are no norms intrinsic to health care practice that should guide determinations of what the best action is in practice
2. There are fundamental ethical principles, shared among diverse ethical theories that should guide ethical action in health care. These principles are:
   - Autonomy: respect the views, choices, and actions of others
   - Nonmaleficence: avoid causing harm
   - Beneficence: act for the benefit of others
   - Justice: treat people fairly

3. Particular moral judgments involve applications of these principles and rules to concrete situations (Emanuel, 1995, p. 38).

These four principles, Beauchamp and Childress (2001) maintain, have been drawn from a “common morality, the set of norms that all morally serious persons share” (p. 3). In other words, the four principles are universal in nature. Where there may be a conflict in application between principles, the PBE model stipulates that none of the principles is a priori privileged (McCarthy, 2003). The final judgment of a particular principle, in relation to an ethical problem, “is presented as valid, and it is presupposed that every rational person should agree with it” (Widdershoven, 2002, p. 42).

**2.1.1 PBE in hospice palliative care**

The PBE approach was specifically designed with ethical issues in medical practice in mind. It seems, for whatever reasons, that the HPC literature has, by and large, adopted this approach. Possibly the adoption of the PBE approach in hospice palliative care ethics comes hand in hand with the medicalisation and mainstreaming of the professional. There are some arguments for and against the use of the PBE approach in end of life caring practices. These arguments are explored further in chapter six. At this point it is important to note that the central, and for a long time, only text on HPC ethics, offered by Randall and Downie (1996; 1999), adopted the dominant PBE approach.

Randall and Downie (1999) assert that the practice of HPC requires a framework of ethical principles. Randall and Downie (1999) go so far as to link the goals of HPC practice with the four biomedical ethics principles. However, they do make the caveat that “the ethical principles which govern practice are necessary, but not sufficient to ensure that each individual patient receives the most appropriate care” (Randall & Downie, 1999, p. 26, original italics). Yet, the importance and centrality of a
biomedical, principles-based approach to ethics is evident throughout these texts and has influenced the usage of this ethics framework in HPC practice.

Similarly, Webb (2000; 2005) is another scholar who has written about the ethics of HPC practice and who adopts the PBE approach. Webb (2000; 2005) writes that “ethics is not just a matter of opinion, but requires reason and rational thinking to arrive at several possible solutions [and it is] the four principles that form the basis of this reasoning” (p. 8). The four principles include beneficence, nonmaleficence, justice and autonomy. Notice that what comes with the principlist approach is a focus on rationality, as mentioned in the initial description above. This means that it is through reasoned deliberation of these principles that ethical practice will follow. In fact, this is what principlism is; a rational and simplistic problem solving method, although the creators of this approach, Beauchamp and Childress, did not intend it to be interpreted in this way (Emanuel, 1995, p. 38).

2.1.2 Helpful or problematic?
The rational and concise approach of PBE to the ethical problems of practice can provide health care professionals with a concrete and abstract set of normative principles that can be followed and utilised in ethical decision making. Indeed, McCarthy (2003) concludes that the PBE approach “provides a method of supporting ethical decisions that has a strong justificatory force” (p. 68). Similarly, Emanuel (1995) writes that the appeal of principlism is its simplicity; “Knowing a small number of principles, non-ethicists had a framework, or a check list, by which to confront the many difficult ethical problems they encountered in medical practice” (p. 38). It is understandable to justify its appeal to busy health care professionals, looking for a methodical approach to understanding ethics.

However, within the field of ethics the modern, moral philosophical paradigm, and the PBE approach more specifically, has been criticised and alternative frameworks suggested. Gadow (1999) simply suggests that “they [the principles] provide less certainty than they promise … interpretations of a principle can conflict in clinical
situations” (p. 61). Widdershoven (2002) proclaims that “many authors have criticised the abstract and rationalist approach embodied in the ‘Georgetown mantra’ (PBE) and have proposed alternatives” (p. 41). Indeed, Elliot (1999) goes so far as to suggest that the “attack on the principles-based approach to bioethics is symptomatic of a much deeper and broader worry about philosophy” (p. xvii). Elliot (1999) likens the domination of the moral philosophical tradition to a disease and outlines some of the problematic elements of it. It is for Elliot (1999) a problem with theorising that is at the heart of the disease, especially when Beauchamp and Childress put forth such statements as

Judgments about what ought to be done in particular situations are justified by moral rules, which in turn are grounded in principles and ultimately in ethical theories (p. 5).

Aside from the problem of theorising, Elliot (1999) outlines his main concerns about the use of the modern, moral philosophical tradition to include the presentation of ethical problems and cases as general, impersonal and factual. The ethical problem in question is usually presented, in health care settings, as general in that it does not refer to a particular person, with a particular life biography. The ethical case is presented in an impersonal way, which means that the professional caregiver takes the position of objective and neutral observer. That is, Elliot (1999) maintains, “it is not a case in which you, the reader, are involved, nor is it one in which I, the narrator am involved, nor for that matter is it one in which any agent whatsoever is involved” (p. xxiii).

Finally, Elliot (1999) complains that ethical cases are often presented as factual, in that the privileged information is the empirical facts that a professional can make a rational decision about.

Overall, Elliot (1999) upholds, it is the suspicion of universality, which is the main symptom of the disease in moral philosophy. Gadow (1999) points out that this appeal to universalism is false in that any principle requires interpretation, thereby compromising its universality. These interpretations of a principle will differ according to the perspectives of the people involved (Gadow, 1999, p. 62). This is evident when considerations of harm or good are discussed and the varied interpretations of these
principles are offered. Thus, alternative frameworks for the understanding and doing of ethics now focus on the “locally contingent frameworks of understanding” (Elliot, 1999, p. xxiv). Or, in other words, frameworks that focus on the particularities and the richness of the ethics of practice. For “our moral intuitions start to kick in only when we know a lot more” (Elliot, 1999, p. xxiv). Knowing a lot more means adopting a position of understanding, particularly shared understandings, and dialogue; a communicative process between two or more people (Widdershoven, 2002; Isaacs, 1998).

Similarly, Isaacs (2001) draws out the inadequacies of the modern, moral philosophical tradition and the PBE approach. It is problematic in its approach because it views the nature of doing applied ethics as “primarily a cognitive, technical and, largely, theoretical task”, writes Isaacs (2001, p. 7). Like Elliot (1999), Isaacs (2001) is suspicious of the privileging of theorising. The dominant moral philosophical approach, in addition, has positioned the philosopher or ethical expert as the only one able to ‘do ethics’, thus the philosopher is required to ‘guide’ others in the ‘how to’ of ethics (Isaacs, 2001). This, in turn, devalues the place of everyday people’s moral experience and imagination.

For Isaacs (2001), it is the view of personhood - the ontological account of what it means to be a person – that is at the heart of the problematic nature of the modern, moral philosophical approach. This approach suggests a type of neutral person, as Elliot (1999) suggests, without agency and not connected to other people, or from a particular time and place. Brody (cited in Widdershoven, 2002) states that the person in question “is regarded as a technical object, not as a person with specific wishes and desires” (p. 46). Hence, the moral philosophical account of personhood can include a neutral or invisible type of person, a technical, objectified self, or a rational, thinking being, which thereby privileges the mind as the defining element of a human being. There is a need to understand people, in their ethical worlds, in much richer ways. The engaged ethics approach re-enlivens this consideration of the ontological in the ethics agenda. Our ontological considerations of what is means to be a human being; or who is the living-dying person are reflected upon in chapter four. For the purposes of this chapter it is
simply important to note that critics, such as Elliot (1999), Isaacs (2001) and Widdershoven (2002), suggest that a rich account of the self is largely missing in the modern, moral philosophical tradition.

Aside from these critiques presented above, the HPC literature also presents some questions about the appropriateness of PBE. For example, the principle of respect for autonomy sits uncomfortably with the ‘family as the unit of care’ approach in HPC practice. These considerations of whether the PBE approach is evident, and helpful, in hospice palliative care professionals’ stories are further explored in chapter six. What is important to note is that the original advocates for the PBE approach in HPC practice, Randall and Downie (2006), have recently announced that this approach is redundant. These authors are agreeing with the concerns, noted above, about the privileging of universality, to the detriment of particularity. “Rules, generalisations and broad principles have their place … but we must always come down to the individual case”, write Randall and Downie (p. 14). They denounce the PBE approach suggesting that “health care professionals do not seem to use the principles in the resolution of cases” (p. 15). Rather, Randall and Downie (2006) now promote a case-based approach to the ethics of hospice palliative care. Furthermore, the critiques that Randall and Downie (2006) then present, after repudiating the principles-based approach to ethics, still heavily relies upon the principles of nonmaleficence (harm or risk) and beneficence (good or benefits). Thus, this demonstrates that Randall and Downie are still somewhat embedded in the PBE approach.

2.2 An alternative account of ethics: Engaged ethics

There are, however, alternative accounts of the ethics agenda in the literature; one of these being an engaged ethics approach as presented by Isaacs and Massey (1994). This is the preferred approach to ethics for this inquiry, as outlined in the introductory chapter. The concerns leveled at the modernist agenda are addressed by this transformative, collaborative, contextual and relational approach to ethics. What Isaacs and Massey (1994) have articulated in their engaged ethics approach, is “a fuller
conceptual framework for engaging in ethics” (Isaacs, 2001, p. 11). As stated in the introduction, the understanding of ethics by this approach is concerned with

Creating and sustaining relationships which mutually recognise the needs, interests and aspirations of all participants as ‘ends in themselves’. The focus is on the continuing enhancing of the other and the self within the human social condition as it is actualised within specific situations, roles, practices, institutions and cultures. In short, applied ethics seeks to enhance the ethical form of life (Isaacs & Massey, 1994, p. 2).

Hence, this study concerns the understanding and enhancement of the living-dying person who is in relationship with the HPC professional within the practice of HPC.

By this understanding of ethics we recognise a differing human form; a thicker understanding of the self (ontology) that views human beings as being embodied; as beings of body, thereby not privileging the intellect (mind). This situated self “encompasses not only rationality but emotion, imagination, memory, language, the body, and even other selves”, asserts Gadow (1999, p. 62). Furthermore, engaged ethics re-emphasises the importance, and inescapability, of our social and relational embeddedness and reformulates two central ethical questions - ‘what ought we to do?’ and ‘who ought we to be?’ thereby de-centralising the individualistic approach taken by the moral philosophical tradition, and re-centralising the importance of relationships. Intersubjectivity is central, rather than detachment (Gadow, 1999). Importantly, engaged ethics values particularities, which can be found in thick, storied accounts, rather than in abstract, universal principles. It goes beyond a problem or decisional approach to ethics, and rather sees the ethics agenda as one of flowing through the whole of our lives; everyday and every moment, with each person, and with the aim of enhancing an ethical form of living.
What this alternate view of ethics then translates into is the four interrelated dimensions of the engaged ethics approach. These include the hermeneutical domain; the appreciative domain; the appraisive domain and the transformative domain.

The ethical challenge has many dimensions – it is concerned with raising awareness and developing insight and understanding; it is concerned with cultivating appropriate sentiments, virtues and dispositions; it is concerned with reasoned appraisal and judgment; and it is concerned with strategies of responsive action at both the individual and collective levels (Isaacs & Massey, 1994; Isaacs, 1998, p. 22).

It is important to note that this is not a step by step, linear model. Rather the four domains interweave and are interrelated. Each domain, and the tasks within them, is of equal importance. Therefore, as this thesis embraces the engaged ethics approach, the four domains have played a central role in conducting this inquiry. Indeed, each domain provides the silent and subtle foundation to all that is done and written in this thesis.

2.2.1 Seeking understandings
For the engaged ethics approach a central, and often foremost task, is that of developing understanding. This task requires the “mastery of appropriate hermeneutical understandings” (Isaacs & Massey, 1994, p. 3). The word hermeneutic is derived from the Greek *hermeneuein* which means to interpret. Abbey (2004) indicates that according to a standard definition “hermeneutics is the theory or art of interpreting texts” (p. 29). The aim of this interpretation is “to bring out that meaning or make it more vivid” (Abbey, 2004, p. 30). Early Greek root words of hermeneutics suggest the idea of bringing to understanding, particularly where this process involves language (Leonard, 1994, p. 55).
Understanding ‘texts’ happens on many levels in this thesis. Firstly, I have previously sought, and presented herein, a greater understanding of the living-dying person (Wilson, 2002). Secondly, the HPC professionals’ storied accounts provide the central means of understanding in this thesis. This includes the understanding of the practice, their relationship with the living-dying person, and of themselves as HPC professionals. Finally, understanding was sought through the HPC literature. Indeed, understanding was the central purpose of this inquiry as it was directed by the question: how is the ethical dimension understood by its professional members? I explored the understanding of the philosophy of (total) care; the understanding of personhood and identity; how the ethics of practice was understood; and how the purpose of the practice was articulated. In mapping these new and existing frameworks of understanding I have, in turn, developed rich frameworks of understanding “which are consonant with the complexity of the ethical [practice]” under study (Isaacs & Massey, 1994, p. 4). Ultimately, it was the understanding of people, relationships and practice that guided this inquiry.

2.2.2 Appreciating personhood

Secondly, the appreciative task has assisted me in promoting and exploring relationships with HPC professionals that “acknowledge their richness, complexity, perplexity and, perhaps most significantly, their particularity” (Isaacs & Massey, 1994, p. 6). Within this appreciative domain I challenge the assumptions of what it means to be a person; a professional; and a living-dying person, thereby developing further appreciations of people. Thus, it has been the intention of this study to promote a fuller account of what it means to be a human being. Isaacs (2001) also mentions the importance of dispositions or virtues in the appreciative engagement. Certainly, this is a further crucial element of what has come forth in this study; that is, the role of compassion, honesty, authenticity in caring for the dying. HPC professionals placed these qualities high on the list of how best to care for living-dying people. Furthermore, the appreciative domain encompasses all of “how we respond to an encounter with the other” (Isaacs,

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13 This investigation of virtues or dispositions is included in chapter six where the role of virtue ethics is considered in hospice palliative care practice.
This is a crucial aspect of this inquiry, as the other is the living-dying person, and it is their care, as they die, that lies at the heart of this study. It was the articulations of how to be responsive to the needs of each unique human being which reflected the depth of ethical engagement that HPC professionals practiced.

2.2.3 The role of judgment

According to the modernist philosophical approach the appraisive domain is often the starting point of ethical deliberation. Isaacs and Massey (1994) propose that according to the modern, moral philosophical paradigm, initial deliberations are “born at the appraisive stage”, where one is asked to make a judgment or evaluation (p. 3). As Brody (2003) explains this modernist approach understands ethics to be about “making judgments based on abstract principles” (p. 176). This is why Urban Walker (1998) calls the modernist account of ethics a theoretical-juridical model; the making of moral judgments. Certainly, as a critical exploration this third domain is important. Yet, in the engaged ethics approach it is not the first and central task of ethics. That being said, however, this domain has prompted me to make discerning judgments and criticisms of that which I have understood from the spoken and written texts. This dimension “recognises the place of practical evaluation in human situations” (Isaacs, 2005a, p. 5). Ultimately, this task has enabled me to promote the appraisal of the relationships and practices of HPC “according to ethical criteria rather than, for instance, pragmatic, technocratic or economic criteria” (p. 9). Herein, the place of “practical judgment” is recognised as important (Isaacs, 2001, p. 14).

2.2.4 Strategies of change

In seeking to enhance the ethical form of living, or in other words, the ethical caring practices at the end of life, considerations of change are important. The motivation to conduct this study in part stemmed from a hope of transforming some of the possible erosion of HPC practice. Isaacs (2005a) explains that this transformative dimension “addresses the challenge of responsive action and focuses on developing an understanding and mastery of, appropriate strategies for change” (p. 5). Arguably, with the new understandings and insights that have come forth from this inquiry, new
approaches in HPC caring practices can be offered. In addition, the process of articulation, in the telling of stories by the HPC professionals, is something different, or a strategy of change. This task of the transformative is overtly addressed in the last chapter of this thesis, as it presents an overview of the ethical dimension of HPC practice as understood in this inquiry and the future visions of the practice by its professional members.

To reiterate, these four domains, as they overlap and interweave with each other, have played a fundamental role in this inquiry, as they orientated and guided the research process. To summarise this section on the engaged ethics approach, I conclude with a table that offers the key differences between the dominant modern approach to ethics (moral philosophical tradition and PBE) and the approach to ethics adopted in this thesis (engaged ethics). Table two summarises the key differences between each approach.

**Table Two: Two viewpoints of applied ethics**

<table>
<thead>
<tr>
<th>Moral Philosophical Tradition</th>
<th>Engaged Ethics Approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Based on the assumptions of modernity</td>
<td>Built on new assumptions of postmodernism and ethical pluralism</td>
</tr>
<tr>
<td>Focuses on dilemmas, issues and problems and emphasises the decision making process (the ethics <em>in</em>)</td>
<td>Seeks to enhance the ethical form of life; in each moment, interaction and relationship. How a social practice is carried out overall and who we are (the ethics <em>of</em>)</td>
</tr>
<tr>
<td>Ethical processes as rationally and logically analysed</td>
<td>Ethical processes that acknowledge the role of emotion and intuition, as well as rationality</td>
</tr>
<tr>
<td>Understands personhood in a thin way – as unsituated, impersonal, intellectual, rationalistic, and individualistic</td>
<td>Understands personhood in a thick way – as embodied and embedded in relationships, time, language and nature</td>
</tr>
<tr>
<td>Asks the question – ‘what ought I to do’?</td>
<td>Asks the question(s) – ‘what ought we to do/live/relate/die’?</td>
</tr>
<tr>
<td>Thereby, focusing on the individual moral agent</td>
<td>Thereby, focusing on the interrelatedness of human beings</td>
</tr>
</tbody>
</table>
The work of ethics involves the application of abstract, universal moral philosophical theories, principles, rules and codes

Attending to the general, impersonal and factual elements in an ethical case

Ethics as a theoretical and technical task, carried out by the philosopher or ethicist (external to the practice)

Ethical universalism: Objective certainty based on rational detachment (Gadow, 1999)

The work of ethics involves engaging with the four key tasks of the hermeneutics, appreciative, appraisive, and transformative, with and through the use of narratives.

Attending to and appreciating the rich particularities in stories and contexts

Ethics as a human endeavor carried out by all health care professionals (internal to the practice)

Ethical engagement: Intersubjective contingency based on relational narrative (Gadow, 1999)

### 2.3 A social practice framework (SPF)

A further important conceptual foundation, a social practice framework (Isaacs, 1998), has also been of assistance in the understanding of the ethical dimension in a professional practice. This social practice framework has similar facets to that of the engaged ethics approach, as outlined in the table above. It also has particular unique features, as described below.

The notion of a social practice has received scant attention over the years. Isaacs was inspired by both Langford (1991) and MacIntyre (1981/1984) in his conceptualisation of a social practice for understanding the ethics in medicine. In *After virtue* MacIntyre (1981) explains that by a practice he means

any coherent and complex form of socially established cooperative human activity through which goods internal to that form of activity are realised in the course of trying to achieve those standards of excellence which are appropriate to, and partly definitive of, that form of activity, with the result that human powers to achieve excellence, and human conceptions of the ends and good involved, are systematically extended (p. 187).
Thus, such things as sports, politics, arts, sciences and professions can be social practices, suggests MacIntyre (1981). Langford (1991) outlined his reflections on *Teaching and the idea of a social practice*, which Isaacs draws from. Langford (1991) was interested in the specific feature of a purpose within a social practice:

A social practice depends for its existence and identity on the overall purpose which its members share and are reciprocally aware of sharing ... a social practice [is] given unity and identity by the overall purpose which gives direction and point to the behaviour of its practitioners (p. 28).

This feature of a social practice, outlined by Langford, is explored in chapter five where the purpose of HPC practice is critically explored. Additionally, Wildes (2001) is an author who explores a social practice framework when discussing the social constructionist nature of medicine. Wildes (2001) focuses on “a moral vision of how the practitioner ought to act” (p. 82) and so is concerned with those virtues or dispositions a caring professional must develop. Wildes (2001) continues by contending that the purpose (goals) of medical practice are socially established and are public and that the most crucial point is that medicine (like HPC) is socially constructed, thereby influenced by the values, moral or otherwise, of the culture in which it is situated. This is certainly the case with HPC practice as it has evolved over the years and been influenced by changing societal values such as autonomy and choice (McNamara, 1998b).

Like Wildes (2001), Isaacs (1998) originally wrote his *Social practice, medicine and the nature of medical ethics* (1998) to pertain to the practice of medicine. Yet, this framework is easily transferable to other professional practices wishing to explore the nature of ethics. This thesis applies and extends this social practice framework into the field of HPC practice. Clearly, HPC is a social practice because it is characterised by humans, in relationship, carrying out activities. It is also aimed towards a ‘good’ and excellence in these activities. HPC practice is usefully conceptualised as a social practice because it is “identified as an entity which belongs within the realm, not of nature, nor of ideas, nor of artefacts, but of the social” (Isaacs, 1998, p. 3). It is constituted by individual persons, relationships between persons and an overall relationship and commitment to the community. It is situated in a social context of time and place. Isaacs (1998) would suggest that HPC would be a particular kind of social
practice because of this distinctive relationship of care and trust it has with the community of people it serves. Hospice palliative care, as outlined in chapter three, came out of a particular historical, social movement. HPC “is a societal creation” (Isaacs, 1998, p. 3). This inquiry utilised this social practice framework (SPF) to examine the ethical dimension of hospice palliative care practice. If I was working from a traditional moral philosophical tradition I would have examined the practice externally, primarily using ethical theories. However, with the SPF an internal examination was privileged, which sought to gain the professional members’ understandings. An internal approach to the ethics of HPC practice, not only required the privileging of the professional voice, but also the focus on the central features of a practice.

2.3.1 The features of a social practice
After understanding what a social practice is, and that HPC is a social practice, we now turn to the central features of a social practice. Isaacs (1998) explains that there are “five interrelated features which characteristically reflect the nature of many social practices” (p. 5). These include

- Social practices are constructed by, and constituted by, persons
- Social practices are directed towards an overall purpose
- Social practices are shaped by a tradition
- Social practices depend on processes of learning and socialisation
- Social practices require an institutional authority structure (pp. 5-8).

Thus, the practice of HPC will have these features. Certainly, each of these features is helpful in this exploration of the ethics of HPC practice. However, this inquiry has focused upon, in the main, the first three of these features.

2.3.2 Practices as constituted by persons
A social practice is recognised as being constituted by people. This feature recognises that a social practice is a practice that can “only exist in, and through people” (Isaacs, 1998, p. 4). This feature is considered through the ontological examination of who the professional care-giver is; how do they see and understand themselves in this caring role; and how do they see and understand the living-dying person in this social practice?
As mentioned above, this ethics inquiry sought to challenge the assumptions about what it means to be a person and develop thicker appreciations of personhood, as required by the appreciative domain of the engaged ethics approach. These ontological considerations are outlined in chapter four. By focusing on this feature of a social practice this inquiry reinvigorates our ontological considerations in ethics.

2.3.3 Practices are embeddedness in time
Social practices come out of a particular time, and thereby are shaped by a tradition. This is a central concern of this thesis, as mentioned in the introduction. Modern HPC practice was borne from a particular time; the 1960s. From this time an important philosophy of care was created to provide a particular way of caring for the dying. This philosophy of care was underpinned by significant values. Therefore, in choosing to focus on the feature of tradition, this thesis sought to explore this tradition of the practice and how it was understood and how it might have changed and, importantly, be changed. These considerations are included in chapter three and six.

2.3.4 Practices with purpose
The final feature focused upon in this inquiry includes the purpose of the practice. The feature of purpose in this social practice framework is understood as the telos, or the teleological features of a practice. Teleology stems from the Greek word *telos* which means end, aims or purpose (OED, 2007). The teleological features of HPC practice are stated in such words as a goal, purpose, objective, aim, ends, or goods.

The telos of the practice of HPC is a crucial element of the ethical dimension, and required close attention and articulation. This is because, as Ricoeur (cited in Widdershoven & Smits, 1996) suggests, it is this teleological nature of the practice that is the basis for ethics. Quite simply, it is “the teleological character of practices [that] is the foundation for moral obligations” (Widdershoven & Smits, 1996, p. 279). Furthermore, the teleological features of the practice of HPC play an important role in the development and maintenance of a professional identity. For they
provide unity to a practice since it provides a common goal that brings together the members of the practice and it provides the justification to the ways of ‘seeing’ and ways of ‘acting’ which are taken as the appropriate means to the goal as an end. It provides identity since it allows both the members and those external to the practice to demarcate the practice as distinctive from other practices which are differentiated by virtue of their different purposes or ends (Isaacs, 1998, p. 6).

Arguably, it is this exploration and articulation of these teleological features of the practice that the HPC profession currently requires. The telos of HPC practice needs to be clear “for its existence and identity”, asserts Langford (cited in Isaacs, 1998, p. 6). The telos requires a shared understanding between its members (Langford, cited in Isaacs, 1998). Thus, for several reasons the exploration and clarification of the purpose of HPC practice is an essential component to the ethical dimension. The considerations of this important feature are presented in chapter five.

The remaining two features of the social practice framework (Isaacs, 1998) - social practices depend on processes of learning and socialisation and social practices require an institutional authority structure - are certainly as important as the other three. However, it was not within the scope of this thesis to include them to any great degree. Certainly, the two remaining features are included in several places, as each of the features is interrelated. The feature of learning and socialisation is an important one (Isaacs, 1998). It acknowledges the importance of learning processes over time, as new members join the profession. Isaacs (1998) explains that the practice is able to have continuity through time “inasmuch as one generation teaches, inducts and socialises the next” (p. 6). This is certainly an important consideration for HPC practice as it evolves over time. It is known throughout the profession that there is a shortage of HPC professionals, that there are questions being asked about how to mentor new professionals, and a great deal of attention is being paid to education processes for HPC practice. The final feature of a social practice that alludes to organisational authority (Isaacs, 1998) is the dimension which “legitimates, protects, and regulates what counts as authentic interpretations of both the purpose of the practice and its guiding tradition” (Isaacs, 1998, p. 6). Similarly, with the learning and socialisation feature, this feature of authority is crucial in HPC practice. This feature inherently is about power and any
ethical examination requires an examination of issues of power. Thus, there are points throughout this thesis that highlight the complexity and embeddedness of issues of power. It is an implicit consideration throughout.

Finally, Isaacs (1998) explains that there are a further three features important to consider in social practices. Firstly, that they are embedded within a broader social setting, alongside other social practices. Certainly these contextual considerations are important in this exploration. For example, the influence of the practice and values of biomedicine are bringing about notable changes in HPC at present. Secondly, social practices have the capacity for good or evil (Isaacs, 1998). Certainly, this is evident in HPC practice. For example, some HPC professionals articulated in their stories that they know best about how to care for a living-dying person and this translates into a powerful advocacy role. This role of the advocate for a living-dying person could have the potential to be equally harmful or helpful.

The final feature for consideration in the SPF is that practices are “vulnerable and fragile realities since the practice can only be actualised through the beliefs, actions, commitments, fidelity, and presence of its adherent members” (Isaacs, 1998). Isaacs (1998) maintains that erosion of membership and beliefs of a social practice may lead to the demise of the practice. This is certainly an important feature at this time for HPC practice, and for the concerns and questions of this thesis. This is especially because it can pertain to lost or altered beliefs and values. Certainly, important questions need to be asked such as: Is there demise in HPC or is it simply taking a new shape? If it is taking a new shape, is the new shape aiming towards or away from the good? Is it more or less ethical? These are important questions and ones that reinforce the understanding that a social practice “has a precarious existence of vulnerability and fragility” (Isaacs, 1998). Arguably, as Rumbold proclaimed in the 1990s, “hospice and palliative care are at present in crisis, facing both risk and opportunity” (1998, p. 14). I would suggest that present day HPC is still experiencing vulnerability, change and fragility.
All of these features of a SPF, but particularly the first three, have been invaluable in providing the parameters with which to explore the ethical dimension of HPC practice. The development of the inquiry, the questions and interviews undertaken, and the structure of this thesis have all been assisted by this particular framework for understanding social practices. Indeed, both of these foundational understandings of ethics, as outlined above, have been central to this thesis. However, they do not stand alone, for there is one further conceptual underpinning that requires outlining in this chapter. The theories, understandings and methods of narrative inquiry have also played a crucial role in the foundations of thought and processes of research of this inquiry.

**Table Three: Features of a social practice framework**

<table>
<thead>
<tr>
<th>Main Features of a Social Practice</th>
<th>Other Features of a Social Practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social practices are constructed by, and constituted by persons</td>
<td>Social practices are socially embedded</td>
</tr>
<tr>
<td>Social practices are directed towards an overall purpose</td>
<td>Social practices can be powerful instruments for promoting good or evil</td>
</tr>
<tr>
<td>Social practices are shaped by a tradition</td>
<td>Social practices are vulnerable and fragile</td>
</tr>
<tr>
<td>Social practices depend on processes of learning and socialisation</td>
<td></td>
</tr>
<tr>
<td>Social practices require an institutional authority structure</td>
<td></td>
</tr>
</tbody>
</table>

**2.4 Narrative inquiry: A world of stories**

Narrative plays a central and unifying role in this thesis. The next section of this chapter includes an outline of my understanding of narrative, and its relationship and relevance to this inquiry. In addition, the features of narrative are discussed in terms of its linkage with concepts such as knowledge, time, self-identity, illness, ethics, and research approaches. This is, by necessity, a brief look at each of these concepts as the theories of narrative now cover a hefty range of disciplines and texts. It is suggested that there is now a ‘narrative turn’ in many disciplines, including the field of ethics. As Denzin (2004) states, “the narrative turn in the social sciences has been taken” (p. 447).
This ‘narrative turn’, first called this by Mitchell in 1981, has, no doubt, many and complex causes (Davis, 2002, p. 3). Tamboukou (2006) affirms that the study of narrative “forces the social sciences to develop new theories, new methods and new ways of talking about self and society” (p. 1). Human beings are inherently storytellers; therefore the activity of narration creates meaning in our lives (Tamboukou, 2006). Arras (1997) simply announces that “theory is out and stories are in” (p. 66), thereby denouncing the centrality of theory, and replacing it with the importance of story in the ethics agenda. Brenner (1994) believes that “narrative answers and provides for most of the criticisms leveled at principles-based ethics” (p. 145) and this is why it has become so popular in ethics. Ultimately Squire (2005) contends that

The narrative turn can be associated with many other social-scientific moves in the late twentieth and early twenty-first centuries: turns to qualitative methods, to language, to the biographical, to the unconscious, to participant-centered research, to ecological research, to the social (in psychology), to the visual (in sociology and anthropology), to power, to culture, to reflexivity … [and thus] looking at the ‘narrative turn’ is to view a snapshot of what these turns have yielded (p. 91).

There are certainly varying reasons for the current appeal to narrative. With this appeal, and the multiplicity of settings embracing narratives, means that “no single definition or approach can exhaust its meaning” (Davis, 2002, p. 11). Narrative can mean many things, to many people. In saying this, it is recognised that a multiplicity of definitions are acceptable for what is a narrative. Some even suggest that narrative cannot be defined at all. McQuillan (2000) announces that “narrative is the very term which narrative theory wishes us to understand but which it cannot explain” (p. 323). Furthermore, narrative is often not defined in texts at all, as there is an assumed understanding that everyone knows what narrative means. Davis (2002) found it interesting that in an opening line in a book on narrative theory it stated “Everyone knows what stories are and a fortunate thing it is because it has been extremely difficult, despite many efforts, to formulate a rule that unequivocally distinguishes things that are stories from things that are not” (p. 11).
2.4.1 An account of narrative

However, for the purposes of this inquiry, I do wish to outline my preferred account of narrative. I do not wish to leave this as simply an assumed understanding. Firstly, I embrace a broad definition of narrative. Narratives can be the big ‘truths’ of our society; the smaller, and yet central, ‘truths’ of our identity and life; the accounts of our weekends; the presentations of our media; and the answers of questions that we ask of ourselves, or are told. Stories, for me, are everywhere and in everything. However, this being said, I do agree with Reissman (personal communication, 2007) when she asserts that not every single thing is narrative. I do not go that far with my broad interpretation of narrative.

It is also important to clarify the way I use the words ‘story’ and ‘narrative’. I tell a story that becomes a narrative. Even though I use these terms interchangeably, there is a difference in how they are used in form or speech. In addition, I understand narrative to be both a meaning making and articulation process, in either one’s mind or spoken to another. Thus, there are stories in my mind that are not spoken, and there are stories that are spoken to another; the audience or witness of the story. I also acknowledge that stories can take many shapes beyond the conceptual, imaginary, and verbal. This can include art forms, music and poetry. The narratives that are being referred to in this inquiry are the vocalised, narrative accounts provided by the HPC professionals; the narratives provided in written text format in the literature; and my story as researcher, interviewer, author and HPC professional.

As well as the explanations offered above about narrative, I also utilise a specific account of narrative which is offered by the field of narrative in counselling. Michael White (2001), the co-founder of Narrative Therapy, explains narrative as an account where someone describes or explains an experience or events (one or many), linked in sequence, across time, according to some type of theme or plot (or multiple plots).
With this account, some of the central features of narrative can be noticed. These are

- experience or events;
- linking or linkage;
- time / temporality;
- plot or theme (meaning).

An understanding of these central features corresponds with Elliot’s (2005) articulation of the key features of narrative. Elliot (2005) writes that narratives include (a) temporality – narratives represent sequences of events (b) meaningfulness – narratives carry rich meanings (c) sociality – narratives always have an audience (p. 6). Thus, in an individual sense, the stories we have about our lives (and our selves) are created through linking certain events together in a particular sequence across a time period, and finding a way of explaining or making sense of them. We will tend to select out certain events as important, to fit with a particular plot-line. This means that some events or experiences are privileged over others, according to what dominant plot-line we hold, or are creating. In other words, what we choose to tell.

Certainly, it is not as simplistic as this as our lives and selves are multi-storied. We are interconnected in a world of stories from society, from practices, from relationships, and other competing stories in our minds. As well as this, we can alter stories and change the meaning that we hold about an event or experience. In other words, an event or experience can be storied in many ways. Davis (2002) writes a similar description of his meaning of narrative. Davis (2002) writes that

> a minimal universal narrative form can be described by an emphasis of plot structure, the notion of narrative as an unfolding of events (actions and experiences) and the central importance of time. Past events are selected and configured into a plot, which portrays them as a meaningful sequence and schematic whole with beginning, middle, and end (p. 11).

Although I am mainly in agreement with Davis, I do not necessarily believe that stories require a beginning, middle and an end. Chaos illness narratives, as outlined by Frank (1995), do not necessarily have such structured or sequential elements to them and in my experience of listening to living-dying narratives, these, too, do not necessarily have coherent beginnings and endings.
2.4.2 Narrative understanding

With these central features of narrative in mind, stories then intrinsically provide a gateway to knowing and understanding. The word narrative comes via the Latin terms *narrare* [relate, tell], from the original Sanskrit root *gna* [know] and *gnarus* [knowing, acquainted with, expert, skilful] (Churchill, 1979; McCarthy, 2003). The idea of narrating has its origins in knowing and, therefore, plays a significant role as a system of meaning-making that helps with our understanding of experiences, life and self. Therefore, as this research inquiry has this intention to understand or know, narrative is an excellent form of inquiry to gain this understanding. The stories from the HPC professionals provide narrative knowledge that can illuminate the ethics of this practice. Fundamentally, through and with stories we come to make meaning of our selves, our lives and our practices. It has been several decades since Bruner (1987) outlined his thesis of narrative as a form of knowing, and coined the famous phrase, “a life as led is inseparable from a life as told. A life is not ‘how it was’ but how it is interpreted and reinterpreted, told and retold” (p. 31). There is an inescapability of narrative in our world as Sarbin (1986) suggests, “human beings think, perceive, imagine, interact and make moral choices according to narrative” (p. 8). Polkinghorne (1988) also makes the claim that “we need to make explicit the centrality of narrative in human experience and existence” (p. 125). Narrative is the primary way through which humans organise experiences into meaningful understandings. We cannot separate life or living from story; we cannot detach understanding from narrative. Important understandings and insights can be gained with and through stories.

Thus, narrative inquiry provides for the primary way of understanding the ethics of HPC practice in this research. It is an appropriate conceptual and methodological approach in seeking illumination on this complex topic. Unfortunately, even though HPC is “a discipline with an urgent need for a greater evidence base” (Aoun & Kristjanson, 2005, p. 462), narrative evidence is not greatly valued. Devery (2006) argues that “knowledge derived from individuals: stories of individuals is not adequately being valued in palliative care research” (p. 51). Devery (2006) suggests that
As a community of professionals we need to share knowledge and language that mirrors the complexity and subtleties of everyday clinical care; narrative can assist in this. Too often knowledge derived from individuals is relegated to mere anecdote rather than evaluated as sound evidence. Sharing experiences and insights about individuals can reinforce the principles of palliative care, assist in discussion, education and navigation of ethical issues and assist in developing a language that can fluently articulate the emotional and moral imports of knowledge in palliative care (p. 51).

Therefore, in many ways, as Devery suggests, narrative is of value in the profession of HPC. There needs to be a shift, however, in the valuing of stories as a valid means of knowledge building. The attendance to stories ultimately provides a way of understanding human experience in social practices that is “consistent with the way that people make sense of their self and world” (Rice & Ezzy, 1999, p. 122). It also has the advantage of being open-ended, of valuing diverse opinions and is respectful of many voices and so “may facilitate the emergence of previously unexplored themes in end of life care” (Fins, Guest & Acres, 2000, p. 406). In addition, “a good story not only broadens our imagination, but also gives us a clearer idea of what we mean by such moral concepts as honesty, kindness and respect” (Nusshaum, cited in Jones, 2002, p. 1). This is especially helpful in this inquiry as many such moral concepts are explored.

2.4.3 Temporal understanding in stories

Narrative is not only linked to knowledge, but also to concepts of time. Kerby (1991) believes that if we wish to inquire into human and social interactions we need to begin our exploration with the question of temporality. Indeed, this thesis does pay particular attention to the temporal elements of the practice of HPC, commencing with a consideration of the past of this profession. Narrative has helped assist with this element of time “to the extent that it portrays the features of temporality” (McAdams, 1993, p. 30). Time is inherent in all narratives. Ricoeur proclaims that “time becomes human to the extent that it is articulated through a narrative mode” (cited in Crossley, 2000, p. 49). In order to appreciate a practice such as hospice palliative care we need to have an understanding of how it has come into being (past), what are the current understandings of it now (present) and how it wishes to develop (future). That stories are “sequential, historical, and ‘in time’ can provide a conceptual framework” for understanding the
ethics of hospice palliative care practice since its inception and into the future (Del Vecchio Good, Manakata, Kobayashi, Mattingly & Good, 1994, p. 856).

2.4.4 Identity shaping

Narrative is also linked with self-identity. Narrative assists us in making sense of our identities, as it is self- and other-stories that help us constitute and construct who we are. This, in turn, can be translated into an understanding of the identity construction processes of a social practice. To explain, the particular stories that HPC professionals tell of their practice accumulate over time and form a meta-narrative of the practice. This meta-narrative forms an overall identity of the practice. Importantly, some aspects of HPC practice experience is omitted from the HPC professionals’ tellings, and so do not get incorporated into the meta-narrative of the profession.

Narrative functions by generating a construction, a process and a continuity of identity and can account for how identities are formulated. Over time these stories that HPC professionals tell, or not tell, forms this meta-narrative, or central identity of the practice. Rice and Ezzy (1999) outline their summary of how narrative works for an individual identity. I have modified this explanation to read as describing the processes of the formation of a social practice, or professional identity; the identity of the HPC.

Stories provide a sense of continuity, or sameness, throughout life. However, the story also changes as the social practice/profession has new experiences and as new events occur. The stories professionals tell about the social practice/profession shape how they understand and experience events, and events, in turn, also shape the social practice/professions identity. New events shape social practice/profession identities and new social practice/profession identities lead to new actions and events. Life is an ongoing cycle of actions and events, constructing and reconstructing social practice/profession identities (p. 26, modified).

Certainly, the identity of the HPC profession has changed over time, and these changes to the meta-narrative, or identity of the profession, are considered throughout this thesis. In addition to the assistance that narrative gives us for understanding the identity of the overall profession, stories have also assisted in the understanding of the ontology of the living-dying person and the professional caregiver. The HPC professionals who add

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their voice to this thesis have all articulated their stories of who they are; their professional and personal identity.

2.4.5 Stories in illness, dying and suffering

It can be seen that narrative forms a way of knowing, a way of understanding the temporal features of a social practice, and the identity of a practice and the professional. In addition, narrative is also proving helpful in the exploration and understanding of illness, dying and suffering. Ezzy (2000) demonstrates in his writings and research with AIDS patients that narrative theories are increasingly utilised to study “the subjective experience of illness” and can provide a helpful conceptual framework for our understanding of identity complexities for these people (p. 605). Kleinman (1988) explains that the illness narrative “is the story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering” (p. 49). Frank (1995) further highlights that people tell illness narratives “precisely in order to become the effects of their (performed) stories” (p. 136). Frank (1995) indicates that “the story serves to convince at least the storyteller of who she or he is and can become despite illness” (p. 138).

Certainly, there are many benefits of the attendance to, and honouring of, stories for those who are sick and dying. Frank (1991; 1995; 2000; 2004) is one author who has written extensively about illness narratives and their potential benefits for ill people, health care professionals and as an alternative ethics approach. Brody (2003), similarly, remarks in Stories of sickness that we can make the experience of sickness “more meaningful (thereby reducing suffering) by placing it within the context of a meaningful story” (p. 182). What Ezzy, Frank, Kleinman and Brody are each proposing is the centrality, value and helpfulness of stories when people are experiencing illness and the imperative that listening and responding to stories constitutes an ethical act.
With this understanding and appreciation of stories, as articulated by Ezzy, Frank, Brody and Kleinman, I sought to extend this into the study *Restorying the dying self: A narrative investigation of self-identity at the end of life* (Wilson, 2002). In this study I listened to, and collected narratives from, living-dying people with the intention of seeking an understanding about their identity changes as they journeyed towards death. The insights from this narrative identity research are incorporated into the ontological considerations of the living-dying person in chapter four.

Hence, it can be seen that narrative is inseparable from meaning making processes, and provides for a viable and valuable means for gaining understanding – the central objective of this study being the understanding of the ethical dimension. Narratives can be of further assistance in the illumination of temporality, identities (both individual and practices) and of the dying experience. In addition to these, narrative is also inextricably linked to ethics and research approaches. However, before moving on to examine narrative ethics and narrative research processes it is important to briefly consider constructionism, as this is the postmodern theory that underpins narrative.

### 2.5 The centrality of constructionism

The overarching theory of constructionism provides this research inquiry with the fundamental beliefs about the nature of reality and how we can learn about a social phenomenon such as hospice palliative care. Accepting the standpoint of constructionism means that what we know (knowledge and understanding) is always interpreted. Reality or experiences are always interpreted (Isaacs, 2001). What we as people understand is always located through an interpretive lens. Constructionism suggests that this interpretation (or way of knowing) is developed in meaning-making processes or constructions within the social world; by and with people, in society. Our understandings and meaning-making processes are constructed by our histories, the culture we live in and our own personal experiences. An objective truth is not located out there separate from us, but is an interpreted, situated and constructed understanding that has been agreed by people (and groups of people) over time. De Laine (1997) declares that
[The constructionist viewpoint] assumes that the social world is produced and reproduced by human beings. Reality is considered an inter-subjective world of cultural objects, meanings and social institutions, derived as a consequence of social interactions. The social constructedness of reality presumes there are multiple realities. The notion of interpreting meaning is paramount to this paradigm. The social world is not a ‘real’ objective world, external to, and constraining on the individual. It is constituted of meaning. Reality, as we have come to know it, is not perceived to exist independently of the social meanings that its members use to account for it, and hence, constitute it (p. 35).

This explanation includes the important point that it is people in relationship with each other who co-construct meaning. Or in other words, our understandings of reality have been developed in social ways, between people. Thus, all knowledge is socially constructed (Richardson, 1995). Blaikie (2000) further qualifies this understanding when he writes

The study of social phenomena requires an understanding of the social world which people have constructed and which they reproduce through their continuing activities. People are constantly involved in interpreting their world. They develop meanings for their activities together, and they have ideas about what is relevant for making sense of these activities (p. 36).

As hospice palliative care practice is a social phenomenon, with activities carried out by, and with people, it has been socially constructed over time.

The constructionist epistemology of this inquiry meant that it was necessary for me to enter into social relationships with the HPC professionals in order to understand the socially constructed meanings they hold about their practice, and to indeed construct them together in our conversations. I, and we, immersed ourselves into the constructed understandings of HPC practice to gain insights into the questions of this inquiry.

2.6 Narrative as ethics

With this fundamental basis for understanding the reality of a social practice, we can again turn to narrative and its link to ethics. Narrative ethics is of great assistance for this inquiry. Indeed, in working with stories to understand the ethics of this practice, I have carried out a narrative ethics approach. Frank (1995) writes, “Thinking with stories is the basis of narrative ethics” (p. 158). This is indeed what has occurred in this
inquiry, as the stories of HPC professionals provided the conceptual considerations of the ethics of this practice.

Narrative ethics acknowledges the primacy of a person’s story (and many people’s stories) over abstract, universal theories or principles. Brody (2003) suggests that there are currently two ways that scholars understand narrative ethics. These are

- Narrative ethics as the claim that even when one is using principles or other general moral norms, one is engaged in an activity that relies on or engages narrative in some way; or
- Narrative ethics as the claim that one need not use principles or other general moral norms, but can gain ethical knowledge and provide ethical justification directly through and from narratives (p. 175).

Brody (2003) argues that the latter of the two definitions is more accurate, as “a stronger case can be made for the dependence of principles on narratives, based on how we view the historical process of coming to have principles to begin with” (p. 176). In other words, moral theories and principles have been birthed by stories. Arras (1997) reminds us that narrative ethics is not a new approach, “but rather a recognition and full appreciation of the debt that principle- and theory-driven modes of discourse owe to stories” (p. 72). Arras and Brody assert that principles and theories are constructed through and with stories.

I think at this point my readers, who may be committed to the central principles that guide their practice (or life), would be uncomfortable. Therefore, it is important to outline an example of this storied construction process of a principle as offered by Brody (2003). Let us consider the principle of respect for individual autonomy. This principle is a relative newcomer to the field of biomedical ethics. Brody (2003) points out that it has a “relatively short history in Western culture compared to other moral norms” (p. 180). I quote directly from Brody’s explanation

At some point people began to tell stories about how others thwarted what they wished or desired to do, despite the fact that the others were at no risk of being harmed or directly affected by the proposed actions. Listeners to the stories thought that some moral wrong has occurred, even though they lacked the name of an established moral norm to label this type of violation. The stories were retold to others as examples of that as-yet unnamed sort of moral wrong. Over
time, the collection of these stories grew longer and longer, and it seemed more and more obvious that the wrong that occurred in each story was sufficiently similar to the wrong that occurred in the other stories to be worthy of inclusion under the same general heading. Eventually the term *respect for autonomy* came to function as a shorthand label for the moral feature that this entire collection of narratives had in common. In this way one can view every moral norm or principle as a shorthand label to save us the trouble of having to recount a set of hundreds or thousands of individual narratives that have common moral features (p. 180).

It is not that the principle is wrong, just that we need to recognise how it has been formulated over time, and the centrality of narrative to this formulation process. What this means is that narrative is intrinsically a part of any ethical consideration, and an ethical form of living.

Aside from this inescapability of narrative to the moral form of life, the virtue of stories is that they recover what principles necessarily overlook; the richness of particularity, details and context. In other words, narratives provide a colour picture, rather than a black and white one. Principles are mainly a shorthand version of stories; known for their thinness. This reality of ‘thinness’ was evident in this research, as principles such as respect, autonomy, and harm had not previously been explored, explained or articulated by HPC professionals. “Stories put faces on faceless generalisations”, asserts Lindemann Nelson (1997, p. 2). Tomlinson (1997) agrees when he announces that narrative’s “unique virtue includes their capacity for organising the particular” (Tomlinson, 1997, p. 133). In incorporating the rich stories given by the HPC professionals, the particular has been privileged in this thesis. Thus, this accordance given to the rich professional stories answers the call of engaged ethics to attend to the particularities and contexts of any social phenomenon or experience. Narrative ethics “demands an awareness of the thickly textured individual, social and cultural relations crucial to what anthropologists call ‘lived experience’” (Morris, 2000, p. 10). Thus, if universality is the problem, stories would seem to be part of the solution.
As well as the value of particularities, narrative ethics also embraces and acknowledges multiplicity. McCarthy (2003) proclaims that the task of narrative ethics is acknowledging and embracing the multiplicity of, often contested, meanings that are available in any given situation. What is key for this narrativist account is the idea that many different voices and readings of moral situations and individual lives are possible. And, generally, narrativists focus less on trying to reduce competing perspectives to a commonly shared view and more on involving as many people as possible in the dialogue (p. 71).

Multiplicity and pluralism are also valued in this thesis, as many voices have been included. In addition, there has been recognition of the different ‘tones’ in an individual’s voice, such as a societal tone, a medical tone or a legal tone. Furthermore, in narrative ethics, and indeed in this thesis, no one single answer or ‘truth’ is sought. There is the resistance to generalisation. An illumination of the context or practice under consideration is offered through the voices of many. Ultimately, the benefit and strength of narrative ethics, or the centrality of stories in our ethical considerations and explorations, is that it provides a method and vocabulary for interpreting and respecting the unique and personal stories of people. Narrative ethics places emphasis on the professional-patient relationship as itself an ethical realm which is personal and affective, rather than an ethic of strangers like principlism (McCarthy, 2003, p. 72).

2.6.1 Narrative ethics for social practices
For the understanding of social practices, like HPC, Widdershoven and Smits (1996) believe that stories give us insight into the nature of these practices as “ethical endeavours” (p. 280). These authors even go so far as to suggest that all ethicists should do narrative research, as “stories not only reflect ethical practice; they also sustain and structure this practice” (Widdershoven & Smits, 1996, p. 284). The collection of stories is specifically appropriate for the articulation and understanding of the teleological features of HPC as “narrative displays the goals and intentions of human actors” (Richardson, 1995, p. 200). Concurring with this point Widdershoven and Smits (1996) write that embedded in stories is a view of the ‘good’ and through narrative ethics we
can make this explicit. This makes a narrative approach especially congruent with the objective of this research inquiry. Widdershoven and Smits (1996) write that

_Stories are not about separate actions but about practices. A story shows us what is at stake in the practice. This means that a story presents the activities it describes as part of a larger project that aims at some good. The story highlights the interactional dimension of the actions described and their embeddedness in a shared way of life. A story makes explicit the aim (or telos) of a practice as a shared tradition. Stories elucidate the teleological character of action and prepare the ground for an ethic founded on the notion of practice as an endeavour that is aimed at the good life … narratives make us aware of the teleological character of action. Stories do not just make us aware of teleology; they express and realise it (p. 279/280)._ 

Overall, what these authors are asserting is that stories are highly appropriate as a means of understanding and articulating, specifically the teleological features, and more generally, the ethical dimension of HPC practice.

### 2.7 Narrative in research

After considering the role of stories in knowledge, time, identity, illness, and ethics there can be no doubt as to the applicability of narrative inquiry to this research endeavor. When considering the question of how the ethical dimension of hospice palliative care practice was understood and articulated by its professional members, I fervently believed that stories could provide valuable insights. This is an appropriate methodology for an applied ethics inquiry, as Isaacs (2001) points out “Narrative is an important strategy for discerning latent meanings and understandings at the individual level” (Isaacs, 2001, p. 14). It needs to be recognised that narrative research refers to any study that works with, uses or analyses narrative materials and that there is no single method, “but a spectrum of approaches to texts that take narrative form” (Reissman, 1993, p. 25; Lieblich, Tuval-Mashiach & Zilber, 1998). Narrative inquiry was able to access HPC professionals’ understandings of the ethical dimension of their practice, for when we speak of everyday accounts of practice, we speak in narrative form. Josselson, Lieblich and McAdams (2003) explain that “when we listen carefully to the stories people tell, we learn how people as individuals and as groups make sense of their experiences and construct meaning” (p. 80). This is the value of this methodological approach.
2.8 Ethics clearance and informed consent
With these three dominant conceptual foundations of an engaged ethics approach, a social practice framework and the centrality of narrative outlined, this chapter continues to consider the tangible processes of research such as ethics clearance, recruitment and interviewing processes. Before I could commence the listening to, and collection of, narratives I needed to compile ethical clearance reports and informed consent formats in accordance with the Ethics Committee of Queensland University of Technology (QUT). The Consent Form (Appendix One) and Invitation and Information Sheets (Appendix Two) that I sent to HPC professionals are attached. This inquiry received Level One Ethical Clearance (QUT Reference Number 4071H) through the University Human Research Ethics Committee (UHREC). Consent forms from each HPC professional have been signed and securely filed, and verbal consent was recorded at the start of each narrative interview.

2.9 Inviting hospice palliative care professionals
Once ethical clearance was approved, ‘Invitation and Information Sheets’ (see appendix two), which outlined the project objectives and what the HPC professionals’ involvement would entail, were mailed out. The PCA Service Directory Guide (2004) provided the mailing addresses for the specialised hospice palliative care services. The sending out of this Invitation to Participate constitutes the main form of recruitment for this inquiry: an invitational method. This means that any HPC professional could respond.

Approximately twenty HPC professionals did respond, with an interest to be a part of the inquiry. However, once these twenty HPC professionals were interviewed, I then sought other HPC professionals, utilising a purposive method of recruitment. This means that I then purposely sought HPC professionals that had so far been underrepresented. These missing professionals were HPC medical specialists, pastoral care workers, allied health staff and males. My purpose in seeking these underrepresented professionals was to attempt to enhance the thickness of the narratives, and hence, the richness of understanding. It is also important to note that
in regard to males being underrepresented this largely reflects the make up of the profession which is one that is dominated by women. In the end, gaining one third males in this study was an accomplishment. Assurances were made that each HPC professional who took part in this research would only be known by their role and context. The names used in this study are pseudonyms. Furthermore, in the text itself I purposefully did not delineate what discipline they came from or role they carried out so as to present them all, equally, as hospice palliative care professionals within an interdisciplinary team. Table four presents the professionals who participated and the contexts they work from. Overall, narrative accounts of practice were gained from thirty hospice palliative care professionals across thirteen different types of contexts.

Table Four: Profile of HPC professionals and contexts

| Palliative Care Consultative Service in Acute Care Hospital: | Nina, Clinical Nurse  
Martha, Clinical Nurse Consultant  
Stacy, Medical Specialist |
| Community Hospice Service – At-Home Service (3 organisations): | Julie, Director (Registered Nurse)  
Natalie, Social Worker  
Amy, Clinical Nurse  
Gavin, Counsellor  
Wendy, Volunteer  
Lisa, Clinical Coordinator (Registered Nurse)  
Melanie, Clinical Nurse |
| Palliative Care Consultative Service - Acute Care Hospital and At-Home Service: | Anna, Clinical Nurse Consultant  
Peter, Social Worker |
| In-Bed Community Hospice Service: | Frieda, Director (Registered Nurse)  
David, Director (Minister) |
| Palliative Care Service – In-bed Facility in Acute Care Hospital: | Jim, Medical Specialist  
Zoe, Clinical Nurse Consultant  
Natasha, Medical Specialist |
| Non-Direct Practice Settings - Research, Projects, Education: | Jackie, Director (Registered Nurse and Academic)  
Emma, Project Officer (Registered Nurse)  
Ken, Researcher (Registered Nurse, Academic) |
Some of the details on this table require explanation. Firstly, you will notice that six of the HPC professionals carry out the role of Director. The reader can assume that this role may vary in the differing contexts. Secondly, some of the HPC professionals have a secondary role in brackets. This simply denotes what other roles they carry out, or have carried out in the past. Thirdly, the two dominant settings were either hospital or community based services. The community based services were further distinguished by either an in-bed facility or in-home care. Two aged care settings were incorporated into this study. Finally, the contexts noted as ‘non direct practice settings’ are either academic settings, or research and/or education centres. Please note that the HPC professionals from these settings still have had direct HPC practice experience. As mentioned at the start of this thesis, I am extremely indebted to the HPC professionals for the giving of their time to speak of their understandings of HPC practice and in sharing their wealth of wisdom and knowledge, especially since I know firsthand, how busy and under-funded HPC services are.
2.10 Narrative interviewing

With this picture of who was involved in the inquiry provided, an outline of the interviewing processes follows. Mishler (cited in Murray, 2003) believes that the primary means for obtaining narratives is via interviews. These interviews mainly took place in the work setting, were audio-taped and usually took an hour to conduct; sometimes longer. To facilitate the HPC professionals’ storied accounts of their practice I conducted semi-structured interviews based on a narrative framework of key questions, which included some of the social practice features. These included questions such as:

- How did you get started in HPC?
- What is it about HPC that keeps you committed?
- What do you understand about the philosophy of care that underpins HPC practice?
- What do you hope to achieve in your practice?
- What is the purpose of HPC practice?
- What is your understanding of HPC ethics?
- What guides you in the ethics of your practice?
- What are the values that underpin your practice?
- If you were writing a book about HPC practice, and you are writing the last chapter about the future, what would be in this chapter?

It can be noticed that the questions above adhered to notions of temporality in that they asked about the past, present and future. Not all of these questions were asked of each professional; they simply provided some guiding questions in the storying process. I started with the first opening questions, to initiate the storying process and then utilised the others when they came up in conversation and when there was a perceived gap in the telling. I also listened for implicit values spoken about, and delved further into articulations and expressions about personhood, what constituted good or harm for them, and their understandings of relationship. These questions and themes changed over time according to the person and context as well. I was able to utilise my narrative counselling skills to facilitate the storying process, drawing out more details and particularities from the professionals. Importantly, these narrative interviews were conversational and allowed for the “participants [professionals] to construct answers, in collaboration with listeners, in the ways they find meaningful” (Reissman, 1993, p. 54).
A further important aspect of these narrative interviews was the articulation of values. After reading about other studies which focused on values in practice, and with my experience in facilitating discussions about values with students, I understood that discussions about values could be difficult. In other words, bringing the tacit notions of what is worthy to us in practice is often quite a difficult task, particularly if you have not had a great deal of opportunity to reflect upon these in the past. Therefore, in wishing to be of assistance to the HPC professionals I developed a set of laminated values cards. At a point of time during the interviews, with the professional’s permission, I invited the professionals to consider these values and pick out three that they believed were central to the practice of HPC. The table below presents the values that were included on these cards.

Table Five: List of values cards

<table>
<thead>
<tr>
<th>Original Hospice Values (McNamara, 1998b):</th>
</tr>
</thead>
<tbody>
<tr>
<td>An awareness of dying and an acceptance of human mortality</td>
</tr>
<tr>
<td>Open and honest communication</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PALLIUM Study of Moral Values (Janssens et al., 2002):</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life</td>
</tr>
<tr>
<td>Human dignity</td>
</tr>
<tr>
<td>Acceptance of human mortality</td>
</tr>
<tr>
<td>Total care</td>
</tr>
<tr>
<td>Nonmaleficence</td>
</tr>
<tr>
<td>Authenticity</td>
</tr>
<tr>
<td>Autonomy</td>
</tr>
<tr>
<td>Empathy</td>
</tr>
<tr>
<td>Beneficence</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PCA Standards for Providing Quality Palliative Care (2005) Core Values:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dignity</td>
</tr>
<tr>
<td>Empowerment</td>
</tr>
<tr>
<td>Compassion</td>
</tr>
<tr>
<td>Equity</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Others Added:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring</td>
</tr>
<tr>
<td>Relationships</td>
</tr>
<tr>
<td>Acceptance and non-judgment</td>
</tr>
</tbody>
</table>
The ‘others added’ values cards were included due to the professionals responses over time. Certainly, suffering and comfort are stated goals of the practice, yet these were articulated as valued by the professionals during the interviews. I do not believe that utilising these cards in any way constrained the HPC professionals in their responses, as most often statements were made about how helpful they were in assisting them to reflect upon the values. Some of the HPC professionals did wish to say that all of them were important. I acknowledged this, and strongly recommended that they prioritised three. It is important to note that the three picked were not ranked in order, and that occasionally some professionals picked more than three. Once the values were chosen, I asked the professionals if they wished to say anything about them; to explain how they understood them. The findings of this aspect of the study are included for consideration in chapter six.

2.11 Transcription

Once the thirty narrative interviews were completed, I transcribed them word for word, including my voice, using Power Voice II Software. This software does not analyse, but simply assists in the speed of transcribing. Once finished, this collection of storied accounts of HPC practice generated one hundred and forty five thousand words of text. As agreed to, I sent the transcribed interview to each professional via electronic mail for verification, additional comments and clarifications, and seeking final consent to utilise in this inquiry. This produced some alterations and deletions. I stored these interviews confidentially and securely. The stories from the HPC professionals are included in this thesis by an indentation and 11 point font. As mentioned in the introductory statements, the storied accounts from the professionals have been interwoven throughout this thesis, with my reflections and the literature, to produce a large conversation or meta-story about the ethical dimension of HPC practice.
2.12 Narrative reflection: The art of interpretation
With my mountain of stories, including pertinent literature, I faced the task of constructing this thesis, keeping in mind how it is that I work with stories in an ethical manner. In addition to keeping the ethics utmost in my mind as I worked with the stories, I also have accumulated a great deal of textual advice from narrative scholars that guide and inform me in the task of formulating this thesis. What I outline below, which encapsulates the elements of the work of narrative inquiry as I have constructed it, are the concepts of narrative reflection, the art of interpretation and writing as a research process.

Narrative reflection is a process that requires me to think with the stories. Reflection entails the action of fixing my thoughts on the subject of this thesis and giving it deep and serious consideration. With this process I relate to the advice from Frank (2005b) I do not analyse these stories. I advocate trying to think with them, a process closer to letting the stories analyse us. Stories analyse us by allowing us to notice what attracts us to them, and what we resist about them. These stories contain no hidden or coded meaning that requires analysis (p. 7).

Through listening to, and reading the stories, over time, I have been guided by them in the construction of this thesis. My story that has been incorporated into this thesis has been constructed with a reflective tone, as I ponder the implications of the stories. In keeping this close, attentive listening to the stories in mind, I also needed to do something more than simply present the stories. Massey (personal communication, 2007) asserts that we do need to go beyond the stories spoken in narrative inquiry. Equally, Reissman (1993) stresses this point when she writes that “narratives are interpretive and, in turn, require interpretation: They do not speak for themselves, or provide direct access to other times, places, or cultures” (p. 22). Interpretation processes are inescapable, as the stories have been reduced, dissected and reconfigured.

As a reflective, interpretative process, considerations of habits of thought are important. As a thinker, I have a tendency towards larger themes. This can be noticed throughout this thesis through the use of the features of the social practice framework and the overall structure of my work. Thus, my interpretive processes also lean towards a
thematic style. This means that the dominant content or themes of meaning from the stories were privileged. That being said, however, some attention was paid to how things were said, what was unsaid, the tone used, and the use of particular language.

2.12.1 Writing as research
Writing, too, is an important element of the narrative research process. For as Denzin (2004) so eloquently explains

Writing is an act of discovery. The writer deals with moments of experience. The writer brings all of his or her powers, intelligence and literary skill to bear on these moments to show how … he or she sees those things – like no one else sees them. This is done through the use of clear and specific language; language that will bring to life the details that will light up the story for the reader (p. 454).

I take seriously this call to recognise writing as a method of inquiry and interpretation, as Richardson (2004) suggests. Writing, for Richardson (2004), “is also a way of knowing … a method of discovery and analysis. By writing in different ways, we discover new aspects of our topic and our relationship to it” (p. 473). With post modern methodologies, researchers are invited to write in new ways. The self can be fully present in this writing process and creative possibilities are possible. I could not ignore the poetic nature of the stories told to me, and the metaphors they invoked. I was relieved to be advised by Richardson (2004) that

When people talk, whether as conversants, storytellers, informants, or interviewees, their speech is closer to poetry than it is to sociological prose. Poetry may actually better represent the speaker than the practice of quoting snippets in prose (p. 482).

The poetry of the words of the HPC professionals has been incorporated into this thesis, as well as the metaphors they have created. The point being made by this is that I understand writing to be much more about a process, “rather than as a definitive representation” (Richardson, 2004, p. 485). Yet, the academic boundaries of this thesis required a final product, rather than a process that could continue for a longer period of time. Ultimately, I have written with the aim of “settling words together in new configurations [to] let us hear, see, and feel the world [of HPC practice] in new dimensions” (Richardson, 2004, p. 482).
2.12.2 Interpretation

One final consideration of my reflective, interpretive research processes is the inability to start from any sort of neutral or objective point. For, as Bruner (1987) declares, “A mind is never free of precommitment. There is no innocent eye, nor is there one which penetrates aboriginal reality” (p. 32). I come to this research with preferences, hopes, values, biases, standpoints, concerns, hypotheses, commitments and so forth. These were made transparent at the start of this thesis. These things, Widdershoven and Smits (1996) would suggest, are my “preconceptions about the good that is central to the practice the story is about” (p. 286). I wholeheartedly agree with Lieblich et al. (1998) when they assert that

The mere acts of being together in a room, stating the purpose of the encounter, asking questions, relating to the responses, and participating in the creation of an atmosphere, some interpretive choices have already been made (p. 166).

This, in turn, means that no reading of the HPC professionals’ storied accounts are free of prior interpretation; “that even at the stage of procuring the text, especially in the dialogical act of conducting an interview, explicit and implicit processes of communicating, understanding, and explaining constantly take place” (Lieblich et al., 1998, p. 166). Thus, these interwoven layers of interpretation have resulted in a “fusion of horizons” in which my interpretations are present, alongside the interpretations and understandings of the HPC professionals (Widdershoven & Smits, 1996, p. 286). This fusion then has rendered the narrative texts, both spoken and written, into a meaningful whole according to the questions inherent in this inquiry.

In conducting my interpretations in systematic ways I have generated meaningful and promising ‘findings’, or what I prefer to call insights (Mishler, cited in Reissman, 1993, p. 22). The interpretations have been merged into a constructed meta-narrative of the ethical dimension of HPC practice that is a “partial, alternative truth that aimed for believability, not certitude, [and] for enlargement of understanding” (Reissman, 1993, p. 22). Equally, I acknowledge that another version could have been produced for narrative inquiry can never claim any last word about what a story can mean (Frank, 2005b, p. 4). This inquiry offers, suggests, and ultimately, “can only look toward an open future”, with many more questions in mind (Frank, 2005b, p. 4). In the end, as a
researcher and author, I have “crafted a new narrative”, by “weighing and sifting” through the stories, “making choices regarding what was significant, what was trivial, what to include, what to exclude” (Elliot, 2005, p. 152).

2.13 Narrative quality
In understanding that narrative research processes are interpretive and constructed the question: ‘how do we know if it’s any good?’ then arises. Qualitative scholars now suggest a range of understandings for assessing the quality of narrative research. These new concepts for judging the worthiness of a narrative inquiry are necessarily different from positivist, or quantitative inquiries. The standards for this research inquiry are trustworthiness, integrity and possibility.

2.13.1 Trustworthiness
Within the field of narrative inquiry the criterion of trustworthiness has been formulated as an important consideration (Reissman, 1993; Josselson et al., 2003; Lieblich et al., 1998). Reissman (1993) suggests that to make it possible for others to determine trustworthiness we should

- describe how the interpretations were produced
- make visible what we did
- specify how we accomplished successive transformations
- make primary data available to other researchers (p. 68).

In accordance with these steps, this thesis has included transparent research processes to render visibility in this inquiry. This has included an extensive outline of my research processes; an articulation of my potential preferences and values as outlined in the start of this thesis; and the offering of transcriptions to HPC professionals for comments and adjustments. These interview transcriptions can be made available, upon permission, to other researchers. To further add to this criteria of trustworthiness I endeavour to share my “views and conclusions and [interpretations] with a community of researchers and interested, informed individuals for evaluation; for this is of the highest significance in narrative inquiries” (Lieblich et al., 1998, p. 173).
2.13.2 Integrity
Establishing trustworthiness is not straightforward, yet I believe that the HPC professionals I conversed with appreciated that I am someone who would work with their stories with integrity. Pullman, Bethune and Duke (2005) explain that “maintaining narrative integrity involves respectful and sensitive efforts to identify the central elements that give meaning and purpose to each other’s stories” (p. 282). I have not strayed too far from what were the central elements of their stories, and have stayed close to the particularities they evoked. With narrative integrity I do not claim replicability or generalisability, appreciating that any other researcher may have constructed different interpretations from the narratives. I am in agreement with Bond (2002) when he affirmed that “as a researcher I am not claiming any universal findings or ability to predict what would happen again if the same circumstances were to happen again. The research is local in every sense to the people involved” (p. 137). Lastly, integrity to me means that I was concerned every moment to write as truthfully and respectfully about, and with, the HPC professionals’ narrative accounts.

2.13.3 Possibilities
This last criterion is perhaps the most important, for it is the possibilities that this inquiry evokes that warrants the highest assessment. Mostly, I hope, what is offered in this thesis becomes of practical use for the profession. For, as Ellis and Bochner (2000) explain, narratives matter because of their usefulness

The narrative rises or falls on its capacity to provoke readers to broaden their horizons, reflect critically on their own experience, enter empathically into worlds of experience different from their own, and actively engage in dialogue regarding the social and moral implications of the different perspectives and standpoints encountered (Ellis & Bochner, 2000, p. 748).

This narrative inquiry seeks most of all to provoke others to think, reflect and appreciate this world of dying and caregiving, with a view to change. It is these evocative qualities and this thesis’s ability to elicit the empathy, understanding and critical reflections of the reader that is the measure of its quality (Bond, 2002). I want to elicit new thinking, insights and a greater comprehension of this complex topic of the ethics of HPC.
Overall, the story that has been co-constructed as this thesis “aims to create a better understanding than we had before” (Widdershoven & Smits, 1996, p. 281).

2.14 Chapter summary

In this methodological chapter the foundations of thought and processes of research, utilised in this research journey, have been outlined. This has included the three fundamental conceptual frameworks that provide the basis of the inquiry; that of an engaged ethics approach, of the social practice framework, and of narrative inquiry in all of its complexity. In addition, the research processes of ethics clearance, recruitment, interviewing and transcription were explained. This section included, by way of introduction, a table of all the HPC professionals who play a central role in this thesis. Here the differing contexts and roles of HPC practice were noted. Finally, the particular approach to, and considerations of, the doing of narrative research, or working with stories, has been articulated, including my final considerations of narrative quality in research. All of the elements of this chapter, as conceptual foundations, as interpretive frames, and research considerations enable the reader to now step into the body of this inquiry, which explores the three central features of a social practice. These features start with considerations about the tradition of the practice, and then traverse into the ontological explorations of personhood, and finally, a critical exploration of the teleological features of HPC practice. These three elements of the social practice framework, as applied to the practice of hospice palliative care, make up the ‘walls’ of this thesis.
Part Two
The Walls

Coming Home: To Total Care
See me now
I have many rooms
The kitchen of my physical body
The bedroom of my spirit
The lounge room of my social ties
I come home to my loved ones
The study of my mind
But most of all my heart has many rooms.

Coming Home: To One’s Own Body
Help me feel comfortable in my body
Disease and bodily reactions so out of control
Vulnerable and helpless
I wish to feel connected once again
To this home I have inhabited for so long.
CHAPTER THREE
Tradition: Something’s Slipped Out

It is not easy to die. In the past, dying was a human act whose meaning and ritual were clear. Our ancestors lived closer to the rhythms of nature and died naturally as well. Death was at home, humane, and with moral and social purpose. Each individual’s death was felt by the community and was integrated into its culture, feelings and conscience (Aries, cited in Echeverri & Acosta, 1996, p. 1).

3. Introduction
The ethics of hospice palliative care, when understood through the lens of a social practice framework, requires a greater understanding of the past of this practice. This chapter explores the tradition of hospice palliative care. Isaacs (1998) states that one of the central features of a social practice is that it is embedded both socially and in a particular time and thereby shaped by a tradition. In other words, the ethics of a practice are ‘historicised’. This means that they do not simply appear, but come from a particular time. Isaacs (2001) explains this when he writes

Since persons, relationships and institutions, the sites of ethical engagement confront a future, but also come out of, and are shaped by, a past the ethical engagement needs to be seen as historicised (p. 11, original italics).

Langford (1991), originally writing about the practice of education, also explains the importance of this feature of tradition

A social practice may be said to be carried on in accordance with the way of seeing and doing provided by a tradition, which not only gives it structure at any particular moment, but also maintains its continuity with the past and provides it with direction for the future. A tradition tells those who are guided by it, not only what to do, but also how to do it (p. 31).

This means that how HPC professionals practice in 2007 has been, and continues to be, shaped by the past. Isaacs (1998) further elaborates upon Langford’s explanation when he explains

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14 Both Isaacs and Langford also mention the future in this feature of a social practice. The future of HPC practice is briefly included in chapter seven.
[A practice] reciprocally shares sets of beliefs and sets of actions, as laid down by the tradition of the practice. They guide the individual practitioner and constitute a collective consciousness of understandings, of procedures and of expectations for all the members of the practice (p. 5).

The practice of HPC is shaped by a coherent and important tradition. The concept of hospice goes back to medieval times, yet, current literature identifies the 1960s as the time when the birth of the modern hospice movement commenced. This time coincides with the work of Dame Cicely Saunders and Elisabeth Kubler-Ross. This chapter initially examines this time in the 1960s, focusing upon the changes that were taking place in the nature of dying; the advancements of medicine and the problematic nature of dying in institutional settings. Secondly, the focus of this chapter turns towards the work of Saunders, which includes the formation of a central philosophy of care for the dying. It is important to note how this term philosophy is being understood. Randall and Downie (2006), in their examination of the WHO (2002) definition of palliative care, decided that the term philosophy was being used in a Non-professional sense; close to the idea of an ideology, since it is a statement of assumptions, beliefs, or values held by a group of people, in this case by the WHO representing health care professionals who specialise in palliative care (p. 10).

Therefore, the use of the term philosophy in the HPC profession includes a collection of statements or principles that pertain to certain assumptions, beliefs and values that then translate into practice. In this thesis, this is what is meant by the usage of the word philosophy. The philosophy of care provides for the ways of seeing and doing in the practice and so is a central feature for examination in the ethical dimension of HPC. The WHO definition of palliative care is simply a condensed version of this philosophy. Saunders’ original articulation of this philosophy of care is outlined in this chapter.

This central caring philosophy originally set out to delineate or distinguish it from the profession of medicine. The assumptions, beliefs and values that are embedded in the philosophy are unique to the practice of HPC. Over time, however, HPC practice has been integrated into medical settings which may have influenced the understanding of this philosophy. Hence, first and foremost, this inquiry sought to understand the current understandings of the philosophy of care according to specialist HPC professionals.
Furthermore, it asks whether these understandings still resemble the original philosophy of care. This curiosity about the philosophy came about, as mentioned in the beginning of this thesis, from the statement uttered by one HPC professional - “It’s good to see the philosophy of palliative care being practiced in so many settings”.

What was discovered in this section of the inquiry was that the narratives of the HPC professionals presented an array of responses to their understanding of the philosophy of care. This diversity of responses means that it can be argued that there is not a common, and shared understanding of, and commitment to, a philosophy of care. It can be noticed, however, that the majority of the HPC professionals believe that the concept of total care (whole person care) needs to be central to this philosophy. In other words, total care has continued to be a central concept which has been sustained over time. This notion was contested, though, by some HPC professionals. The literature reinforces this contestation claiming that total care is not carried out, or not understood, or should not be practiced in contemporary HPC practice. In addition, this research discovered that there were some HPC professionals who were unable to articulate their understanding of the philosophy of care, demonstrating that for some professionals this is not a matter that is highly reflected upon. On the other hand, a few HPC professionals gave eloquent and coherent accounts of what they understood the philosophy of care to be about. Finally, there were some storied accounts that suggested that the original philosophy of care is lost. Prior to presenting these storied accounts, though, this chapter provides a brief picture of how dying, and the care of the dying, has changed over the centuries.

3.1 The changing face of dying
Several authors, such as Callahan (1993a/b), Aries (1981), McNamara (2001) and Kellehear (1998; 2007), have commented on the changes to the face of dying over the last centuries. Aries (1981), a French historian, is the most notable author who explores the cultural changes to death and dying over the centuries. Briefly\textsuperscript{15}, what these authors

\textsuperscript{15} A full exploration of these significant changes of meaning of the dying process, death itself, and how the dying are cared for is not given full consideration in this thesis as it is beyond the scope to do so.

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have commented upon were important changes over the last few centuries in the understanding and processes of dying and death. These changes include

- Dying previously was a social experience, but now is an individual and private act;
- The living-dying person largely controlled the experience, but has now moved into a passive role;
- There has been a movement from the familiar home setting in which to die, to an institutional milieu;
- Dying and death was viewed as a natural and inevitable event, to now being understood as a medicalised event, with death being seen as failure;
- Dying was a time that was marked with religious solemnity and ritual, but now is an event which is largely secularised.

3.1.1 Dying as a social event

Importantly, from the Middle Ages to the beginning of the nineteenth century, the process of dying was a social event, largely controlled by the dying person (Aries, 1981; Kellehear, 1998). As Aries (1981) eloquently writes

Death [and dying] is not a purely individual act, any more than life is. Like every great milestone in life, death is celebrated by a ceremony that is always more or less solemn and whose purpose is to express the individual’s solidarity with his (sic) family and community. This community was gathered around the bed where he (sic) lay; death was not a personal drama, but an ordeal for the community (p. 603).

In other words, in the past dying and death was a social phenomenon. A person lived and died surrounded by his or her family and friends, and it was an event that was shared by the community, in a public and ceremonial way. Callahan (1993a) describes this process as

It [dying and death] takes place amid a circle of family, friends, and children, and in many places it was acceptable for strangers to come in off the street to be with the dying person. Only perhaps at the very end, for a few hours only, was a person left alone; otherwise, nothing was more important than to keep the dying fully and richly within the human community until the last moments (p. 28).

This meant that the care of the dying was in the hands of the family. Over time this has changed. The make up of the family unit has changed and the collapse of community has occurred, as individualism has become prized in modern times. Gracia (2002b)

Please refer to Kellehear (2007) *A social history of dying* for a comprehensive overview of the changes to dying over the centuries.
explains that “the family lost its old capacity of being the only unit of caring” (p. 22). Thus, as the make up of families changed, so too did their ability to care for the dying. What this meant is that dying moved into institutional settings, became a private event and moved out of the domain of the social. Aries (1981) contends that dying and death became something “shameful and forbidden; something to be hidden from those around” (p. 16). The consequences of these changes were that the process of dying is now “less within the control of the individual and his or her close social network” (McNamara, 2001, p. 6).

The living-dying person is no longer center stage in the final act of his or her life. In the past, the experience of dying and the care of the dying person often did not require medical opinion or intervention (Aries, 1981). Accordingly, the living-dying person was the “most powerful and controlling person during illnesses including the final one – dying” (Kellehear, 1998, p. 291). Aries (1981) explains that the “tame death” was one where “the dying person was sure of his (sic) role in preparing for the end according to ritual or custom” (p. 16). Kellehear (1998) outlines the changes of the role of the ill and dying patient, and notes that the living-dying person moved from being the ‘director’ of one’s own dying, to the ‘good patient’ who was expected to be “compliant and passive, taking their doctor’s advice” (Kellehear, 1998, p. 292). The centrality and authority of the living-dying person waned over time and “succumbed to the encroachment of professionalism in law, medicine, the funeral industry, but also changes within the family itself” (Kellehear, 1998, p. 289).

### 3.1.2 Advancements in medicine

These changes in the social realm went hand in hand with considerable advancements in curing the diseases that often led to death. Curative measures became the predominant and valued practice, and no place was left for the dying. This is described by Doyle, Hanks and MacDonald (cited in Echeverri & Acosta, 1996) below

Almost unnoticed doctors began to change their goal from palliative caring to absolute curing. Hospitals were seen as being for investigations, treatment, and early discharge home. Those who could not be cured were often made to feel less welcome and less deserving of highly educated medical input. Those who
were dying were given the lowest medical priority, and death itself became not the fact of life it had always been, but a medical defeat or embarrassment (p. 4).

Certainly, the rise of medical knowledge and technology brought with it significant advancements in the management and cure of illnesses, the relief of physical suffering and the general care of the sick person. Yet, the dying person was seen increasingly as a failure of medical practice (Clark, 2000). Still, dying people were taken to hospitals and treatments were given, until they were left to die in clinical environments (McNamara, 2001). Gracia (2002b) agrees when he explains

The increasingly technical orientation of hospitals, and not least the capacity to manipulate death and dying, has made hospitalised death much more common, even when curing strategies become ineffective and irrational (p. 22).

More recent statistics from PCA (2005) point out that approximately seventy percent of Australians die in hospital or aged care settings.

3.1.3 Problems with modernised dying

With these changes in the diminishment of the social realm, increased medical knowledge and institutional dying led to eminent researchers looking closely at, and drawing attention to, the experiences and problematic nature of dying in modern times (Glaser & Strauss, 1965, 1968; Sudnow, 1967; Kubler-Ross, 1969 & Saunders 1964, 1967, 1969). With these studies came new insights into the process and care of the dying. This coincided with a growing discontent with how people were dying in institutional settings. For dying had become, as Kellehear (1998) explains, a medical event, typified by notions of failure.

Key researchers, such as Glaser and Strauss (1965; 1968), Sudnow (1967), Kubler-Ross (1969) and Saunders (1964, 1967, 1969), found many distressing problems inherent in this institutionalised dying process, and with how dying people were cared for. This included Glaser and Strauss’ (1968) discovery that there was a lack of communication from health care professionals and a closed awareness of dying by the terminally ill person. Kubler-Ross (cited in Brookes Cowen, 2004) pronounced that dying people were being treated like children and not being told what was happening to them. Saunders, in her first paper in 1957 (cited in Clark, 2002), reported
It appears to me that many patients feel deserted by their doctors at the end. Ideally, the doctor should remain the centre of a team who work together to relieve where they cannot heal, to keep the patient’s own struggle within his (sic) compass and to bring hope and consolation to the end (p. 22).

Similarly, Balfour Mount, a physician from Canada who conducted research in the 1980s, expressed similar sentiments

- Firstly, we discovered that patients had unmet psychosocial needs. Also, we found that patients had unmet physical needs, including inadequate control of pain and other symptoms, and poor nursing care. Communications were blocked, patients experienced isolation and distrust. Doctors visited less frequently when they knew the patient was dying and nurses felt uncomfortable (cited in Hamilton, 1995, p. 335-6).

These expressions of inadequate care of the dying in hospital settings were also articulated by the HPC professionals in this research inquiry. When I inquired as to what brought them to the profession, they responded in terms of noticing the harms or problems in the care of the dying in hospitals

- Because I thought it wasn’t done well [caring for dying people]. Patients were more or less abandoned. You know, put them in a private room, make it all dark, put the family in there and don’t come in too often. I knew that we had to be doing something better for these patients (Martha)

- [After watching how her partner was cared for in a life threatening situation] I thought if he dies, I’m going to be a nurse and show people … teach them that this isn’t how you treat people who are dying (Julie)

- I think the inadequacy. People were left to die on their own in hospital settings (Amy)

- We all saw an absolute need for palliative care (Anna)

- [Recounted a story where medical professionals weren’t being honest with a family and they had no opportunity to prepare for dying]. So that was really what made me start thinking that there must be something better. This was a whole area of need that wasn’t even being addressed (Elizabeth)

- I could see that people died poorly (Fiona).

Therefore, even up until recently in the Queensland context, and perhaps even to this day, these problems were being noticed and provided the impetus to care for the dying in other ways.
A further seminal research inquiry, carried out by Kubler-Ross, also took note of the processes and problems of living and dying in a hospital setting. Like Saunders, Kubler-Ross was highly influential in changing the way that dying people were cared for and so deserves attention here. When she first wished to interview dying people, she was told that in the six hundred bed hospital that she worked in, “that nobody is dying on my floor” (cited in Brookes Cowen, 2004). The denial of dying and death was so profound that the hospital professionals did not acknowledge that anyone was dying. Kubler-Ross’ research found that health care professionals, at that time, were profoundly uncomfortable with the notions of dying and death. With this understanding, Kubler-Ross decided to become a spokesperson for the dying, and so sat, listened and recorded their stories. Ultimately, Kubler-Ross discovered “If you can sit and listen and hear them, this is the greatest gift to them” (cited in Brookes Cowen, 2004).

The living-dying people that Kubler-Ross listened to spoke of their profound loneliness and isolation. They also talked about the difficulties in the mental adjustments that were required by them as they moved towards death (cited in Brookes Cowen, 2004). Kubler-Ross (1969) continued to be concerned about what dying people were experiencing in modern, hospital settings writing that

Dying nowadays is more gruesome in many ways, namely more lonely, mechanical, and dehumanised; at times it is even difficult to determine technically when the time of death has occurred” (p. 8).

It was clear to this medical physician and psychiatrist, Kubler-Ross, that “the patient is suffering more; not physically, perhaps, but definitely emotionally” (p. 10).

As an outcome of her research Kubler-Ross (1969) enforced the importance of an awareness and acceptance of death, for “if we cannot face death with equanimity, how can we be of assistance to our patients?” and of the importance of open and honest communication (p. 31). Kubler-Ross (1969) wrote “I believe the question should not be stated, ‘do I tell my patient?’ but should be rephrased as, ‘how do I share this knowledge with my patient?’” (p. 36). Here it can be seen that Kubler-Ross is referring to the acknowledged and problematic paternalistic medical practices of the past.
Fundamentally, she emphasised that dying and death were a part of life that need not be feared and should be discussed openly (McNamara, 2001). This research that Kubler-Ross carried out had a significant part to play in the development of the modern hospice movement and the important philosophy underpinning the care of the dying. Kubler-Ross\textsuperscript{16} fervently hoped that living-dying people could become our teachers, and we in turn were responsible for helping them die with peace and without fear (cited in Brookes Cowen, 2004).

Overall, commentators during the 1960s were aware that living-dying people were being, most likely, sufficiently cared for in the physical sense. However, concerns were being raised about issues of social isolation and desertion; loneliness; lack of communication; unmet psychosocial and spiritual needs; a closed awareness of dying and the denial of death; and the organisational processes of dying in a medical setting (Kubler-Ross, 1969; Sudnow, 1967; Glaser & Strauss, 1965, 1968; Saunders, 1964, 1967, 1967). The life prolongation focus of the new medical technologies sat in tension with the realities of death and dying. Doctors struggled with the perceived failure when faced with a dying person (Kellehear, 1998). Ultimately, dying had become “medicalised, controlled and hidden, and without tenderness” (Echeverri & Acosta, 1996, p. 2).

3.1.4 Shameful dying

Nowadays, in a period Kellehear (2007) termed “The Cosmopolitan Age”, dying is now more “shameful” (p. 210). The features of a shameful dying include

\begin{itemize}
  \item An erosion of awareness of dying
  \item An erosion of support for dying
  \item The problem of stigma
  \item Dying has become a trial or set of trials
  \item Dying as a terrifying this-world journey (p. 210-212)
\end{itemize}

This shameful dying process becomes “increasingly tragic and antisocial”, explains Kellehear (2007, p. 214). This author asserts that dying itself “appears to be

\textsuperscript{16} I would like to acknowledge the death of Elisabeth Kubler-Ross on the 24\textsuperscript{th} August, 2005. She continues to inspire me in my work.
disintegrating” (p. 218). Here he is referring to the recognised period of time which was understood as ‘dying’ now seems to be disappearing. Deaths do occur, but not dying. For dying

- as a shared set of overt social exchanges between dying individuals and those who care for them – is increasingly unrecognized in institutional settings outside hospital or health service settings in both global or domestic contexts. Public recognition, even some personal recognition of dying, has become an abstract political affair now severed from its earlier biological, psychological and interpersonal moorings (p. 253).

I would reinforce Kellehear’s assertions here by stating that even in some hospital settings dying is not acknowledged or recognised. This recognition of ‘the dying time’ was something that was overtly addressed by the hospice movement: specific places were needed to care for people during this dying time.

3.2 Something new was needed

With this changing face of dying, coupled with the new insights into the concerns of how people were dying in institutional settings, came the recognition that something new was needed in the way people were cared for at the end of life. The concerns raised about the medicalised care of the dying prompted the birth of the modern hospice movement. Overall, Clark (2002) suggests that this hospice movement

condemned the neglect of the dying in society; called for high-quality pain and symptom management for all who needed it; sought to reconstruct death as a natural phenomenon, rather than a clinical failure (p. 269).

At this time of heightened social change, the 1960s, Saunders is noted as saying “A society which shuns the dying must have an incomplete philosophy” (cited in Clark, 2002, p. 269). A transformed approach to the care of the dying was initiated. Now that the changes to the dying process and the care of the dying have been outlined, this chapter now turns to the development of the modern hospice movement and its corresponding philosophy of care.
The 1960s heralded a time of protest and civil rights. Florance Wald, a hospice pioneer in America at this time, expressed in the video, *The Pioneers of Hospice*, that they were “developing these changes [developing hospice] at a time of protest and change. Society was receptive to hospice through the growing unease of the perceived negative effects of medicine” (Brookes Cowen, 2004). Glaser and Strauss (1968) reinforced, at this time, that there was a “need for a systematic, comprehensive, concentrated, and determined effort to reform contemporary modes of caring for the dying” (p. 253). Thus, hospice founders set out to establish something distinctive from the medical care of the dying; not forgetting, however, the important contribution that medicine would still play in the care of the dying (Saunders, 1983). Yet, coupled with this medical care of the dying, there would need to be something more, suggested Saunders (1983).

This something more became a new and distinctive practice, which incorporated medical interventions, but distinguished and separated itself from the profession of medicine. “Modern hospice did not reject scientific and technological medicine, but rather humanised it” (Echeverri & Acosta, 1996, p. 1). Hence, the hospice founders were determined to start fresh with a new set of values and beliefs that underpinned the care of the dying (Abel, 1986). This created the practice of hospice palliative care which emerged as “one of the great social innovations of the twentieth century” (Clark, 2002, p. vii) which would transform thinking about the care of the dying, worldwide (Clark, 2002, p. 8).

### 3.2.1 Dame Cicely Saunders: The founder of the modern hospice movement

The time was ripe, the findings of the research were significant, and Saunders stepped in to profoundly change the way we cared for living-dying people. Saunders is recognised as the founder of the modern hospice movement and consequent philosophy of (total) care (Clark, 1998; Clark, 2002; McNamara, 2001). It was her tireless work in research, teaching and practice, carried out over several decades, coupled with the

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17 I would like to acknowledge the death of Dame Cicely Saunders on 14th July, 2005. Dame Saunders continues to inspire me in my work.

18 I am profoundly grateful for the work of David Clark and associates for researching and documenting the history of Dame Cicely Saunders work.
establishment of her hospice, Saint Christopher’s, that propelled hospice palliative care into the world.

Over the period 1960 to 1980 the modern hospice movement developed a hospice philosophy of (total) care which separated the care of the dying from mainstream medicine (Randall & Downie, 2006). This new philosophy and practice of caring for the dying came directly from the narratives of dying people themselves (Clark, 2002). Saunders started with the term hospice to denote the professional care of the dying. Hospice is derived from the Latin word *hospes*, which originally meant ‘stranger’, but which came to be understood as ‘the welcome to the stranger’ or hospitality (Clark & Seymour, 1999; Bennahum, 1996; Saunders, 2004). This is what Saunders had in mind; a place, separate from hospitals, where people would be welcomed and cared for whilst they died. It was important to her that this place provided a homely atmosphere and “a place of rest and nurture for those wearied at the end of life’s journey” (Clark, Hockley & Ahmedzai, 1997, p. 84).

This notion of a particular environment to be cared for towards death was coupled with the recognition of the importance of controlling pain. These two central concepts then translated into a philosophy of (total) care for the dying “which would harness together medical innovation in pain and symptom management with wider concerns for the practical and social needs of patients and families, as well as a responsiveness to spiritual matters” (Clark & Seymour, 1999, p. 72). Ideally, Saunders wanted “something between a hospital and a home” (Saunders, 1964, p. 1). These important concepts then became “a new caring strategy and hospices were conceived as the new environments for the total care of dying patients” (Gracia, 2002b, p. 29).

In effect, hospice became a place and a philosophy. What was central to this place and philosophy was, above all, to “just be there” (Saunders, 2003, p. 4). To elaborate, Saunders (2003) explains
Our most important foundation for Saint Christopher’s Hospice is the hope that in watching we should learn not only how to free patients from pain and distress, how to understand them and never let them down, but also how to be silent, how to listen and how just to be there. As we learn this we will also learn that the real work is not ours at all (p. 8).

With this listening, Saunders developed the hospice philosophy of (total) care, which included the following principles

- There must be an awareness of dying and the inevitability of death must be accepted in some way;
- The patient’s total care (physical, psychological, social and spiritual) must be managed by a skilled interdisciplinary team whose members communicate regularly with one another;
- The common symptoms of terminal disease, especially the palliation of pain in all its aspects, need to be controlled effectively;
- The patient and family as a single unit of care must be recognised;
- An active home care program should be implemented;
- An active program of bereavement care for the family after the death of the patient must be provided;
- Research and education should be ongoing (cited in Sheehan & Forman, 1996, p. 6/7).

3.2.2 Divinely inspired

These important principles that made up the philosophy of (total) care were motivated by a strong belief in, and commitment to, Christianity. The development of hospice, for Saunders, was a calling from God (cited in Clark, 2002). To elaborate upon this, Saunders (cited in Clark, 2002) writes

I have been interested in the problem of the care of the dying for a long time, and believe that I was led by God to read medicine in order to do this work. He has seemed to me, of late, to be calling me to try and found another work rather similar to that which is going on at Saint Joseph’s (p. 20).

Saunders believed that the Saint Christopher’s project was being “divinely guided and inspired” (Clark & Seymour, 1999, p. 72). Hence, the care that hospice offered was born of a religious tradition. Davis, Konishi and Mitoh (2002) maintain that Christian influences, in name and values, are apparent in the philosophy of (total) care. Bradshaw (1996) asserts that the Christian foundation of hospice was (and is) of vital importance. Saunders (cited in Bradshaw, 1996) believed that
St Christopher’s project has a religious foundation, based on the full Christian Faith in good, through Christ. Its aim is to express the love of God to all who come, in every possible way; in skilled nursing and medical care, in the use of every scientific means of relieving suffering and distress, in understanding personal sympathy, with respect for the dignity of each patient as a human being, precious to God and man (sic) (p. 412).

With this Christian foundation, it is recognised that Saunders secularised the work of the religious order (Bradshaw, 1996, p. 412). She brought together the best of medical science with the Christian values of compassion and vocation to those in need. It required this notion of vocation, “for she [Saunders] believed that only this will attract and sustain the staff” (Bradshaw, 1996, p. 411). Clark and Seymour (1999) explain that modern hospices sought to “rekindle the tradition of devotion, calling and the ethic of service which was enshrined in the religious foundations of their predecessors” (p. 66). Saunders (cited in Woods, Webb & Clark, 2001) emphasised “the dual importance of a rational or scientific approach to symptom control coupled with a moral regard for the dying individual” (p. 93). The whole project of carrying out research, and building Saint Christopher’s, “had taken on a sense of something predetermined and meant to be: some part of a greater purpose” (Clark, 2002, p. 12).

It was this Christian ethical foundation, or moral regard for the person, that underpinned this new approach to the care of living-dying people. Certainly, this “powerful religious commitment” (Clark, 1998, p. 45) was central at the time and this commitment to aiding those who are dying is still central. Unfortunately, Bradshaw (1996) concludes, “the original spiritual ethic and its influence on the history and development of the hospice movement is virtually ignored” (p. 416). Even though the articulations from today’s HPC professionals tend to be secularised, they still hold this commitment to making a difference in how dying people are cared for – a moral regard for the person who is dying.

Hospice care for me is a working from the heart, a calling. Not just work, a way of life (Lisa)

I think it is driven by my motivation of helping others (Kieran)

I guess I like to believe that I can make a difference. I think we all have some sort of responsibility in life to do something to help our fellow man [sic] (Nina)
That maybe there is something that I have done that has made that final journey somehow a bit easier for the person and the family (Frieda).

I decided then that the only thing I would do is palliative care and try and make some sort of difference (Fiona).

It’s like a daily reminder about why I’m doing it. When I meet patients and families [pause] that I’m able to make some sort of difference to the way they’re dealing with the illness. That’s what makes it worthwhile (Michael).

It requires vocation. You cannot go into it without that commitment (Jackie).

One experienced HPC professional, who embraces the original Christian underpinnings, articulated her understanding of the philosophy of (total) care in this way:

I look at hospice in its Christian meaning, which was a place of sanctuary and comfort for the needy and poor. That philosophy should still apply. The needy, as in those whose needs have increased because of their physical disease and these needs aren’t being met by the general health system. So it’s about [the philosophy of care] the heartfelt caring approach of Christianity … about the caring with compassion. I still would prefer that this hospice philosophy was still, at least predominant in our current models of what we call palliative care, because Dame Cicely adopted it because of that Christian basis and that Christian meaning of compassion. It was a very deliberate choice. You don’t need to be a Christian. It’s about compassion, the commitment, and the caring, in a human sense, that you feel for another sufficiently for you to provide what they want (Jackie).

Jackie’s articulation makes the point that it is the values and practices of compassion and care that are most important, rather than the need to identify oneself as a Christian. It is the motivation to care, and the concern for others, that is most important. A further example of an adaptation from Christian language to secular form is the original belief that ‘each person is uniquely loved as a child of God’, which has now been translated into ‘you matter because you are you’ (Randall & Downie, 2006, p. 6). I do not believe Saunders would be disappointed about these particular types of adaptations of her original philosophy. Once, when she was being interviewed, she was asked about whether all hospice care required these Christian foundations. Saunders replied “I couldn’t say yes, because I would be closing doors. So I said ‘no’. You have to look towards your basic philosophy” (Saunders, cited in Brooks Cowen, 2004). The philosophy is about care, commitment and compassion, whether you are Christian or not. What this has meant was here is a philosophy of care which could be adopted widely across many settings and cultures.
3.3 Contemporary hospice palliative care practice

It was, therefore, the central philosophy of (total) care which has been carried forth to guide the contemporary practice of HPC. Saunders’ (cited in Clark, 2002) orientation to care is articulated in the words below:

It calls for a positive approach which sees this as a time not of defeat, but of life’s fulfilment, recognising that there will be many different paths to life’s ending. Here comfort and care become the prominent aims in a ‘middle way’ between too much and too little treatment, where understanding and compassion are vital (cited in Clark, 2002, p. 127).

This orientation of caring for the dying, coupled with the establishment of Saint Christopher’s Hospice, became a source of inspiration for others. People from all over the world came to Saint Christopher’s and learnt about the importance of the centrality of the living-dying person; sophisticated pain and symptom control procedures; of working from an interdisciplinary basis; and the commitment to the psychosocial and spiritual in this approach to caring for the dying (Clark, 2000, p. 53). This learning, in turn, was able to be taken away and interpreted into various other settings around the world. Saunders’ inspiring commitment to this approach to caring for the dying has translated into the development of eight thousand hospice palliative care programs around the world (Brooks Cowen, 2004). In Queensland there are approximately eighty to ninety specialised services in operation today (PCA, 2004).

A Canadian surgeon, Balfour Mount, was someone who came and learned from Saunders at her hospice. Mount is credited as being the first person who transferred the philosophy of (total) care into a tertiary hospital setting; the Royal Victoria Hospital in Montreal. In 1974 Mount then called this new service ‘palliative care’ (Clark, 2002)\(^\text{19}\). Mount believed that “hospice was an inappropriate name for a ward or service in a hospital” (Gracia, 2002b, p. 30). This was a crucial turning point for hospice palliative care practice. It meant that the philosophy of (total) care that underpinned hospice care

\(^{19}\) It is important to note that although most texts credit Balfour Mount as the first to coin the term palliative care, it was actually Dr Herbet Snow, Surgeon to the Cancer Hospital, Brompton, London, who in 1890 published a book on The Palliative Treatment of Incurable Cancer, thereby being the first person to coin the term palliative care (Doyle et al., 2004, p. 18). It was, rather, Mount who was the first person to call a service ‘palliative care’ in modern times.
could now, under a new name, “be promulgated in a variety of settings” (Gracia, 2002b, p. 30). Gracia (2002b) explains

These developments demonstrated that hospice care did not have to be limited to a separate building, but that the new attitudes and skills could be practiced in a variety of settings (p. 30).

Indeed, hospice palliative care has been transferred into a range of different settings, each with variations as to how it is practiced. This is especially the case with HPC being practiced more often in acute medical settings nowadays. Clark (2002) recognises that more often now “palliative care is preoccupied with many of the wider questions relating to the work of health care systems in the modern world: costs, benefits, access, equity” (p. 271). With these health care preoccupations, and the geographical shift back into medical settings, this has meant that a greater conceptual clarification and a sharper focus on where HPC’s boundaries begin and end is needed (Clark, 2002).

### 3.4 Which one: Hospice or palliative?

At this point, it is important to note that Saunders did not relate to this term of palliative care. In her earlier writings “palliation is understood in the classical sense as a merely symptomatic treatment” (cited Gracia, 2002b, p. 29). The verb ‘to palliate’ means to “alleviate the symptoms of a disease, to mitigate the suffering of, to ease” (OED, 2007) and so has been, and continues to be, an important concept in the practice of medicine (Gracia, 2002b). Certainly, this is an important component of HPC practice, but for Saunders it did not embrace the full expression of providing caring practices that aimed at total comfort. This total care of the living-dying person began when all curative and palliative measures were exhausted. Thus, Saunders did “not consider palliation a correct word to express the hospice philosophy” (Gracia, 2002b, p. 29). Comfort, rather than cure or palliation was the central aim (Saunders, 1966, p. 225). We can be in no doubt about this aim when Saunders (1967) writes

> Care for the dying person should be directed no longer towards his (sic) cure, rehabilitation or even palliation but primarily at his (sic) comfort (p. 385).

The tradition of hospice care, therefore, believed that cure and palliation were acceptable for people with treatable illnesses, but not for dying people. For Saunders (1967) the correct goal of hospice care was comfort.
3.4.1 Differing values

The original philosophy of (total) care, which included this central goal of comfort, coupled with separate contexts of care, was underpinned by important, coherent and unique values. These values, notes McNamara (1998b), were the importance of open and honest communication, the awareness of dying and a re-claiming of the acceptance of death (McNamara, 1998b). Hospice care was formed, with these values at the heart, as a “unique form of care” (McNamara, 2001, p. 120). HPC became a social practice that differentiated itself from medicine, by honouring these unique values, which then became “a new, positive approach to terminal care” (Clark & Seymour, 1999, p. 62). Hospice evolved to correct the “imbalance created by technological medicine” (Kearney, 1996, p. 22) and to reincorporate the social in the dying event, as well as the central role of the living-dying person. Saunders (cited in Clark and Seymour, 1999) presented both “a conceptual critique and a workable, alternative model of delivering care to seriously ill and dying people” (p. 88).

3.5 The philosophy of (total) care

3.5.1 Total pain: More than physical

With an understanding of the changes in dying, the concerns of medicalised dying, coupled with the initiation of the hospice movement and the promulgation of the philosophy of (total) care into other settings, this chapter now turns to understanding in greater detail the key concepts of the original philosophy of (total) care. These central components of the philosophy are the concepts of total pain and total care; the importance of the social and spiritual realm; and dying as natural and accepted.

It was, first and foremost, the concept of total pain that preoccupied Saunders research. Through listening to patient’s narratives, and “tuning into their priorities”, Saunders was able to better understand the processes and needs of the dying (cited in Brookes Cowen, 2004). Through her research a thorough analysis of the problems and treatments of pain in some nine hundred patients was carried out. She focused on what drugs were administered and how. Saunders wrote that
We should anticipate distress and pain by our treatment so that the patient does not continually do so himself. If pain is constantly allowed to occur, each time the patient has to ask for something to relieve it. Not only does he then make it worse by his fear and tension but he is reminded of his dependence upon the drugs and the person who gives them to him (cited in Clark, 2002, p. 9).

Saunders’ conclusion was “that the use of opiates in terminally ill patients was okay, without fear of provoking dependence” (Gracia, 2002b, p. 27). Thus, there could be, in most cases, the constant control of pain through the use of oral morphine. This had not been done before and so was a revolutionary step.

It was, however, the concept of mental pain that most preoccupied Saunders, as she noted that it was “perhaps the most intractable pain of all” (cited in Gracia, 2002b, p. 27). Hinton (cited in Saunders, 2004) documented “the physical and mental distress of the dying and the need to address problems largely ignored by the main thrust of medical development in general hospitals” (p. 18). Saunders argued that “physical and mental suffering are seen almost dialectically: each capable of influencing and shaping the other” (cited in Clark, 2002, p. 9). The view of pain that she developed “moved beyond the physical, to capture the social, emotional, even spiritual dimensions of suffering” and dying (Clark, 2000, p. 59). Saunders learnt from her patients that pain is something that is not just physical, but is involved in the whole of the person. “She [Saunders] crystallized out the full-blown concept of total pain, to include physical, social, spiritual and psychological problems”, explains Gracia (2002b, p. 27). In her own words, Saunders (1996) clarifies this new concept of pain

It soon became clear that each death was as individual as the life that preceded it and that the whole experience of that life was reflected in a patient’s dying. This led to the concept of ‘total pain’, which was presented as a complex of physical, emotional, social, and spiritual elements. The whole experience for a patient includes anxiety, depression, and fear; concern for the family who will become bereaved; and often a need to find some meaning in the situation, some deeper reality in which to trust. This became the major emphasis of much lecturing and writing on subjects such as the nature and management of terminal pain and the family as the unit of care (p. 1660).

What this new understanding of pain meant was “a profound challenge issued to the Cartesian body-mind dualism of modern medical practice”, thereby distinguishing HPC practice from this preoccupation in the medical domain (Clark, 2002, p. 9).
3.5.2 Total pain equals total care

What this above articulation of total pain then translated into was the aim of providing total care (whole person care) to the living-dying person. This total approach to care has been based on the fundamental understanding that “a person is an indivisible entity, a physical and a spiritual being” (Gracia, 2002b, p. 32). Thus, care needs to address this understanding to be wholly effective, most especially in end of life care. For Saunders it meant that professional caregivers needed to include physical symptoms, mental distress, social problems, and emotional difficulties into their sphere of practice (Clark, 2002, p. 9). This, in turn, required a range of professionals to care for the living-dying person, and his or her family. Consequently, an interdisciplinary approach to care was crucial, “which could work together to explore the needs of individual patients at the deepest level, but which could also support and enrich itself” (Saunders, cited in Clark, 2002, p. 128).

Unfortunately, this concept of total care has been misunderstood and criticised over the years. In response to her critics, Saunders (cited in Clark, 2002) sought to explain that “what I was trying to bring out is the importance of knowing each patient and their reaction to their pain and/or discomfort. I think the care of the dying calls for something rather more individual” (p. 17). Saunders did not mean that every nurse or carer should become “a pseudo psychiatrist” (Saunders cited in Clark, 2002, p. 366). Rather, HPC professionals should simply be aware of the whole situation in which a person finds themselves and understand that there is much more to a person than the physical body and its disease. One palliative care medical specialist interviewed for this research inquiry understood Saunders point when he explained to me about his understanding of the philosophy of (total) care

The philosophy of care, for me, is to try and keep it simple. That is, that it’s about a house of care. To me hospice and palliative care is about holism and looking at the four rooms of physical, social, psychological and spiritual. All four rooms being equal and connected, intimately, and never doing justice to a patient’s care unless you look at those four rooms. So in a nutshell it’s about the social, psychological, spiritual and physical domains of care that are central to the philosophy. I mean, I don’t know why people have trouble with that. You cannot treat people purely physically or purely spiritually without understanding those linkages. Yes, I might have a lot of science of cancer knowledge, but that still means that I can’t do justice to that person’s care if I’m not
aware; at least aware of the psychological, spiritual and social parameters that interact with those physical symptoms and diseases (Jim)\textsuperscript{20}.

With this concept of total care Saunders was emphasising a particular conception of personhood and corresponding caring practices for the final journey in life. The establishment of this caring framework was increasingly influenced by psychology and theology, which understood ‘person’ as seen in interrelationships (Clark, 2002). This caring framework recognised that each person is a complex being, who is much more than a physical being, with varying facets which are impossible to disentangle or separate. This way of ‘seeing’ a person, Saunders (2003) believes, requires of us to include “the whole context of their culture and relationships, thereby giving each his or her intrinsic value” (p. 35). “We are concerned with persons and we are concerned as persons” (Saunders cited in Clark, 2002, p. 128).

### 3.5.3 Importance of the social realm

This concept of total care included the fundamental understanding that a person is intimately connected with his or her family, friends, community and culture. This meant that the philosophy of (total) care recognises and values the centrality of the social in its caring practices. This recognition meant that dying, once again, is acknowledged as being an inherently social event. This symbolized an attempt to bring back the family and friends into the dying process, as it had been in times before the medicalisation of dying. This valuing of the social realm, or the social process of dying, put forth that living-dying people are not “discrete entities separate from their social networks, but people whose psychic and relational boundaries are negotiated with those around them” (McNamara, 2001, p. 55). Or, in other words, most people understand their sense of self

\textsuperscript{20} Please note that Jim’s version of the philosophy of (total) care comes from a newsletter article written by Kellehear (2000c). In this article Kellehear explains the importance of the social in hospice palliative care. He does so by using the metaphor of house. He talks of the four houses of palliative care: the House of the Physical, the House of the Spiritual, the House of the Psychological and the House of the Social. Kellehear (2000c) writes that “these four houses are home not only to the style and type of our efforts in caring for the dying and their families, but also the thrust of our research efforts, and the foundation of our education and training” (p. 6). Unfortunately, Kellehear argues, the House of the Social is missing. He suggests that “palliative care is one house with four semi-detached parts. The devaluing of one part devalues all the other houses” (p. 8). Hence, he is suggesting that with the devaluing of the social we are devaluing all the other components of care (and of the person). This palliative care medical specialist, Jim, has simply used the term room instead of house.
through the significant roles and relationships that they are a part of. Thus, the family and significant friends of the dying person is the ‘unit of care’ in HPC practice. HPC practice tries, as much as possible, to include the family in the living-dying person’s care and to offer support, at the time leading up to death and afterwards, whilst grieving.

Two of the HPC professionals emphasised this important component of HPC

I really feel very strongly that it’s not just the patient, but the patient within their community or family networks as well (Elizabeth)

For me, it’s more about how I can support the family to care for their loved one, rather than taking over (Fiona).

Unfortunately, the importance of the social embeddedness of living-dying people, and the required corresponding practices, have been misunderstood. The WHO (2002) definition states that “Palliative care is an approach that improves the quality of life of patients and their families”. As a consequence of the way this aspect of the philosophy is translated into this WHO definition, Randall and Downie (2006) suggest that this WHO definition is “generally taken to mean the welfare of the family is as much their [professional care-givers] concern as that of the patient” (p. 75, original italics). This is a misconception because Saunders’ original concept does not translate into an equal obligation to the quality of life for the family and friends. The original philosophy simply meant that HPC professionals were aware of the social nature of human beings, and needed to be inclusive of the family and friends at this significant time of life, and to provide what support was possible. The argument put forth by Randall and Downie (2006) goes too far in stating that the concerns of the family are of equal consideration to that of the dying person. Therefore, Randall and Downie (2006) conclude that “the philosophy of palliative care should not state that the aim is to achieve the best possible quality of life for the relatives of patients” (p. 90). I do not believe that this was ever the intention inherent in the original philosophy. Finally, Randall and Downie (2006) suggest that in terms of the care we give family members we should simply offer words of comfort and friendly advice and provide information and explanations (p. 90). This redefinition and misconception exemplifies one example of the dilution and confusion of the original philosophy of (total) care as it has grown and changed over the years, and especially as it has relocated itself into the domain of medicine.
3.5.4 The centrality of the spiritual

Aside from the reintegration of the social into the philosophy of caring for the dying, the centrality of the spiritual or religious\(^\text{21}\) was also re-established in the philosophy of (total) care. Gracia (2002b) acknowledges that “she [Saunders] stressed especially the need to take into account the spiritual dimensions of pain and death” (p. 28). In explaining some of her articles, Saunders (cited in Clark, 2002) wrote, “I have found in writing them that the religious aspect will keep breaking through as I do feel that this cannot be left out of this kind of work” (p.14). She even went so far to propose that

> On the spiritual side, I know that the spiritual work is of paramount importance and while it goes hand in hand all the time with our medical work, it is the only lasting help that we can give to our people (Saunders, cited in Clark, 2002, p. 23).

This quote of Saunders demonstrates that although she wished to bring together the dual benefits of medical and humanistic-spiritual guidance, she valued the spiritual highly in the total caring approach.

Unfortunately, this too, like the social component of the philosophy of (total) care, has been misconstrued. The WHO (2002) definition states “the assessment and treatment of pain and other problems, physical, psychosocial and spiritual”. Thus, two problems emerge from this definitional understanding. Firstly, it is a problem based approach. Secondly, it is about assessment and treatment of spiritual problems. What this amounts to is a reinterpretation of this philosophy by medical interpretations. The understanding of human beings which includes the elements of the psychological and spiritual were not ever meant to be assessed and treated. This is a fundamental medicalisation of the original philosophy. Once again, Randall and Downie (2006) argue that “the goal of assessing and treating the patient’s psychological and spiritual problems … should be abandoned” (p. 179). The reasons Randall and Downie (2006) state for this abandonment of attending to the spiritual is that it is impossible to assess these spiritual or religious problems, and as a consequence of demanding resources and no evidence of benefit, the psychological and spiritual aspects of care should not be given any significance. Like the importance of the social realm, this aspect of the philosophy of

\(^{21}\) Saunders used the terms religion and spirituality interchangeably.
(total) care has been redefined incorrectly and the practices of attending to these domains have been medicalised. Spirituality was never supposed to be assessed and treated; and evidence of benefit is not necessarily quantifiable according to medical research methodologies. This demonstrates that the philosophy of (total) care that underpins HPC practice has been misinterpreted and reconfigured over time.

### 3.5.5 Dying and death as a natural part of life

The philosophy of (total) care incorporated the understanding that pain was more than physical, and that a ‘total’ or whole understanding of personhood was required in end-of-life care. This included the importance of the social and spiritual realm. The next important component of the philosophy of (total) care is the recognition of dying and death as a natural part of life. The hospice movement meant to readdress the medicalised view of death as failure. This, of course, included the denial of dying and death. Hospice founders wished to return to the time when dying and death were seen to be a normal and natural time of life; one that is inevitable for us all. Rather than denying death, Searle (1989) writes that this ‘return’ included a willingness to talk with patients about their dying. An awareness and acceptance of dying and death was crucial, with the understanding that levels of acceptance were individual and dynamic. This central belief and value, which this thesis refers to as ‘an acceptance of human mortality’, placed great importance on viewing death as a normal process and an inevitable part of the life cycle. This commitment to awareness and acceptance of dying and death was further influenced by research from Glaser and Strauss (1965) which found that people in hospital settings had a ‘closed awareness’ of dying. Acceptance of human mortality is then translated into a valuing of a personal awareness of dying and death, open communication between the dying person, family and caregiver, and an overall acknowledgement of impending death (McNamara, Waddall & Colvin, 1994). What this means is that honesty becomes an imperative in HPC practice. The standpoint of acceptance of human mortality was spoken about as a significant value that underpins the practice, but not discussed to any great length under the banner of philosophy.
Therefore, discussion on this central concept is further explored in chapter six. Two HPC professionals did mention the importance of dying as natural in their understanding of the philosophy of (total) care

The philosophy of care is about the acceptance of death, as a part of life (Julie)

It seems to me that the hospice philosophy is about accepting the reality of death; that’s the basic thing … that people aren’t able to be cured, so acceptance of the reality of dying. So to me hospice care accepts that sort of reality (David).

One could question whether it is problematic that acceptance of human mortality has not been largely spoken about as a fundamental belief in the philosophy of (total) care, but rather is positioned as a significant value that needs to underpin the practice of HPC. I do not find myself concerned with this issue, particularly in that acceptance of human mortality was the value most mentioned by the professionals, meaning that it still plays a central role in guiding HPC practice.

3.6 Narratives of the philosophy of (total) care

In a brief way, the key components of the original philosophy of (total) care have been outlined above. This included Saunders’ commitment to understanding pain in ways that went beyond the physical, the explanations of total care which included the importance of recognising the social and spiritual dimensions of people. Finally, the commitment to viewing death as a natural and normal part of life played a significant role in the original philosophy of (total) care. With this understanding of the original philosophy in mind, this chapter now sets out the narratives from the HPC professionals. When asked what their understanding of the philosophy of (total) care was about the responses from the HPC professionals were varied. Within this variation, however, a commitment to total care is still central for many of the HPC professionals. On the other hand, even though total care was expressed as important, it is contested.

The guiding statements from PCA (2003) still emphasise the total care approach in its documentations by explaining that

People’s needs vary widely as death approaches, but commonly include the need to understand what is happening, resolve issues with family and friends, achieve a sense of completion emotionally and spiritually, and come to terms with significant life changes. Palliative care can support this process by relieving pain
and other symptoms, addressing practical and financial problems, and providing appropriate psychological, social and spiritual support (p. 8).

This PCA standard is often understood by the term holism\(^{22}\). When the notion of a philosophy of (total) care was raised in the narrative interviews with the HPC professionals, and I enquired as to what that meant to them, total care was the most mentioned concept. Importantly, this also coincides with total care being the second highest value underpinning the practice. Consequently, with these articulations, as outlined below, this thesis argues that the concept of total care must be central to the philosophy of (total) care and practice of HPC. For many of the HPC professionals, the philosophy of (total) care meant

- I think the key thing is recognising that what we do is completely holistic and I’m as concerned about someone’s spiritual or existential distress, as I am about their physical symptoms. For me it’s managing what is the most distressing thing for that patient at the time (Stacy)

- For me the philosophy is about the value of total care. That means that we see the person as a whole person. I still like to believe that we … that they are not just a patient and not one individual can look after this person. We have a team to call on to help (Frieda)

- That for the patient, it’s not just the physical and the biomedical stuff. It’s looking at how that comes together as a whole, especially looking at the emotional side of it and a lot of spiritual stuff as well. Their own life journey and being guided by the patient about where their needs are. I think palliative care, certainly the hospice model, does this. Whereas an acute model doesn’t even come close. So a great sense of holism and how this is distinctive from other health care practices (Elizabeth)

- Bringing your humaneness to the situation and looking at the whole person. That is, looking at the physical, spiritual, psychosocial and emotional and giving them care that’s appropriate to these domains (Jennifer)

- The philosophy of care being that it is a much overused term, holistic care. That is, that it encompasses the physical, emotional, spiritual, psychological, total care. So it’s not just medical care. So a pretty big call really (Natasha)

- I suppose the main thing to me is holistic care. So that we’re looking at all the areas; the social, spiritual and everything like that. So that’s the main aspect of the philosophy for me (Fiona)

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\(^{22}\) This thesis prefers not to use the term holism, but rather will continue to write this as total care or whole person care. Where the HPC professionals use the term holism, this is kept in, but the reader can understand that total care, holism, and whole person care are terms that are used interchangeably and that they mean the same thing.
There’s so much talk about holistic care, but I think it’s the one time you actually get time to do it. So this is an opportunity to really apply that principle. So much of what we do is not about the medical stuff. It’s not the pain relief. Often it’s all the other things. It’s helping people work through family relationships and sorting things out (Naomi).

It’s about giving them full, total care. That is, medically, socially, spiritually. In every way possible (Kieran)

That care be holistic. That it brings together support for the person; the individual, the family and community and that it crosses spiritual, mental, emotional, psychological. It embraces all of that (Gloria)

I think that the palliative care philosophy is about the holistic approach. That it tends to see the person and their family as a whole, much more than other areas of health care. The nature of our work in palliative care is that we’re looking at the whole person. We want to find out every symptom that they have and try and deal with it. Whether we always deal with those symptoms in a totally holistic way is another matter. So yes we do look at just not the physical symptoms, we look at what’s happening socially, spiritually. Well, that’s the ideal anyway and that’s central to the philosophy (Michael).

Clearly, it can be seen that this concept of total care is still a vital one in the current understandings of the philosophy of HPC.

3.7 Contestation and erosion of total care

As can be seen from the professionals’ stories, total care is a central component of the philosophy that guides HPC practice. Total care, however, is being eroded and contested. As Kellehear (2005) asserts “it appears that the original holistic philosophy of hospice care of the dying is experiencing serious challenges and threats” (p. 7). These challenges and threats come, in part, with the medicalisation of the practice, as outlined in the introduction. This medicalisation thesis argues that the HPC approach, which includes sets of values, beliefs, and assumptions which were distinctive from those of the profession of medicine, have now become medicalised and therefore has lost its original intentions and practices (Abel, 1986; Bradshaw, 1996; Clark & Seymour, 1999; Janssens et al., 2002; Kearney, 1992, 1996; Kellehear, 2001, 2003; Manima, 2003; McNamara, 2001, 2004).
The medicalisation of HPC, and the corresponding erosion of the concept of total care, can be viewed as a potential threat. Ten Have and Janssens (2001) suggest that HPC and its relationship with mainstream medicine has reached “an ideological stalemate” (p. 4). There are tensions involved in this uneasy relationship between HPC and medicine. Firstly, it could be heard in the storied accounts from the HPC professionals’ statements pertaining to the distinctive nature of the practice; in effect, ‘we are different from medicine’. On the other hand, other HPC professionals believe that integration into the mainstream health care system, including the corresponding scientific knowledge base required, is essential for the future longevity of the practice.

A further fundamental tension is the clash between curing or life prolongation and acceptance of dying-as-natural. The belief that death is a normal part of life inherent in HPC practice is not, by and large, adopted in mainstream medicine. “The suffering of dying is a problem to be solved [in a medical context]”, explains Kearney (1992, p. 41). Aries (cited in Clark & Seymour, 1999) argues that death, “through the forces of medicalisation, becomes a ‘problem’ of professional health care”, rather than an accepted, inevitable and visible fact of life (p. 117). Crucially, Kearney (1992) emotively suggests that with the development of palliative medicine “I am afraid we may be in the process of selling our soul to the very medical model whose excesses have created the needs our specialty sets out to meet” (p. 41). What this statement is referring to is that the motivation and establishment of hospice came about as a result of needing something different from medicine, but that it has come full circle and is now becoming more like medicine. Kellehear (1999b; 2003) is one author who strongly suggests that HPC practice now has simply become a set of medico-nursing clinical responses, which focuses on physical symptom control, “simultaneously de-emphasizing psychological, social and spiritual care” (p. 9).

Placing the physical components of care at the forefront is not congruent with the original philosophy of (total) care. Some HPC professionals do believe that the relief of physical symptoms has become the central and most important task of HPC practice. Here are some further responses to the question of what the philosophy of care meant
I think we’ve placed too much credence on all of these emotional symptoms that they have. Let’s just fix the physical ones. That’s how I think we should make a difference. Fix the physical stuff and make them comfortable. That will most likely lead to their emotional comfort anyway. The priority should be physical comfort, because patients will say, “Don’t even talk to me about spiritual distress, for God’s sake, just fix up my pain” (Martha)

I see the symptoms as very important because you can’t do deep and meaningful conversations with someone who’s got their head in a vomit bowl or who is in excruciating pain. So I’ve always taught my students “treat the symptoms first” so that you can get to the person. Always focus in the beginning what’s wrong with them physically, so that’s where we need to start (Anna)

It’s about the many ways to treat things and the confidence in using them [medications] in order to relieve the physical symptoms (Stacy)

I think it’s all become about good symptom control [laughing]. She says without hesitation. I’m afraid that’s it. There will be other things that we like to do, but those are the margins (Jackie).

It is interesting to note that the first two of these HPC professionals work in acute care settings (hospitals), and so are likely to be influenced by curative values and the dominant Cartesian mindset. Certainly, I have never heard a living-dying person use the words ‘spiritual distress’. This is a professional term.

Conversely, some HPC professionals were concerned about placing physical symptom control at the top of the hierarchy of care

There’s a lot more focus on symptom control and I think, to be honest, that medical symptom control is highly overrated. I’m not saying there’s no value in it, just that it’s overrated (Julie)

It’s not just medical care. I just think it’s not just health care and that’s part of the problem with palliative care at the moment. Getting mainstreamed into such clinical, medical settings. Now that it’s being seen as a medical specialty and I think that’s sort of sad in some ways. In some ways that philosophy is being lost (Emma)

The social, psychological and spiritual aspects, as you know, are much tougher. So I suppose, due to my maturity in palliative care now, to me that’s much more important, and that in turn, because of the links to the physical domain, if we get those aspects right, often the physical care does become easier (Jim)

Total care is definitely important for the palliative care philosophy, so not just the physical. I think the physical is a very small part of it really, in the grand scheme of things. If you had a pie graph, it would just be a sliver and there would be all the other stuff (Elizabeth)
We use the language of holism, but I think that we are as about as sophisticated with that as we are with issues like autonomy. If palliative care professionals really thought about what holistic care meant we would be up in arms trying to change the emphasis on a set of medical and nursing activities. I see holism is one of those tenets that are held up as what we provide and I think that we’re probably only about half way there (Ken).

Thus, as can be seen in these differing articulations, we have a fundamental disagreement in the understanding of the philosophy of (total) care. Total care is largely central for many HPC professionals, but total care is being contested and eroded. This insight is supported by McNamara’s (2001) research which found that there is now a hierarchy of care where

precedence is given to physical causes and treatments … [and] psychological, social and spiritual components of care, while considered important, are placed lower in the hierarchy of care. It is not surprising that the physical component of care is always placed first and that medicine is seen as the primary means of alleviating suffering” (p. 126).

3.7.1 Total care requires teamwork

With the commitment to total care comes the imperative of an interdisciplinary23 approach. In other words, the total care of the dying person can only be achieved when working from a basis of an interdisciplinary team of professionals. This is the only way that total care can be ensured. From its inception, HPC has placed importance on a non-hierarchical, team approach to caring for the dying. Saunders (cited in Brookes Cowen, 2004) announced that, in the beginning, “we needed to challenge the central role of the physicians” thereby emphasising interdisciplinary meetings and seminars.

Initially, in the past, this team consisted of doctors, nurses, counsellors and members of the clergy. Nowadays, it can consist of palliative medical specialists, palliative nurses and clinical consultants, allied health staff including physiotherapists, counsellors, social workers and psychologists, and spiritual support workers including chaplains, pastoral

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23 There is some confusion with the usage of the terms multidisciplinary and interdisciplinary, especially in the PCA Standards Guidelines (2005). This thesis adheres to the term interdisciplinary to emphasise that the philosophy of (total) care usually emphasises a team of HPC professionals, who come from differing professional groupings, but who each have specialist palliative care education, knowledge and skills. For example, a social worker, who has a social work degree and background, but who is also trained in HPC practice. Each of these disciplines is represented, included and the care of the dying is done via ‘inter’ disciplines. Where this text includes the term multidisciplinary, it can be understood as meaning the same as interdisciplinary.
carers, and spiritual advisors, and volunteers. Some services are lucky enough to include music therapists, occupational therapists, aromatherapists, art therapists, biographers, dieticians and natural therapists. Each of these professional groupings still requires specialised HPC training. A HPC model of service delivery is expected to have this interdisciplinary approach, or the valuing of each discipline’s contribution to care (Clark, 2000). Each member of the HPC team is recognised as of equal importance and value. Zimmerman (1986) notes

An important feature of multidisciplinary care in a hospice program is the lack of sharp distinction between the functions of the various team members. Although each has an area of expertise and primary responsibility, each must be alert to the problems and needs of the patient in other areas. All should share in providing psychological and emotional support to the patient and family (p. 99).

The Standards for Providing Quality Palliative Care (PCA, 2005) provide a definition of an interdisciplinary team as

a team of health care providers who work together to develop and implement a plan of care. Membership varies depending on the services required to address the identified expectations and needs of the target population. An interdisciplinary team typically includes one or more physicians, nurses, social workers/psychologists, spiritual advisors, pharmacists, personal support workers, and volunteers. Other disciplines may also be part of the team (p. 12).

With this definition of the interdisciplinary team in HPC, the standards also set out to delineate different levels of HPC practice. Without clarifying these, it needs to be noted that these levels and the corresponding professionals for each level, have been confusing and controversial. To illustrate this confusion and concern, one community HPC service that was included in this research inquiry is not recognised as a specialist palliative care service because it does not have a palliative medical specialist in its team, but rather is a nurse-led service, which fosters significant relationships with General Practitioners in the community. On the other hand, a palliative care consultancy service that was included in this research inquiry, located in an acute care hospital, is recognised as a specialist palliative care service of the highest level, because it does have a palliative medical specialist in its team, but the team is only made up of doctors and nurses; no chaplain, pastoral workers, counsellors or volunteers were included. As a consequence of these two examples, the levels outlined in the PCA standards, and the required team members, have been quite controversial.
During this inquiry it was noted that this team approach to care varies greatly according to the different contexts where HPC is carried out. Indeed, it was difficult at times to locate allied professionals - hospice palliative care professionals other than doctors and nurses - to interview. McNamara (2001; 2004) reports that the value of interdisciplinary work espoused by the hospice philosophy is being undermined by medical practices which tend to favour hierarchical systems, with the doctor at the top. Interestingly, discussion about the team approach in HPC practice did not receive much attention in the storied accounts. Here are the few comments offered pertaining to the importance of the interdisciplinary approach

**Teamwork is central to palliative care philosophy as well (Jim)**

It’s very much the total team. And even though it’s led, it’s not up here ‘I am the leader’ [as in hierarchical]. And that was a new experience for me. I didn’t have someone standing over my shoulder. And sometimes I found that quite difficult (Fiona)

Within the philosophy, we offer it in a multidisciplinary, holistic way. Some people may never need a doctor, but they may need a social worker because they are so frantic about the personal affairs and financial affairs. And some people might need a psychologist. You know, it’s about what the person needs, and trying to meet those needs as best as possible (Stacy)

That it should involve the interdisciplinary team. That you’ve got people who specialise in their own areas like the counsellors, the physiotherapists, occupational therapists, and obviously, not every hospice is able to have all those sorts of positions, but that’s the ideal (Michael).

Finally, this powerful quote was offered by Zoe

I will go on record in saying this. You can quote me. Everybody says palliative care is about team work, and palliative care is all about everybody having equal say. But excuse me [talking as the doctor] “I’m the doctor and this is my service”. It doesn’t matter whether it’s male or female. [Talking as the doctor] “This is my service because I’m in charge of it”. Excuse me, who died and made you God [laughing]. Because if we are so egalitarian how come we have to have an authority figure. And one who says they actually have the last word. Because that’s not what is about … that’s not what palliative care is supposed to be about (Zoe).

Perhaps the ideal of a non-hierarchical team approach in HPC is fading, when you consider comments like this. Fervently, this nurse is articulating that responsibility is a complex concept and she is jointly involved in being responsible. The commitment to total care requires a varied group of professionals to work together. The contestation and erosion of total care could also mean the same for interdisciplinary and non-
hierachical practices. Certainly, the concern is there, as Clark, Hockley and Ahmedzai (1997) write

> It is important that this multidisciplinary strength is not undermined by the fact that palliative medicine has now become a specialty. The clear danger is that all that has been built up over the years could be undermined if the multidisciplinary emphasis is to be watered down because of overly strong medical or nursing direction (p. 95)

### 3.8 To live until you die: Popular expressions

Aside from the expressions of the importance of total care, and the contestations of these, including the possible decline of the interdisciplinary team approach, other understandings of the philosophy of (total) care included popular expressions from the tradition of HPC. This includes expressions such as ‘walking with’ and ‘journeying with’, and ‘to help you live until you die’, this last one being a famous and oft quoted phrase from Saunders. These expressions include

> [The philosophy] is about to live until you die. To help them be as comfortable as possible (Nina)

> You’re kind of walking along side them. This includes respecting where they are coming from. Yes, walking along side by side with them. Not looking down or up. Just two human beings connecting (Julie)

> To help people to live until the moment that they die. That’s really very important. That’s acknowledging the importance of every single part of a person and every single moment that they are a part of humanity (Elaine)

> Our philosophy is about helping people to live until they die. Under that umbrella comes helping people with their symptoms, in an ethical way, causing them no harm. It’s about being alongside the patient (Kieran).

What is of concern about this use of popular expressions is that it may be used unreflectively. HPC professionals may not have thought about what ‘to live until you die’ means for themselves or for others. What we can know is that this notion of ‘to live until you die’ has translated into the contemporary goal of HPC practice: the improvement of quality of life. Problems exist with this goal, such as what qualifies as quality of life? These considerations are explored in chapter five.
3.9 Confused about the philosophy

Aside from the use of popular expressions used to explain the philosophy, there was also an array of confused and vague responses. These include such statements like

It’s about the things written on the wall [the hospital philosophy]. I think we have the same philosophy. I’m not sure whether they do have the same philosophy? (Nina).

This HPC professional is certainly not quite sure about what the philosophy is about, but thinks it is about the philosophy of the hospital that she works in. Another HPC professional, also from the same acute care setting, when talking about how to assist other health care professionals (not HPC professionals) in the hospital about how to care for dying people, said about the philosophy

It’s a term that’s a bit nebulous I think, and definitely the clinicians on the floor, their eyes glaze over when you talk about a philosophy. So I don’t think the philosophy is helpful. We need to give them a check list instead (Martha).

What Martha is suggesting is getting rid of the fundamental underpinnings of how HPC is practiced and developing a check list instead. This confusion about the philosophy of (total) care often translated into a difficulty of being able to put it into words

It’s weird isn’t it [pause] the more you try to define it the less you can and the broader it becomes (Elizabeth)

It’s hard to actually try and verbalise it. I just think it’s about caring for human kind. Really doesn’t make much sense, does it? (Emma).

On the other hand, two of the HPC professionals in this inquiry had perhaps had more of an opportunity to reflect upon what the philosophy meant to them and provided eloquent accounts

I understand that [the philosophy] to be a way of trying to capture a particular approach to supporting people who are dying. That approach embraces compassion and the concept of living as fully as possible, even in the presence of a terminal disease. It’s about maintaining human dignity, even when there are assaults to body image and function. I think it’s a mixture of the sorts of values I was just describing [compassion, holism, acceptance of human mortality], but I also think that there’s a kind of historical consensus about how those values are actually best practiced (Ken)

The philosophy says a number of things to me. It is that the care of the person is paramount. So you are obviously not looking at cure anymore. You are looking at whatever needs to be done to make the person as comfortable as possible and that may still involve what used to be thought of as quite active interventions, such as radiotherapy. Then of course in palliative care the client … the unit of care is not just the person with the identified illness. We look after, or we try to
look after the needs of the whole family. And that this should involve the interdisciplinary team … that you’ve got people who specialise in their own areas. When I say my philosophy, it’s my set of personal beliefs about hospice (Michael).

Both of these articulations of the philosophy include much of the central components and concepts of the original philosophy. Thus, it can be seen that HPC professionals may have an understanding of the philosophy of care and be able to articulate it, whereas others are not really sure what it is all about. This is a concern when it is understood that the philosophy of (total) care, as established by Saunders, provides for the fundamental underpinnings of how to practice HPC.

3.10 The philosophy is lost: Something’s slipped out

Finally, aside from not being sure about what the philosophy means, there were some HPC professionals who were disbelieving that there was a philosophy, or that the profession has lost the original hospice philosophy. This is one of the central questions for this chapter; whether the original hospice philosophy is still evident? According to some HPC professionals, it is not

The philosophy of palliative care … I don’t think anyone’s really defined what that is. I think they’ve just taken out hospice and left philosophy. Because philosophy is about a value and belief system, and I don’t think anybody knows what that is in palliative care these days. I think something’s slipped out. I don’t think there is a philosophy of palliative care at all (Jackie)

When we started hospice care, way back, we had this great philosophy that people were individuals, that they would be having the right type of death the way they wanted it, but I think we’ve lost it (Anna)

Now that it’s [HPC] being seen as a medical specialty and I think that’s sort of sad in some ways. In some ways that [hospice] philosophy is being lost. Yes, the philosophy [pause]. I think it’s a bit of rhetoric. It’d be lovely to say it is a shared and understood philosophy, but at this stage I’m not certain (Emma).
Over time, with the changes that have taken place in HPC, perhaps the philosophy of (total) care has changed so much it has been lost? Possibly, because of the inarticulation\textsuperscript{24} of it, or the HPC professionals all assuming that they each understood what it meant, it has been lost. Maybe the medicalisation of the practice has further eroded the professionals understanding of it. Unfortunately, the answers to these questions are not available at this point. It can be noted, however, that there is a concern that the central philosophy of hospice palliative care has been lost; something’s slipped out along the way.

\textbf{3.11 Chapter summary}

This chapter has thoroughly explored the tradition of HPC practice as required by a social practice understanding of ethics. This commenced by examining how the processes of dying, and caring for the dying, have changed over the years. Notably, this includes the decentralising of the social and spiritual realms, and the centralisation of medicalised dying and caring practices. The problems with these changes included isolation and loneliness, understanding dying as failure, poor attendance to matters not pertaining to the physical, closed communication about an illness status, and the overall denial of death. These problems, in turn, prompted a social movement to address these, and sought to find optimal ways of caring for living-dying people. Saunders and Kubler-Ross were noted as being central to this hospice movement, and the establishment of buildings, and a philosophy of care, commenced in the 1960s. This philosophy, which contains the central concepts of total pain and total care, the reintegration of the social and spiritual realm, and acceptance of dying as a natural and normal part of life, were included in this chapter so as to contrast this original philosophy with current day understandings. The understandings and articulations from the HPC professionals maintained the centrality of the concept of total care. Total care, as established by Saunders, dominated the replies to the question of what does the philosophy of care mean to you. On the other hand, it was noted that total care is being

\textsuperscript{24} In the introductory chapter the notion of articulation was presented. Taylor (1989) proposes that articulation is the process whereby the “tacit background” or what is unsaid about the ethical domain is expressed and acknowledged. Articulations of the philosophy of (total) care, from the HPC professionals’ narratives, are what have been presented in this chapter. However, inarticulation implies that articulation has not occurred and this could be a possible rationale for the philosophy being lost.
contested and eroded, possibly by the medicalisation of HPC, and with it the importance of an interdisciplinary team approach to care is also being altered. Aside from the considerations of total care, the HPC professionals also articulated popular expressions for their understandings of the philosophy; others were simply confused or unable to express their understanding of the philosophy. Lastly, some HPC professionals proposed that the original hospice philosophy is now lost, especially as the significant underpinnings of total care of the whole person continue to be contested and eroded through the medicalisation of the practice.

Ultimately, what can conclusively be said about this exploration of the central philosophy of HPC practice, which includes important beliefs, values and assumptions, is that it is not commonly shared or understood by the professional members who practice it. The professional care of the dying is not working from a basis of a shared and understood philosophy, even though it is often suggested that it is. Certainly, Saunders believed that it was still operating from this original philosophy. Towards the end of her life, Saunders wrote

So long as we have kept listening to the patients and their families, I believe that on the whole Saint Christopher’s and the Hospice and Palliative Care movement for which it was the catalyst, has continued to match mind, heart and spirit (cited in Clark, 2002, p. 378).

The matching of the mind, heart and spirit, which were the essential foundations of the philosophy, are not necessarily what is happening in the current day practice of HPC, at least here in the Queensland context, as understood by thirty professional hospice palliative care professionals. Consequently, if, as the HPC professionals stated in this inquiry, there is utmost value in this philosophy of (total) care, which has a particular way of understanding people as ‘whole beings’, then a closer examination of what is understood or assumed of ‘human beings’ is required. This is what is contained in the next chapter – an exploration of ontology or what meanings of personhood are presented by the HPC professionals and in the HPC literature.
CHAPTER FOUR
Ontology: Facets of Being

It may not be dying we fear so much, but the diminished self

4. Introduction
The ethics of hospice palliative care, when understood through the lens of a social practice framework, requires a greater understanding of ontology. The first feature of this framework is that of people. Isaacs (1998) explains that social practices “exist only in, and through, persons” (p. 4). In other words, social practices are “both constructed by, and constituted by, persons” (Isaacs, 1998, p. 4). Ontology, or the study of being, asks questions about the nature of being and seeks to understand who or what is a human being (Dreyfus, 1991; OED, 2007). Thus, this chapter explores the questions of how we understand personhood. Isaacs (2005a) asserts that we need

a sensitivity to the ontological … [and that] ethical engagement ought flow from a reflection upon, a sensibility for, and an understanding of the nature of human beings and the realities and possibilities for human beings within their human condition (p. 2).

Thus, an understanding of the ethics of any social practice requires this consideration of what we understand of personhood. There are several terms that are utilised in this type of study including self, person, subject, agent, selfhood, personhood, identity or self-identity. Herein, there is a focus on persons and personhood in the first instance whilst exploring the understandings of ontology. Secondly, it includes identity considerations of the living-dying person. An overt focus on personhood and identity means that the understandings both of how people are similar and how people are unique are included for consideration.

Ontology, or an examination of personhood, is a crucial aspect in the ethics of hospice palliative care practice in that the question of how we are to care for living-dying people all start at the basis or viewpoint of what it means to be a person; particularly a living-dying person. Or, in other words, our ethical engagement and responses come forth from these understandings and appreciations of what constitutes people. Overall, there
is no escape from these ontological considerations, about what it means to be a person, because the HPC professional is concerned with the care and nurture of human beings.

The ‘persons’ involved in hospice palliative care practice are clearly many, including the professionals, the living-dying person, the family and so forth. However, the ontological exploration in this chapter does intentionally focus upon the living-dying person. Understandings about the identity of the hospice palliative care professional are included in chapter six and include Olthuis’ (2007) recent research *Who cares? An ethical study of the moral attitude of professionals in palliative care practice* which explores the professional identity of the hospice palliative care professional. Rather than duplicate this excellent research, priority was placed on examining the understandings of the ontology of the living-dying person which came forth from the HPC professional narratives.

4.1 Why ontology?
A further rationale for the requirement of this ontological exploration concerns the aforementioned argument that the dominant Western moral philosophical tradition has neglected these ontological considerations and presented us with an understanding of personhood that is thin and inadequate. Elliot (1999), Isaacs (2001) and Widdershoven (2002) all suggest that a rich account of the self is largely missing in the Western moral philosophical tradition. As outlined in chapter two, the Western moral philosophical tradition of ethics understands self as primarily being one of thinker or reflective decision-maker; as an individual who is disconnected from social settings; and that the primary locus of self is the mind. These thin understandings of personhood translate into a need to understand human beings, in their ethical worlds, in much richer and thicker ways. Furthermore, understandings of personhood in the hospice palliative care literature nowadays tend to focus on autonomy, respect for persons and a patient-centered practice, yet “there is little consistency in their use and not much explicit discussion …” about what constitutes these personhood concepts (Randall & Downie, 2006, p. 53). Unfortunately, Randall and Downie do not attend to, or even acknowledge, the range of differing accounts of ontology on offer, but rather focus
narrowly on self determination and consent, thereby continuing a thin account of personhood.

Thirdly, the engaged ethics approach in this study requires a focus upon this neglected dimension and the re-enlivenment of our ontological sensitivities via the hermeneutical and appreciative domains. The tasks inherent in the hermeneutical and appreciative domains involve mapping the existing understandings of personhood, including the assumptions and limitations of these; acknowledging the “richness, complexity, perplexity and, perhaps most significantly, the particularity” of people; thereby “attaining an enrichment and enlargement of our appreciation of who others are” (Isaacs & Massey, 1994, p. 10). Hence, it has been one intention of this study “to promote [and] develop a fuller, deeper and richer appreciation of others” (Isaacs & Massey, 1994, p. 8).

Understanding these above reasons for including this ontological chapter means that what is presented in this chapter is a mapping of the understandings of personhood from the hospice palliative care professionals’ storied accounts and the HPC literature. It focuses on the living-dying person and how their personhood is understood by the professionals, including noting the assumptions and limitations of these. Several theorists are utilised in this exploration of personhood. These consist of a Taylorian (1988; 1989; 1995) understanding of identity and Heidegger’s (1962; cited in Dreyfus, 1991) writings on being. A typology of personhood, offered by Cassell (1991a; 1991b; 2005) is drawn upon, particularly because of its connection with understanding suffering. Conceptualisations of embodiment theory are drawn from Frank (1991; 1995) and Toombs (1988; 1992; 2001). Finally, Isaacs’ (2005b; 2005c; 2006; 2007) account of ontology and the implications for the illness experience are also included. Overall, these ontological explorations and understandings are fundamental to ethical engagement in the caring relationship between hospice palliative care professionals and living-dying people, and thus warrant greater attention in the understanding of the ethical dimension of hospice palliative care practice.
4.2. Personhood as historically and culturally shaped

It is crucial to recognise from the outset that our understandings of personhood have been culturally and historically shaped: what we currently take for granted in our understandings of ontology have been shaped according to Western culture and altered over time. Cassell (1991a) makes this point when he writes that “our views of personhood are not static; [they have] gradually changed over history” (p. 33). In addition, the notion of ‘self’ is a modern phenomenon. Taylor (1989; 1995) has charted the historical development of the modernist, Western understandings of self and asserts that “only in modern Western culture have we begun to speak of the human person as ‘the self’ and of people as having and being selves” (p. 57).

Furthermore, understandings of personhood are different in varying cultures. For example, modern, Western images of personhood include notions of individualism, autonomy and independence, such that “individual autonomy is seen to be the central core of identity” (Candib, 2002, p. 219). However, other cultures, namely Asian cultures, may understand personhood as “embedded in the family and community within a complex web of obligations that create interdependence” (Candib, 2002, p. 219). Ho Mun Chan (2004), in his study about advance directives, autonomy and the family, posits that a Western view of self is that of a separate, objective self, valuing such notions as autonomy and independence, and fearing connection and dependence. On the other hand, Asian cultures understand the self as a connected and particularistic self, valuing connection and responsiveness, and fearing separation and abandonment (Ho Mun Chan, 2004, p. 95). These brief examples demonstrate that understandings of what it means to be a human being have been, and continue to be, shaped over time and according to particular cultures. It is important, therefore, to examine the implicit and explicit understandings and articulations of personhood offered by the HPC professionals and seek to understand whether these are predominantly Western, modernist views.
4.3 Modernist account of personhood: Individual, thinking beings

The HPC professionals’ narratives did reflect a Western, modernist understanding of personhood. This dominant paradigm of what it means to be a person, as understood in today’s contemporary discourse and practices, “is both deep and widespread in our culture and emerges from that powerful intellectual and social movement in Western history that we know today as modernity” (Isaacs, 2005c, p. 3). Isaacs (2005c) elaborates on this dominant, modernist understanding of personhood. “Within that movement [modernity]”, writes Isaacs (2005c), “the self is seen as

- essentially a rational, thinking being who has the capacity to acquire certain knowledge and understanding, including moral knowledge and understanding;
- this rational self is detached and disengaged from the world;
- this rational self is detached and disengaged from its body;
- this rational self is detached and disengaged from others – it is a punctual, atomistic or individual self;
- accordingly, the moral self is that self who is detached from the influences of the world, of the body and of others and who freely accepts the requirements of rationality in how they live their lives – right thinking leads to right decisions which give rise to right action” (Isaacs, 2005c, p. 3).

As can be appreciated by Isaacs’ account, this person who is suggested by a modernist paradigm is a detached being; disconnected from the world, from others and from body (Isaacs, 2005c). Human beings are primarily understood as autonomous, independent, individual and thinking beings. The HPC professionals’ articulations reflected this understanding of personhood in several ways.

4.3.1 Person-as-individual

Firstly, an overt focus on individualism reflects a modernist account of personhood. This is not surprising, as individualism has been a part of the language and practice of hospice palliative care since its inception. One example of this dominant understanding of person-as-individual came from Lisa who proposed that “you can only approach them as an individual. You need to individualise your approach to each person. Because they are all individuals, who have their own particular needs. So it’s developing sensitivity to individual needs”. Similarly, Nina refers to individual wants: “I think because you have to really be doing what the patient wants. It’s really about their wishes and about how they see whatever track they are going down”. This quote also includes the importance of person-as-
decision-maker that plays a role in the modernist understanding of personhood. The living-dying person is positioned as an individual, decision-maker in both of these articulations. This focus on person-as-individual and person-as-decision-maker continues with Anna who believed that HPC practice is “about the patients’ needs. We can’t make decisions for them and we have to let them walk their own journey. So if they say to me “I’d like to be sedated” then it’s not whether I ethically think that’s correct. It’s what the patient wants”. Again, it can be seen that person-as-individual and person-as-decision-maker is dominant in this professional’s understanding of what it means to be a person, and accordingly how she will conceptualise and prioritise her caring activities and responses.

In addition to the professionals’ narratives, an overt focus on people as autonomous individuals in the hospice palliative care literature abounds. Research studies such as *Patient participation in decision making at the end of life* (Sahlberg-Blom, Ternestedt & Johansson, 2000) are very common. This research focused on the patient’s ability to make decisions independently, which led to outcomes such as greater self-perception and an increased quality of life (Sahlberg-Blom et al., 2000). The authors found that “there is much to indicate an increased demand for autonomy” (Sahlberg-Blom et al., 2000, p. 310). However, what goes unacknowledged in this study was that the researchers held a particular view of personhood and one that stems from a modernist, Western stance. This unarticulated viewpoint of person played a significant role in the formulation of the study, the types of questions asked, and the particular focus and, one could argue, the outcomes or findings of the study.

Similarly, in *Lessons from cancer patients* (Blindman & Cherny, 2005), loss of autonomy was found to be one of the three defining components of existential suffering. However, this study did not take into account that autonomy or individualism, as a dominant understanding of personhood in contemporary Western societies, would be valued, privileged or dominant in their patients’ narratives. What was interesting about this study was that my interpretation of some of the patients’ comments pertained more to their understanding of their ability or dis-ability to walk around and do purposeful
things, not about autonomy. Autonomy is most often primarily understood as a cognitive phenomenon: the ability to self-decide. This has more to do with one’s relationship with body, as will be discussed further along in this chapter, and an ability to do. This demonstrates that there continues to be a variety of definitions, and perhaps misconceptions, about the complex concept of autonomy. All too often, it seems that autonomy is simply applied without considerations of what this might mean for the people conducting the study, or the people under study. Finally, this study concluded with generalisations about the importance of autonomy, without acknowledging that at least one patient’s story mentioned that the loss of autonomy was not a problem for him: “My wife helps me at home. I am not bothered by my loss of autonomy” (Blindman & Cherny, 2005, p. 374). These are just two brief examples of research literature that start from an assumed understanding of personhood which stems from a modernist perspective. The authors do not make transparent that this is the position they are coming from. Finally, they conclude their studies with statements about the centrality of autonomy and individual decision making in end of life care. These two studies do not stand alone in starting with, assuming and valuing a Western, modernist account of personhood.

Of particular note, this privileging of an autonomous view of personhood in the HPC literature took an interesting turn in the Randall and Downie’s (1996; 1999) texts. After publishing their first ethics text on palliative care practice (Randall & Downie, 1996), these authors were highly criticised for outlining an approach that apparently resulted in “an unjustifiable infringement of the patient’s autonomy” (p. 278). As a consequence, in their second edition, Randall and Downie (1999) outlined “a reply to critics” concerning what they called “the supremacy of autonomy movement” (Randall & Downie, 1999, p. 278). In this reply Randall and Downie reflected upon ten possible negative consequences of putting autonomy first in HPC practice. Without going through each of these consequences, one in particular resonates with how personhood is understood. The tenth consequence, explained by Randall and Downie (1999),
is perhaps morally the most serious for society, for it is the tendency to locate the value or worth of human beings in their autonomy … [This would mean that] people tend to think that being autonomous is what makes a human being valuable, or gives him or her worth (p. 283).

This is a central moral consideration for understanding the ontology of personhood in the HPC arena. If autonomy continues to be put forth as the assumed defining aspect of persons, then we as a society could come to view all people as essentially autonomous beings, and thus if we perceive someone not to be autonomous then we may view them negatively; as somehow not quite human. Some may suggest that this is already the case for certain marginalised people in our society; for example, people experiencing mental illness or dementia. In summary, Randall and Downie are at least two hospice palliative care authors who are clear about the problems associated with understanding people as autonomous, individual beings. Unfortunately, however, these authors do not explore an alternative account of what it means to be a person.

Of concern, therefore, with this tendency to assume a modernist account of personhood, is a de-centering or silencing of a person’s significant ties to others and their embeddedness within a web of interpersonal and social relationships. Furthermore, autonomy with its associated focus on mind and rationality means that so much else that makes up a human being is missed or neglected. It means that a person is thought to be disengaged from his or her context and is making decisions solely as an atomistic being. This does not take into account the significant influences that come from others and society. Certainly, comments over time have been offered about the paradoxical nature of the privileging of autonomy and individualism against the notion of total or whole person care, with its emphasis on the social dimension of personhood and the understanding of ‘family as a unit of care’. This paradox has not gone unnoticed (Kellehear, 1990, 1998; McNamara, 2001).

A further limitation of the modernist understanding of personhood; of person-as-individual and person-as-decision maker, is that more often than not it does not represent the lived experience of living with a terminal illness and being cared for within a professional or health care context. This is something that becomes obvious when
considering Anna’s comment above. The request to be sedated is not something that an individual can decide because of the legal limitations in Australia. HPC professionals will not keep sedating a living-dying person simply because he or she decides this is what they have chosen. Ken makes this point when speaking about the role of autonomy in HPC practice: “People say to me autonomy is really important … the patient needs to decide. But, I mean, if palliative care as a profession was absolutely committed to their expression of autonomy as an absolute principle we would be euthanising patients because it’s what they ask for”. This is also alluded to in a further consequence outlined in Randall and Downie’s (1999) response to the problems of putting autonomy first. Randall and Downie (1999) assert that professionals may come to believe that what a person autonomously decides is necessarily best for them. Rather, lived experience shows us that a living-dying person’s decisions and choices are always mediated through societal narratives and parameters, such as the legal system, the HPC professionals with their powerful voice as the specialised people who care for the dying, and lastly, the significant loved one’s surrounding them.

It is not surprising, however, that HPC professionals include this modernist understanding of personhood in their articulations and understandings. Firstly, one reason for this is because HPC professionals are influenced by the culture and time they live in, and thus have this vision of a person as autonomous individual. Secondly, there has been a preoccupation with individualism since the inception of hospice. No doubt, Saunders spent much of her time focused upon what it meant to be a human being; who is dying and in pain, as she listened to, and recorded her patients’ stories. As a consequence of her research, she coined the term total care or whole person care as outlined in the previous chapter. This formation of a practice aiming at total or whole person care speaks volumes about what it means to be a person; a multi-faceted being who is made up of physical, psychological, social and spiritual elements. Yet even though Saunders sought to go beyond the dominant biomedical understanding of personhood, which tended to separate mind and body, her writings still reinforced a self-as-individual image. This individual being is the dominant ontological understanding in Saunders writings, asserts Thoresen (2003).
Thoresen (2003) studied a body of Saunders’ writings. In these she identified individualism as the main feature of the hospice philosophy. When writing about David Tasma, a dying patient, Saunders (1978a) expressed “His need for care had to be based upon who he was, his individuality”. Hence, “the dying person, their personal needs and individual care became a striking aspect of hospice care” (Thoresen, 2003, p. 20). Of note, therefore, is that the overt focus upon self-as-individual in the hospice philosophy as developed by Saunders, which hoped to care for the whole person by recognising the four domains of a person, which includes the social, is in direct contradiction to the individualism that features in Saunders’ work. Certainly, Saunders does emphasise the importance of family, as Thoresen quotes “after all, you spend your life learning to be a person in relationship with other persons” (Saunders, 1978b). However, her understandings still largely encompass an individualistic, and thereby modernist, understanding of personhood.

This privileging of individualism necessarily includes associated concepts such as successful control, autonomy and self-fulfillment, which were also present in Saunders’ writings (Thoresen, 2003). Certainly, this should not be surprising as Saunders was a product of modern times and “an individualised identity is one of the most central concepts in modern times” (Taylor, 1997). Individualism, writes Taylor (1991), is a main feature of modernity, coupled with “a strong belief in man (sic) and human reason, closely connected to the freedom to choose for oneself” (p. 22). This reinforces Isaacs’ (2005c) depiction above of the modernist self. Thoresen (2003) asks, however, how individual care can be carried out in a way that “also implies dialogue, community and something beyond each individual” (p. 23) and states that the hospice philosophy is “too focused on autonomy and control … Dying with dignity might be about individual needs, but it is also a question about being fragile and dependent upon others” (Thoresen, 2003, p. 23). In studying Saunders’ writings I would suggest that uniqueness, rather than individualism, is perhaps the concept of personhood that would better suit end of life care. That is, caring responses that are uniquely suited to a person and their lived particularity. Maybe, this is what Saunders had in mind all along.
Given the above explorations, two points can be proposed. Firstly, the dominant viewpoint of person-as-individual is just one understanding of what it means to be a human, and one that has emerged from a modernist agenda. This is not the only understanding of what it means to be a person. Researchers and authors need to make transparent their conceptualisations of personhood. In other words, ontological articulations need to be considered, recognised and acknowledged. Secondly, if HPC professionals are going to attend to total or whole person care, which includes the social domain of personhood, then these modernist understandings of personhood need to be reconceptualised. An alternative account of being is one which understands people as being embedded in a social-relational dimension. It is not that individualism is not important, rather that both person-as-individual and person-as-relational are both crucial aspects of personhood. However, the question can be asked: how helpful or appropriate is the person-as-individual view of personhood in the hospice palliative care profession? Let it be known at this point that chapter six clearly demonstrates that the principle of respect for autonomy is viewed in a dubious way by the hospice palliative care professionals in this study, and as a value it came virtually last on the list of values that underpins practice. What this could mean is that the HPC literature and practice are not necessarily congruent in the valuing and privileging of autonomy.

### 4.3.2 Person-as-mind

Further understandings of personhood influenced by a modernist paradigm came forth from the HPC professionals’ narratives. This next feature of the modernist self, as pointed out by Isaacs, is the understanding that people are understood to be essentially rational, thinking beings; or what I call person-as-mind. This person-as-mind viewpoint of personhood dominates our current understandings of personhood (Cassell, 1991a). This reflects, in part, the thesis of personhood by Rene Descartes, *Cogito ergo sum*, which translates into “I am thinking, therefore I exist” (Honderich, 1995, p. 138). For Descartes, his understanding that he is alive, that he is a human being, rests on his ability to think. This has translated into the understanding that human beings are essentially mind, or thinking beings. Thus, modernist understandings of personhood centralise this ability to think, reason and decide as the determinant of personhood.
The HPC professionals’ articulations of person-as-mind came about through the implicit valuing of knowledge, information and education. This was so highly commented upon and valued that it was added as a significant value, as outlined in chapter six, where it came in as the fifth highest value. This could be because people experiencing a terminal illness these days demand such information and knowledge. Thus, the HPC professionals are simply being responsive to the needs of current day citizens. However, by stipulating that the caring response needed to include information and knowledge, meant that many of the HPC professionals were centralising mind as the locus of being. Indeed, for some professionals knowledge was the caring act: “information is so important … people need information. If they have that knowledge … that is enough to help someone” (Nina). As a professional caregiver, Nina believed that she can help best by providing information which would lead to an increase in knowledge for the living-dying person and this is the best way to help them. To explain further, if Nina held a concept of personhood as relational her caring response would have been different. However, her dominant conceptualisation of personhood is person-as-mind, so her dominant caring response is providing information that leads to knowledge: a cognitive focus. In other words, what comes with the person-as-mind viewpoint of personhood is that knowledge is the highest priority and value. Similarly, Elizabeth responded with “we need to give them as much knowledge as possible for them to make informed choices”. Hence, the focus in this quote is again on the giving of knowledge, the centrality of mind, and the importance of individual and free choices, or person-as-decision-maker (for choices are but decisions). For Fiona, caring for the dying was all about information: “So it’s information provision that is of utmost importance. A lot of people in the area [of being terminally ill] are not given information, and so are not given choice. So for them to reach what they want … they can really only do that if they have the information to decide”. Additionally, Melanie thought this knowledge was crucial: “I think people appreciate knowledge. They want to know why and when and how. This helps them immensely”. Clearly, each of these professionals is focusing on mind, knowledge and decisions in their caring responses, according to how they view ‘the self’. Knowledge and knowing is a central element in this modernist account of what it means to be a person.
The limitations of viewing person-as-mind are complex. As with the central understanding of person-as-individual, it decentralises or omits something else. A person is not simply their mind; people are complex and multi-faceted beings, beyond their ability to think. For example, embodiment theories would suggest that our bodies provide a way of knowing as well. Additionally, as pointed out by Isaacs (2005c), humans do not simply think, but we also do and act. We are creators beyond our cognitive abilities. If there is an overt emphasis on person-as-mind, that mind constitutes personhood; this then could lead to the de-valuing of some people. Certainly, many examples abound of what happens to the status of people when they are deemed irrational or not quite of full capacity in their mind. For example, people experiencing the illness of dementia might have their status of personhood diminished in various ways as health care professionals deem someone who is not quite in their right mind not to be fully human or even living. For the living-dying person, if they are affected by drugs, thereby altering their ability to think, they or others may perceive a lessening of self. Certainly, mind is an important component of what makes us people, and what distinguishes us from animals; however, we are also much more than our minds. The limitation of the viewpoint of person-as-mind is that usually this is unquestioned, centralised and viewed as the only significant basis for personhood.

At this point in the chapter it can be argued that the HPC professionals’ accounts of personhood have assumed a modernist viewpoint of personhood in that they voice a type of person who is an individual, autonomous, thinking, deciding, choosing being. In addition, this individualistic and autonomous understanding of personhood has played a role in the HPC literature for some time now. However, theorists now are challenging this largely assumed modernist account of personhood. Isaacs (2005c) argues that “whatever kind of being the modernist self might be, it could be argued that it is not a human self, it is not a self that reflects the kinds of beings we humans are” (p. 3).

25 The concept of embodiment is theorised in different ways by various disciplines e.g. cognitive studies; phenomenological writings, feminist literature, and the philosophical writings. This thesis largely draws upon a phenomenological theory of embodiment. A phenomenological theory of embodiment is primarily utilised in this thesis and is further outlined in 4.4.3.
addition, Bauman (1993) is concerned about this modernist account of personhood when he writes

One by one, modernity stripped man of all particularistic trappings and pared him to the (assumed) all-human core – that of the independent, autonomous, and thus essentially non-social moral being (p. 82).

Accordingly, both of these authors, Isaacs and Bauman, ask the questions: Is this a plausible account of the human self? Perhaps there are alternative possibilities for understanding who a human being is? What do these modernist understandings of personhood silence about the lived experience of what it is to be a human being?

Furthermore, these modernist accounts of personhood do not reflect the profession’s commitment to a philosophy of (total) care or whole person care, which aims at addressing the physical, social, psychological and spiritual elements of the living-dying person. This ‘total’ account of personhood represents an understanding of human beings as multi-faceted, or containing many elements; and not one being more important than the other. This is certainly a critical point given that total or whole person care is understood to be central to the practice, as outlined in chapter three. This concept of total care, as it is so central for the HPC professionals, requires a greater reflection upon ontology. What can be of assistance with this are alternative accounts of personhood, suggested by various scholars as mentioned in the introduction to this chapter. These alternative understandings of personhood deconstruct the dominant modernist understandings of what it means to be a person. The elements of an alternative account of personhood are outlined in the next section of this chapter. Unfortunately, the HPC professionals’ articulations did not incorporate much of an alternative account of personhood, except to note the importance of social ties. In other words, the HPC professionals implicitly spoke of a modernist personhood.
4.4 An alternative account of personhood: The metaphysics of embeddedness

Isaacs (2001) asserts “The human condition is irreducibly a condition of embeddedness” (p. 9). An embedded and embodied account of personhood posits a radically different account from the modernist understandings of what it means to be a human being. This account understands the human self to be fundamentally embodied (I AM body) and embedded in a complex web of interconnections and relationships. According to this account of personhood, the concept of embedded means that a person is always situated within a larger context; a person is understood as being an integral part of a surrounding whole (OED, 2007). This in turn means that you cannot separate yourself from ‘the whole’. The context that is ‘the whole’, according to Isaacs (2007), is world, society, culture, time, language, relationships, a moral terrain and a spiritual horizon.

Accordingly, this account of personhood argues that “the human self is to be seen first as a doer or actor, rather than a reflective thinker, who is an embodied self and embedded in the world, physically, socially, temporally, in language, in a spiritual horizon” (Isaacs, 2007, p. 1). Similarly, Cassell (1991a; 2005) provides a rich account of personhood which parallels Isaacs’ account. Cassell (1991a; 2005), in his meditations on the meaning of suffering, writes that personhood includes

- a personality, a character, a lived past, a family, the family’s past, a cultural background, social and professional roles, relationships with others, a relationship with one’s self, and a political being, among others. Persons also do things; persons have an unconscious (by whatever name or definition), regular behaviours, a body and relationships with body, a secret life, a perceived future, and a transcendent dimension. The person is the whole entire being, selves and everything else (2005, p. 304).

With these two accounts of personhood, articulated by Isaacs and Cassell, it can be understood that a much greater inclusion of the various facets of being are included for consideration. Some of these facets may be more central than the others for particular people. For example, someone’s particular relationship with their body might be a priority for them, or identification with a professional or social role might be more central. However, these accounts have one thing in common: they are much thicker and they take into account ‘the whole’ that a person is immersed in, influenced by, and
connected to. Importantly, these accounts of personhood resonate with the lived experience of living-dying people.

This alternative account of personhood argues that a human being cannot be separated from the elements that make up the whole or the multi-faceted elements that make up who they are. Of note, is that two HPC professionals did include this sense of an embedded personhood:

You can never take apart a person (Elaine)

I can’t separate … each element. Not even element … in the beginning is the individual, in the circle, then the family, then their sense of community and belonging … and then that’s across time as well (Gloria).

Unfortunately, the articulations of a modernist personhood far outweigh these two brief expressions. Thus, through an overt focus on individualism and autonomy, this embedded aspect of personhood is often neglected. People are deeply meshed in the world and in relationships. Thus, the alternative account of personhood, as suggested in this chapter, negates and deconstructs the disengaged or detached view of being, that is suggested by the modernist account; as people who stand alone, separate from other beings and the world. Rather, this alternative account proposes that people are always part of “a multi-faceted engagement shaped by complex links of interconnectedness mediated through our embodiment and embeddedness” (Isaacs, 2005a, p. 4). The person is “engaged in practices, as a being who acts in and on a world” (Taylor, 1995, p. 60). Importantly, human selves have the ability to interpret and reinterpret the world and are therefore actively engaged in this world, rather than somehow distant from it. What this embedded account of personhood assumes and privileges is “interconnectedness, engagement and a deconstruction of the primacy of a monological consciousness” (Taylor, 1995, p. 61). Therefore, Taylor (1995) and other philosophers emphasise the significance of dialogical engagements and the centrality of language.

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26 It is important to note that living-dying narratives - stories collected directly from living-dying people - are not abundant. Kellehear (1999b) writes that “most of the research in palliative care has revolved around care-giver’s views of dying … very few articles are based on research with dying people” (p. 154, italics added). Therefore, I justify my inclusion of the narratives collected in my research: Restorying the dying self (Wilson, 2002).
4.4.1 Language animals

In the first instance, Taylor (cited in Abbey, 2000) argues that one of the most distinctive features of the human being is that we are “language animals” (p. 59). By this Taylor means that we as human beings are able to express ourselves. In Taylor’s (cited in Abbey, 2000) account of personhood, he focuses on the fact that we are language beings, which includes the appreciation of the central role of expressionism. It is important to note that language is being understood by Taylor “as not merely a medium for representing an independently existing reality” but rather recognises the “power of language to shape and perhaps transform those things that come into its domain” (cited in Abbey, 2000, p. 4). In other words, the language we use is constitutive of the world, our lives and our self. Also important to note is the recognition that “the language I speak … can never be just my language, it is always our language” (Abbey, 2000, p. 69, original italics). Whilst I might customise how I put words together in my own unique way, the language, and perhaps even the meanings of words I use, is provided by the society or culture that I live in.

A person, therefore, is embedded in language. Isaacs (2005c) explains that

> It is language that links us with others, that mediates our sense of time; that mediates our understandings and engagements; that provides meaning in our lives and opens up new and creative possibilities (Isaacs, 2005c, p. 3).

Not only does language create new possibilities in our understandings of our self and our world, it also can constrain. Noticeably, as a person acquires new and different vocabularies for talking about self and self-experiences, emotions, hopes and so forth, these understandings can change. The story one tells about oneself and one’s life is determined by the language we have available to us. This in turn creates the identity of self, for “we become the autobiographical narratives by which we tell about our lives” and by which others tell about our lives (Bruner, 1987, p. 15).
For the living-dying person language mediates their experiences of illness and dying. For example, the stories that living-dying people tell, and the language used in them, may become medicalised; filled with professional and technical terms, procedures, times and terminology. These new stories of experiences are often dominant. Frank (1995) suggests that illness narratives first need to speak the medical narrative, in that language, to find meaning in the lived experience of illness. This was evident in Martha’s story where she had integrated the medical language as a way of describing herself: “because I’m not cancer … I am other types of life-limiting illnesses” (cited in Wilson, 2002, p. 64). Martha had become, in many ways, an illness; this was her identity. This identity included the medical explanations of illness, doctors as central people in her life, and intricate details of operations and recovery times. This became Martha’s dominant story or her self and her life. This medical and illness story even permeated into her relationship with her grandson who, when he came to visit, role played the doctor’s position with his sick grandma (Wilson, 2002). Here it is evident that ‘medical speak’ or medical language may affect how a person views oneself and how oneself is viewed by others.

A further consideration is that the language of dying might be a new one for any particular person and one that is, arguably, unavailable in a society that denies and shuns dying and death. What language can be used when curative measures are not available anymore, but still medical language dominates? Hospice palliative care professionals supposedly bring a new language that includes such things as ‘now that you are dying’ or ‘making the most of the time left’. This language, hopefully, is one that provides an alternative to medical speak. In addition, it is hoped that part of the care that is provided by hospice palliative care includes the assistance in locating new language to make meaning of this new phase of life; the living-dying experience. Isaacs (2005b) implores us to ask: “how sensitive are we to language that is responsive, communicative, reassuring and at a level or of a kind that reaches out to the other?” (p. 9). The central point in this appreciation of language as an important facet in our understandings of personhood, however, is that everything about what it means to be human, what it means to care for living-dying people, and what it means to be at the end stage of life is
mediated, constructed and constrained by the language on offer in any particular setting, institution and culture.

4.4.2 Interpretive beings

With this embeddedness in language comes a human being’s unique capacity to interpret and re-interpret. As “creators” or constructors, rather than simply thinkers, human selves “are capable of both interpreting [and re-interpreting] their world and their place within it” (Isaacs, 2005c, p. 3). Taylor (cited in Abbey, 2000) is adamant about the centrality of the human ability to interpret in our understandings of personhood. “Human beings are self-interpreting subjects … one of the things that makes a person what she is is the understanding she has of herself” (p. 58). Similarly, Heidegger (cited in Dreyfus, 1991) recognised this central component of being

To exist is to take a stand on what is essential about one’s being and to be defined by that stand. Thus Dasein [a human existence] is what, in its social activity, it interprets itself to be. Human beings do not already have some specific nature. It makes no sense to ask whether we are essentially rational animals, creatures of God, organisms with built-in needs, sexual beings, or complex computers. Human beings can interpret themselves in any of these ways and many more, and they can, in varying degrees, become any of these things, but to be human is not to be essentially any of them. Human being is essentially simply self-interpreting (Dreyfus, 1991, p. 23).

These self-interpreting processes use, of course, the interpretive frames on offer in one’s culture. We can be left in no doubt that for Heidegger self-interpretation defines the nature of human beings. Heidegger’s thesis is that “human beings are self-interpreting beings: that human existence is expressive of and constituted by meanings shaped by self-interpretations” (Smith, 2004, p. 31). Thus, central to our understandings of personhood is the process of meaning making (interpretations) and the implications this has on such things as our understandings of identity, care, suffering, life, death and so forth.
For example, the experience of pain is mediated through one’s interpretations of pain, self and life. Heidegger makes this clear in that life becomes how we interpret it; self becomes how we interpret it.

In the course of interpreting its fundamental concerns, a human existence [Dasein] becomes what it distinctively is. In other words, human existence is constituted by the meanings things have for it, meanings determined more or less explicitly by self-interpretations. Who I am, as a subject or person, depends on what is meaningful or what is an issue for me; and even before I know it, my identity is shaped by the way those concerns and issues are interpreted. Interpretation is conceived fundamentally as a natural human capacity which at once makes human existence a set of possibilities and circumscribes those possibilities within a horizon of finitude (cited in Smith, 2004, p. 31).

The last point of this quotation by Smith, who is explaining Heidegger’s philosophy of being, is that language, and then the activity of interpretation and re-interpretation, then “circumscribes” our possibilities, our understandings, our realities, and these are fundamentally affected by our culture or the context that we find ourselves positioned in. This is a crucial point for our understanding of the living-dying person and the living-dying process. It means that a person can have a particular interpretation about something, change that interpretation; or not feel able to change that interpretation; or hold conflicting interpretations at any given time; for “no self-interpretation needs to be fixed” (Abbey, 2000, p. 59). Thus, a person’s sense of themselves, a sense of their experience of illness and the meanings they hold about death and dying can all be confused, incomplete, adjusted, reconfigured and so forth.

A pertinent example of the centrality and importance of interpretation can be found in the work of Frank (1995). In The wounded storyteller (1995) Frank outlines three types of illness narratives: the restitution narrative, the quest narrative and the chaos narrative. Each of these is simply a variation of interpretation about one’s illness experience. Thus, for the living-dying person, one day they could tell a restitution narrative that interprets the illness experience as ‘today I am well, but with the help of medical technology, tomorrow I will be repaired’ (Frank, 1995). Martha (cited in Wilson, 2002) certainly was someone who was telling this story; especially when she emphasised the possibility of stem cell research as a possible cure. Or, a living-dying person could re-
interpret their illness experience as ‘quest’. Certainly, Michael J. Fox (2002), as a person experiencing a life-limiting illness, tells the story of his gratitude for what his illness has given him, interpreting his life and his self as having overcome his illness and transformed his life. Finally, for the living-dying person, I would argue, it is the chaos narrative that most prevails in their interpretations of their illness, their dying and their self identity. This chaos narrative, or as Ezzy (2000) calls them “polyphonic narratives”, includes “overlaid, interwoven and often contradictory stories and values” (Ezzy, 2000, p. 613). Chaos narratives imply several interpretations that may be conflicting and attempts at reinterpretations for the living-dying person.

This centrality and recognition of interpretation for understanding personhood has crucial ramifications. This links into how people are unique, for we can each interpret an event, experience or person in varying ways. It means that in caring for the living-dying person professionals need to recognise that everything that is happening is interpreted in various ways. Even the ‘information and education’ that was viewed as central in the caring act will be variously interpreted. Isaacs (2005b) implores us to ask: “to what extent do we appreciate the deep need of persons to interpret, ‘to make sense of’ their predicament …” (p. 36). Therefore, there needs to be a fundamental recognition that, as Bruner (1987) asserts, a life [or self, or experience] is not ‘how it was’ but how it is interpreted and reinterpreted, told and retold” (p. 31). All interpretations and understandings are fluid and changeable, complex and polyphonic, mediated through language, and particularly unique to the living-dying person and his or her embeddedness. With this understanding of the centrality of language and interpretation, as being fundamental to the personhood, this then translates into the ethical imperative for the act of listening to living-dying stories (Wilson, 2002) to gain a richer understanding of a person’s interpretations.
4.4.3 Embodiment: Body-relatedness

That the body is not a mere extrinsic machine but our living center from which radiates all existential possibilities is brought home with a vengeance in illness, suffering and dying (Leder, 1984, p. 34).

A further important facet of this alternative account of personhood is embodiment. Isaacs (2005c) maintains that “the body is the medium of one’s being-in-the-world and of engaging with the world” (p. 4). Body is not something that is separate to who we are, but rather is an intrinsic part of our being-ness. Yet, one of the most common boundary lines we construct when thinking about ‘who is this person’ is a “boundary line within the organism [human beings]”, explains Wilber (1981, p. 6, original italics). Modern individuals, Wilber (1981) argues, feel that they have a body; as if they owned or possessed it much as they would a car, a house or any other object. As Wilber (1981) goes on to explain

The body seems not so much ‘me’ as ‘mine’. The person identifies more basically and intimately with just a facet of his total organism, and this facet, which he feels to be his real self, is known variously as the mind, the psyche, the ego, the personality. Biologically there is not the least foundation for this dissociation or radical split between the mind and the body. The mind-body split and attendant dualism is a fundamental perspective of Western civilization. The boundary is drawn between the mind and the body, and the person identifies squarely with the former. He even comes to feel that he lives in his head, as if he were a miniature man in his skull, giving directions and commands to his body, which may or may not obey (p. 6 - 7).

Wilber makes the point that this boundary line between body and ‘self’ or mind is firmly located in a modern Western cultural view of personhood. As mentioned above, it was Rene Descartes who is acknowledged with being the chief architect of this ontological understanding. With the modernist preoccupation of an ontology of a rational, thinking being comes the Cartesian view that the mind is entirely distinct or separate from the body; “that the body is not necessary to his essence as a thinking thing” (Honderich, 1995, p. 123). Cartesian thinking purports that

the mind is an entirely separate substance from the body, and, moreover, that its nature is wholly distinct from the nature of anything physical; it is an incorporeal, indivisible, non-spatial, unextended thing, which is entirely distinct from the body” (Honderich, 1995, p. 124).
The Cartesian body, writes Leonard (1994), “is mere res extensa, a machine driven by mechanical causality … extrinsic to the essential self” (p. 52). Sometimes, it would seem that the body’s only purpose is to carry our heads about. This would also imply that I could leave my body at home if I choose to.

What is important to note is that the practice of medicine has, for the most part, adopted this Cartesian paradigm, understanding the physical body in purely objective and mechanistic terms; and thus as separate from the self. This biomedical approach to care then translates into the treatment of a person as an object. Yet, even though Cartesian dualism has been heavily critiqued over recent years it is difficult to deconstruct and alter this dominant way of thinking and its corresponding caring practices. For example, hospice palliative care purports total or whole person care, which does attempt to deconstruct the separation between mind and body. However, increasingly the physical aspects of care are prioritised, as mentioned in the introduction and chapter three, with the medicalisation of the profession. Thus, this separation between mind and body is further reinforced by an overt focus on pain and symptom management. An example of this self separate from body came from Anna, a hospice palliative care educator, who said “I’ve always taught my students to treat the symptoms first, so that you can get to the person”. This highlights the view of a separation between body and self which, unsurprisingly, is increasing with the creeping medicalisation of the practice. Unfortunately, this separation between self and body could grow if the medicalisation of HPC practice continues. The priority of attending to the physical symptoms of the living-dying person adheres to a prevailing modernist account of personhood. It does not take into account that mind and body are not separate and that body is self.

The viewpoint of body as self, or I AM body, is known as embodiment. At its core the notion of embodiment refutes Cartesian dualism as absurd, for if a self is a pure incorporeal mind, wholly distinct from the body, “then it is hard to account for the character of our ordinary feelings and sensations, which seem intimately bound up with our bodily nature as creatures of flesh and blood” (Honderich, 1995, p. 124). This means that what I experience, know or understand is not separate from my body, but
rather is conducted through and with my body. Or, in other words, human beings are embodied in that we do not simply possess a body, as you would possess any other object, but we are our bodies (Frank, 1991; 1995; Toombs, 1988; 1992; Taylor, cited in Abbey, 2004). Body-relatedness implies an inseparable relationship or connection between self and body (Frank, 1995).

With this recognition of body-relatedness or body being fundamental to personhood comes the recognition and acknowledgement that personhood is altered or changed in the living-dying experience. One’s relationship with body is changed fundamentally when illness comes (Toombs, 1988; 1992). Frank (1991), during an illness experience, tells us that

My body is the means and medium of my life; I live not only in my body, but also through it. No one should be asked to detach his mind from his body and then talk about this body as a thing, out there (p. 10).

Frank is referring to the way the body is referred to and talked about in the illness experience, from the standpoint and practices of a biomedical approach. Similarly, Toombs (1988) emphasises this same point of not simply possessing, but being body. Toombs (1998) writes

I am embodied in the sense not that I ‘possess’ a body but in the sense that I AM my body. Rather than being an object of the world, my body is my particular point of view on the world. Indeed it is by means of my body that I have access to the world in the first place (p. 202).

This access to the world, that Toombs refers to, can only be gained through one’s body. Thus, my knowledge and perception of the world, or experience of the world, is via body. We do not have a body, which could be left at home like any other object; body cannot be detached from self. Taylor (cited in Abbey, 2004) explains that knowledge, in the first instance, comes from embodied existence and experience. That is, “the way we encounter the world cognitively is shaped and constrained by the fact that we are bodies” (Taylor, cited in Abbey, 2004, p. 3). Similarly, Toombs (1988) declares that “to perceive something is necessarily to be related to it by means of my body” (p. 203).
What this appreciation of embodiment might mean for the living-dying person is that their body-self is changed, altered or disrupted somehow. As body is not something distant, this means that the whole dying process is experienced through one’s body. When interventions are done to one’s body, it affects personhood. For example, Belinda Emmett, a popular, Australian television actor who recently died of cancer, composed a video account of her dying. Belinda at one point spoke about how it was not until her hair fell out that she realised that she was sick and dying. An experience of body meant that she now cognitively, emotionally and otherwise realised her dying status and thus, changed her self identity to ill and dying person. In other words, the knowledge of her dying process was understood through a physical, bodily experience (Australian Story, ABC, 2007).

Crucially, changes to one’s body almost always will alter a person’s sense of themselves; that is, their identity may be threatened, disrupted, damaged or altered somehow. Put simply, a discontinuity of embodiment, or a disconnection of body-relatedness, will threaten a sense of identity (Little, Paul, Jordens & Sayers, 2002, p. 173). In Blinderman and Cherny’s (2005) study of people who were experiencing cancer, changes in their body meant changes in them as people. For example, one person said “I feel like less of a person. Not like I once was. I have no hair left. I am weak, alone. I don’t care. I feel like an invalid” (Blinderman & Cherny, 2005, p. 374). Notably, the degree of influence on identity will be different for each person. For example, in the same study by Blinderman and Cherny (2005) other people experiencing cancer adapted to changes in body: “I was initially bothered by my body image. It was painful to accept how I had changed. But over time I became used to it” (p. 374).

Frank (1991) makes the point that moving and changing from a perfectly comfortable and functioning body to one that is sick and ill forces him to ask: “What’s happening to me? Not it, but me?” (p. 13). With this body-relatedness, illness, disease and dying “can so alter the relationship that the body is no longer seen as a friend, but an untrustworthy enemy” (Cassell, 1991a, p. 42). Equally important, also, is what others believe is happening to ‘me’. Interestingly, Cassell (1991a) insists, “the body does not actually
have to be altered to cause damage to the wholeness of the person – damage to the person’s relationship with the body is sufficient” (p. 42). Toombs (1988) goes on to explain that illness “disrupts the fundamental unity between body and self” (p. 214). Some of the ways that this relationship changes, asserts Toombs (1988) is that body can become an object for scrutiny, it can become alien and out of control, whereas previously it was viewed as being within one’s control, and that body almost becomes in opposition to the self; or somehow against you (Toombs, 1988). In Mary’s (Wilson, 2002) account of her living-dying experience she discusses an attempt to reconcile this dis-unity between self and body. Mary simply stated “I look in the mirror and think to myself, its certainly not the body beautiful, it’s rather ugly and it’s got bits out everywhere, but it’s still me” (Wilson, 2002, p. 77). The central point here is that body is me.

The embodied nature of human beings is of central importance when considering the total or whole person care of those who are dying. A person’s body is not separate from themselves; when ill and dying a person’s body translates into changes in self, and in the sense of connection with body. Isaacs (2005b) implores us to ask: “how do we touch, dress, handle, and speak to the embodied self” (p. 36). Importantly, embodiment theory, which includes a growing body of research and literature, can assist HPC professionals to gain a greater understanding of the role of body-relatedness in the living-dying process and provide a reconceptualisation of the Cartesian view of person that predominates. Appreciating and acknowledging that body IS self will go a long way towards understanding the experience and potential suffering of the living-dying person.

4.4.4 Personhood as purposefulness

What links with this understanding of body-relatedness is the ability to act intentionally; to be purposeful in life or to have ability to do something. Human purpose is another fundamental facet of ontology. Thus, human agency is understood as having the basic capabilities that enable one to act. As quoted previously, Isaacs (2005c) asserts that “the human self is … an actor, or doer” (p. 3, original italics). With body-relatedness we are able to act. In other words, the body is the medium of possible action.
In its directedness towards, or attentiveness to, the world the body thus exhibits a bodily intentionality. Embodied consciousness, is, then, in the first place not a matter of I think, but of I can (Toombs, 1988, p. 204).

It is this ‘I can’ or ‘I do’ that is often a central qualifier of personhood, especially in Western societies, which places such importance on the ability to do. Cassell (1991a), too, emphasises this centrality of action or acts in his typology of personhood

Persons do things. They act, create, make, take apart, put together. They know themselves and are known by these acts … things come out of their mouths, or are done by their hands, feet, or entire bodies that express themselves (Cassell, 1991a, p. 41).

For Cassell this understanding of personhood is crucially important as the illness experience threatens this ability to act, or be purposeful, and thereby the integrity of that person. “Each one of us is what he pursues and cares for. In everyday terms we understand ourselves and our existence by way of the activities we pursue and the things we take care of”, wrote Heidegger (cited in Leonard, 1994, p. 49). Taylor (cited in Abbey, 2000) explains that our self understandings and interpretations will always make reference to our purposes. This is another factor that Taylor understands to be constitutive of personhood

Persons are beings with purposes that have special significance for them, playing an important part in their sense of who they are. Purposes are, of course, closely related to goals: to have a purpose means that one desires a particular outcome and strives or acts to achieve it. Having purposes is an ontological feature of selfhood (Taylor cited in Abbey, 2000, p. 62).

Importantly, Cassell (1991a) makes the point that each and everyday is filled with purposeful activities, even if it is as simple as making a cup of tea for oneself. These purposeful activities, on either a grand or small scale, “create a qualitative distinction between humans and animals on the one hand and the rest of nature and inanimate objects on the other” (Abbey, 2000, p. 64) and are self-defining. Without the ability to do, to act, to be purposeful a person’s understanding of themselves is altered, disrupted or damaged. This also links into role identities where that role depends upon our ability to act. Acting also means engaging. Thus, action is linked with the social relationships as well. One’s being a mother depends on one’s ability to act as a mother in relationship with children. In the living-dying experience, however, “the sphere of bodily action and
practical possibility becomes circumscribed; [in other words] the ‘I can’ is rendered circumspect” (Toombs, 1988, p. 208). Thus, as Cassell (1991a) points out, when suffering is present, “the identity that the sufferer fears will disintegrate is an identity expressed in purposeful actions – legs walk, hands grasp, eyes see” (p. 25).

Cassell (1991b) views daily life as filled with intentions and purposes which are self-defining. In the exploration of self identity changes for living-dying people it was this sense of purposefulness or the ability to do that was often central to their understandings of self (Wilson, 2002). The changes with body-relatedness and the ability to do that comes with advanced illness and the dying process greatly affected the living-dying person’s being if they could not, or perceived that they could not, do certain things. In each of the living-dying accounts included in the study articulations about the loss of ability or purpose were central (Wilson, 2002). Joyce emphasised still doing things to help her daughter; Mary was very vocal about her sedentary state and the loss of her ability to do for herself, including how that affected her sense of self. Martha was adamant that she had to rely on herself and no one else (Wilson, 2002).

What these articulations translate into is the appreciation that selfhood “is fundamentally tied to bodily capacity, with a loss of self occurring as patients lost the ability to perform tasks for themselves” (Lawton, 2000, p. 101). Each of the above living-dying accounts demonstrates the centrality of the ability to do, to act, as being central to personhood. I proposed, in my previous study, that we needed to change the Cartesian quote from “I think, therefore I am” to “I do, therefore I am”. Overall, the ability to act, even if it is just to make a cup of tea, can define who I understand myself to be. For Byock (1997), when terminal illness “alters or amputates these activities, one’s sense of self and personhood are under assault, and suffering follows” (p. 60).
4.4.5 Beings-in-the-world

A further component of our ontological nature, as proposed by Heidegger (cited in Leonard, 1994), is that human beings are not separate from the world, but rather are beings-in-the-world. In other words, an important facet of being centres on the relationship of the person to the world. It is important to note that ‘world’ is understood as “the meaningful set of relationships, practices, and language that we have by virtue of being born into a culture” (Leonard, 1994, p. 46). An understanding of being requires the appreciation of a person growing up interpreting oneself within a context of culture, institutions and practices. These all contain interpretations of what it is to be a human being. A simple example of this is that, arguably, individualism, as outlined in the start of this chapter, is currently a dominant understanding of personhood in this particular time, in this particular culture (Australia); we are influenced by our embeddedness in this time and place. However, if a person lived in another time and place this dominant understanding and valuing of individualism would likely be different.

With this understanding of world, and a person’s relationship with it, or embeddedness in it, it can be stated that world is both constituted by and constitutive of the self. The world is constitutive in that the self is raised up in the world and shaped by it in a process that is not the causal interaction of self and world as objects, but rather the non-reflective taking up of the meanings, linguistic skills, cultural practices, and family traditions by which we become persons and can have things show up for us at all (Leonard, 1994, p. 47).

Heidegger argued that the modern view of the self passes over the world, by not seeing that it is world that circumscribes our choices and creates our possibilities – our becoming (Leonard, 1994). This too can mean that world can limit our being-ness as well. Overall, Heidegger attempts to dismantle the “monological consciousness dogma that separates and disengages people from their world” and focuses on how we are not separate of the world, but as beings-in-the-world (Leonard, 1994, p. 47). This philosopher used the term ‘thrownness’ to express his view of the person as always already situated. In other words, a person is “not a radically free arbiter of meaning”, but is a being who is thrown into and shaped by world (Leonard, 1994, p. 47). It is the world that sets up possibilities for who a person can be and be-come. One HPC
professional, in explaining her understanding of holism, captures some of this understanding when she said that holism meant for her

To be included … to be participative and to never just look at one influence on a person. The whole world influences the person. So if you’re going to talk holism then you have to consider the whole person in his or her world (Elaine).

What this being-in-the-world facet of personhood could mean for the living-dying person is that when the importance of ‘dying in one’s own way’ is articulated, or an individual way of dying is valued, the options for how to do this are written by the culture a person is embedded in. For example, a dominant script of how to die in Australia is what I call ‘the fighting story’: I have to fight to the end to win this battle with cancer. If a person lives their dying in this way, they are not individually choosing to take up this option for how to die, but are rather picking from the dominant, and often socially sanctioned, way to die. On the other hand, if a person chooses to not accept treatment for his or her terminal disease, this is often not seen as an acceptable way of being as it does not fit with the dominant ‘fighting’ script. I have seen many living-dying people criticised for not taking up the option of treatment, and hence being labeled as giving up, or in other words, for not fighting.

Certainly, the living-dying self is still a unique being capable of writing variations on cultural scripts; however, an acknowledgement of their embeddedness in the world is often not recognised. That is, it is not recognised that the way a person dies, and in fact the way they are cared for, is highly influenced by the culture and time we have been born into, the world that is our own community and a dominant Western world view of dying as negative. This is a critical point for who it is that a living-dying person can be and be-come in Australian culture at the present time, and correspondingly how our caring responses are shaped. Cassell (2005), drawing upon the philosopher Wittgenstein’s work, sums this point up well when he wrote

There can be no private meanings. Suffering and illness take shape amid a complex interaction of private, personal, and public dimensions, in part because they are inescapably connected with the meanings ascribed by specific cultures (p. 306).
Thus, when a person, whether it be a living-dying person or a HPC professional, states that he or she must die in their own way, there may not be a recognition that ‘their own way’ is ‘inescapably connected’ with the culture or world that we are embedded in.

4.4.6 Inextricably linked with others: Social beings

What goes hand in hand with this escapable connectivity with world is the understanding that people are also inextricably linked with other beings. Or, as Cassell (2005) asserts All persons are social (p. 305). There is no self without others; there is no consciousness without a consciousness of others, no speaker without a hearer, no dreamer who does not dream in relation to others, no act or object or thought that does not somehow encompass others. There is no behaviour that is not, was not, or will not be involved with others (Cassell, 1991a, p. 40).

A central facet of personhood is a human being’s connectedness with others; a self is embedded in relationships with others. Thus, we are not disengaged and atomistic beings, but always situated in a social matrix; embedded in a social world. Hence, this appreciation of people differs from a modernist ontology.

However, it is difficult to step away from a modernist, atomistic understanding of selfhood. This is because, as Wilber (1981) explains, the most common boundary line drawn up to understand the self is the skin-boundary. This means that everything inside the skin is me or ‘self’ and everything outside of the skin is not me or ‘other’. As Wilber (1981) explains

When you are describing or explaining or even just inwardly feeling your ‘self’, what you are actually doing, whether you know it or not, is drawing a mental line or boundary across the whole field of your experience, and everything on the inside of that boundary you are feeling or calling your ‘self’, while everything outside that boundary you feel to be ‘not-self’. Your self-identity, in other words, depends entirely upon where you draw that boundary line (p. 4, original italics).

This boundary line translates into ‘I am me’ and ‘you are other’. Certainly, a person’s otherness is a unique feature of human beings, but this must go hand in hand with an acknowledgement of the bonds that tie us together. This bond between humans translates into ‘I am who I am because of and with you’. Taylor (1995; Abbey, 2000),
too, highlights this aspect of personhood when he writes about the dialogical self. Taylor believes that

at the very core of identity is the ongoing real or imagined exchange with others: My discovering my own identity doesn’t mean that I work it out in isolation, but that I negotiate it through dialogue, partly overt, partly internal, with others … My own identity crucially depends on my dialogical relations with others (cited in Abbey, 2000, p. 67).

This means that who we are, how we interpret experiences, what we understand of pain, suffering or illness, are all intimately connected to our relationships with others. Who I am always points beyond me as an individual to my relationships with others; “to my partners in dialogue who help to constitute my identity” (Abbey, 2000, p. 69).

Importantly, what this dialogical self translates into “is a … blurring of boundaries between self and other” (Abbey, 2000, p. 68). For Taylor the modernist account of personhood as individual and autonomous is a myth (Abbey, 2000).

This dialogical selfhood, or person as embedded in social relationships, is articulated in living-dying accounts. For example, Mary in considering her identity offered this statement

No I’ve never really thought about who I was. I suppose I thought I was always mum. I’ve always been the carer, I’ve always been the nurturer. I’ve always been everything and now all of a sudden I can’t do it anymore (Mary, cited in Wilson, 2002, p. 74).

Mary’s identity, in her living-dying story, is that of mother, carer, and nurturer. Mary can only ‘be’ this identity because of her intrinsic relationship with others. Clearly, we can hear also Mary’s anguish in believing she is not able to ‘be’ these things anymore as she is unable to carry out these roles. Cassell (1991a) notes this in his explorations of suffering, writing that “by middle age the roles may be so firmly set that disease can lead to the virtual destruction of a person by making the performance of his or her roles impossible” (p. 40). Suffering, for Cassell (1991a), can occur “because our intactness as persons, our coherence and integrity, come not only from intactness of the body, but from the wholeness of the web of relationships with self and others” (p. 40). This means

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27 Taylor’s dialogue is to be understood to encompass a broad range of human interactions or encounters; imagined or internalised as well (Abbey, 2000).
that for the living-dying person, inevitably there will be identity reconfigurations and suffering as the roles and relationships for that person will change. For some human beings, this relational embeddedness that is translated into identity roles can be the basis for their worth of themselves; their evaluation of their worthiness as human beings (Storey & Knight, 1997).

This evaluation of self makes this facet of being a central consideration when caring for the living-dying. Fortunately, the social nature of people is something that is embraced and emphasised in hospice palliative care practice. Perhaps more than other health care settings, HPC professionals are much better at recognising the significance and importance of family ties – the interconnectedness of beings. Kellehear (2005) writes that, with the mantra of ‘family as the unit of care’,

there is a long-standing recognition that people are part of a social system that cannot be arbitrarily divided during any professional intervention without serious consequences to the health, morale and wellbeing of that person (p. 13).

This social connectedness of personhood is something that HPC professionals do appreciate; that people are inextricably connected to their significant others and this needs to be included in the consideration of how they are cared for. In the HPC professionals’ narratives many examples were provided of this appreciation. For example, Jackie demonstrates her understanding of living-dying people being much more than individuals

They [living-dying people] are members of a collective. You are a part of a family, part of a community. That would influence how you would react to a person because you would know that what you are doing for them, would impact the people around them. They are not separated from others (Jackie).

Similarly, Ken understands people are being embedded in relationships with others

Well to me that’s relationship. My sense of myself as a person, and as a citizen is always relational (Ken).

Thus, even though some HPC professionals articulated an ontology that was based on person-as-individual, for some other professionals their articulations included this recognition of the relational

I really feel very strongly that it’s not just the patient, but the patient within their community or family networks as well (Elizabeth).
Therefore, when we consider the care of the living-dying we must consider who they are connected to and who they define themselves as in relation to others. These people, too, are a part of the caring relationship. In addition, there needs to be a closer examination of the contradiction between the emphasis on individualism and social relationships in HPC practice.

However, as mentioned in chapter three, this social aspect of HPC practice is being contested and eroded. For example, in Randall and Downie’s (2006) critique of the philosophy of palliative care, their discussion of the social aspects of practice minimally recognises the importance of the social ties of the living-dying person. Rather they focus on the problems that can occur if the family and individual patient are in conflict, using concepts such as ‘conflict of interest’. These authors conclude that “so long as a clear priority for health care professionals is the care of the patient, not the relatives, all will be well” (Randall & Downie, 2006, p. 78). It is at this point they do mention - “it might be claimed that the welfare of the two parties cannot be separated” - but do not address this claim in anyway whatsoever. It would seem that these authors have embraced a modernist account of personhood in this text. Again, Randall and Downie have not acknowledged that there are differing understandings of personhood and that Saunders clearly responded to the pain of dying people as an interconnected notion with family. Randall and Downie (2006) concluded that the only way that family needs to be implicated in caring practices is by providing information, offering advice on the care of the patient, and behaving sensitively in the face of the inevitable family distress (p. 92). Nowhere does it acknowledge that understanding the living-dying person, their experiences and their needs, requires an appreciation that they cannot be separated from the significant people in their lives. Overall, Isaacs (2005b) implores us to ask: “how sensitive are we to the relational, familial and cultural contexts of the other” (p. 36).

For many Asian cultures, in particular, the individual may not be understood outside of social connectedness to others. The Confucian Chinese concept of personhood – *jen* – does not end at the boundaries of the skin but extends into the family and the intimate social circle. Similarly, in Japan, *ningen* – the term for person means ‘human between-
ness’ and defies Western individualistic notions of self (cited in McNamara, 1998a, p. 175). Kleinman reminds us, many members of emerging industrialised societies, as well as members of multicultural societies, may view the body as “an open system linking social relations to the self, a vital balance between inter-related elements in a holistic cosmos” (cited in McNamara, 1998a, p. 175).

### 4.4.7 Moral self

Thus far this alternative account of personhood has included the ontological facets of language, interpretation, embodiment, purposefulness, and a person’s embeddedness in the world and social relationships. A further important facet of personhood is that the self is also embedded in a moral context. The self exists essentially in moral space, writes Taylor (1988, p. 300). Or, as Isaacs (2005c) explains

> the self is embedded in a *spiritual horizon*, that is, human selves direct their lives as guided by an ‘horizon’ of values (spiritual/moral/religious) that both gives direction and meaning to their lives (p. 4, original italics).

This alternative account of personhood understands that “being a self is existing in a space of issues, to do with how one ought to be, or how one measures up against what is good, what is right, what really worth doing” (Taylor, 1988, p. 298). A self cannot be separated from ‘the goods’ of their life. For too long, argues Taylor, the moral philosophical tradition has focused upon what it is right to do, rather than who it is good to be (Kerr, cited in Abbey, 2004). What constructs people’s lives and selves are central values, or what Taylor (cited in Smith, 2004) calls “strong evaluations” (p. 43). This view of personhood again differs from the modernist account which views the moral self as an individual whose “right thinking leads to decisions or choices, which lead to right action or practices” (Isaacs, 2005c, p. 3). This then means that the good life, or the good person, is the life/self of “free and open choices pursued according to the requirements of rationality and individualism” (Isaacs, 2005c, p. 3).

The strong evaluations, or sets of values, that a person prioritises for oneself, are central to our sense of who we are. They define who or what kind of person we wish to be and be-come. Isaacs (2005c) further explains the interconnection between our strong evaluations and personhood.
In a sense they provide an horizon to our being and becoming in that they give both direction to our engagement within the world and also provide us with a sense of meaning, a sense of identity … Thus this horizon of values gives purpose to our lives in that it designates the kind of choices, the kind of direction in life, that we are committed to. Taylor characterises this horizon as spiritual in the sense that these values transcend the material, the ordinary, the everyday in that they constantly draw us on to greater heights of being, becoming and fulfillment (p. 6).

What this means is that “my identity is firstly expressed in what I strongly value, admire and love (Isaacs, 2007, p. 1). Morality is inseparable from personhood.

This was certainly recognised in living-dying narrative accounts, as the appraisal of one’s life and self was a central activity in the final phase of life. Joyce (cited in Wilson, 2002) explained that “I think I’ve had a good life and I did the best I could for my family” (p. 73). Similarly, for Mary (cited in Wilson, 2002), she recounted that “as far as I was concerned I’d done the best I could all my life. I tried to help people, be kind, cared for other people. I’d helped out in all sorts of ways. I’ve tried to live as best as I can in my life” (p. 73). Martha (cited in Wilson, 2002) also appraised herself in the light of what she valued: “I’ve always been a loving, giving person and I think that’s just being me. And I just loved people and wanted to do so much for them” (p. 73). It seemed as though these strong evaluations became even more important as life was coming to a close. These moral appraisals that were articulated pointed to an overall evaluation of self and life as a living-dying person interpreted it. I would argue that such self appraisals at the end of life are crucial, as a person reflects back and considers the question of whether they have had a good life, or whether they have been a good person. Indeed, each and every aspect of their experience of living their dying and how professionals care for them requires the consideration of strong evaluations or the values that are central to people’s lives and selves. This consideration is further explored in chapter six where the significant values that underpin the practice are considered and how these are central to the hospice palliative care professional’s moral identity.
4.4.8 Embedded in time

The next facet of being to be presented is that of temporality or time. Isaacs (2005c) writes that

the self is embedded in time: while our conscious awareness is always that of the present we also come out of a past and look towards a future. Conscious awareness is complemented by both memory and imagination. Human understandings and human engagements are also embedded in time so that we are both temporal beings and historical beings (p. 4).

Cassell (1991a) concurs with Isaacs when he writes “a person has a past … [and] a perceived future” (p. 36). Similarly, for Heidegger (cited in Leonard, 1994), temporality is constitutive of being. Time is a consideration not separate from one’s being, but rather a further central component of it. In other words, who I am always incorporates considerations of my memories of the past, my present awareness and my imagining of the future. Considerations of time or temporality are central to personhood.

This is a particularly important consideration for living-dying people who experience time in new and complex ways. One’s experience of sickness “distorts one’s sense of time”, writes Brody (1987, p. 90). Often, it might feel as if time is running out or it might be standing still. Or, that “anguish has its own time-scale” (Brody, 1987, p. 93). People experiencing cancer tell of discontinuities of past and future memory (Little et al., 2002, p. 172). In Yededia and MacGregor’s (2001) study, which provides reports from terminally ill people, they write that “life is in homeostasis, beset by terminal illness – precipitating a crisis of meaning and demanding a reassessment of the past, unique solutions to emerging problems, or a new vision of the future” (p. 817). In addition, Mann (cited in Brody, 1987) writes about “how dependent we are, in our awareness of the passage of time, upon external cues and how quickly we lose any sense of time when those cues vanish” (p. 92). For example, a day in the life of a hospital institution mediates time through routines and procedures: shower at six, breakfast at seven and so forth. I always had this sense, after leaving someone’s home or the hospice, that time had somehow stood still. The living-dying experience, I would suggest, has an element of stillness in it that many people are not accustomed to in this type of society we live in.
Overall, what this means is that time takes on a different character or a sense of chaotic-ness in the illness experience. Toombs (1988) explains this sense of time change in lived temporality:

purposiveness is disrupted. Goals appear irrelevant or out of reach. Preoccupied with the demands of the here and now, confined to the present moment, unable effectively to project into the future (p. 213).

Frank (1991) also explains his disruptions to time and self when he writes, “Others took planning for granted; my future was pervaded by uncertainty” (p. 36). Of the temporal nature of personhood, Frank (1991) concludes that in the illness experience “these losses of future and past, of place and innocence, whether they are ours together or mine alone, must all be mourned” (p. 39). Concepts of time which can include understandings of the past, the length of any particular day, and ‘how long do I have left to live’ all affect personhood, and therefore must be taken into consideration. There is a fundamental encounter of an uncertainty of time, and thus an uncertainty of personhood.

The ‘who am I’ question is often answered by ‘I am who I will be’. This expression portrays our sense of be-coming; or a future-oriented self. In this way, for those who are now dying, this can turn into a ‘who can I be now?’ crisis. For other people who may be more present-oriented, and define themselves in terms of their present accomplishments - the ‘I am who I am’ response – the present however is perceived as including the past and may precipitate a ‘what have I done wrong to deserve this?’ type questioning. This often brings forth the moral appraisals of self mentioned in the previous section: ‘I’ve been good, I don’t deserve this’. Overall, all of our actions, thoughts, and viewpoints – all of the unique aspects that make up our self identity – “takes place in a temporal perspective … it depends on our temporal horizon at the precise moment of its occurrence” (Fraisse, cited in Hulbert & Lens, 1988, p. 296, original italics).

Hulbert and Lens (1988), in their examination on time and self-identity, conclude that “finding meaning in life is closely connected with a tolerable balance of future, present, and past time perspectives” (p. 296). Assisting those who are living and dying in maintaining some sort of balance between these time perspectives is beneficial (Hulbert & Lens, 1988). In addition, understanding where a living-dying person is situating
themselves in accordance to time might be helpful as well. At the end of life, more so than at any other time, assistance needs to be provided so that a person can integrate their experiences over a lifetime, bring these experiences into a meaningful whole, and consider concepts of future time in different ways. Hulbert and Lens (1988) state that “the developmental goal, if there is one, is to create a completed person” (p. 302, original italics). Rather, I would say that HPC professionals need to assist people to integrate time in a way that assists in a sense of completion to life and for that identity, and in a way that takes into account how that person will live on in the memories of others too. Or, as Isaacs (2005b) asks, “how sensitive are we to the temporal needs of the other, especially the need to know the future” (p. 36). To end this section on the temporal self I offer the words of Martha who, after years of living with multiple life-limiting illness, reconfigured her understanding of time into “an experience of immediacy, where the future is deliberately blurred” (Del Vecchio Good et al., 1994, p. 858).

Now it’s just moment to moment. When I go to sleep at night time the last thing I say is ‘Lord if you want me tonight you can have me, but I’d rather be here in the morning’. And then when I wake up in the morning I’m just so glad to wake up and then I’ve got another day to tackle and I just take it as it comes (Wilson, 2002, p. 68).

4.4.9 Unique narrative-selves

A human life must be viewed as a narrative and that the notions of personal identity make sense only within such a narrative framework. Without the passage of time there can be no narration; events cannot take on the meaning that narration gives them if they cannot be located in time (Brody, 1987, p. 92).

What is inextricably linked with notions of temporal ontology is that of narrative. Over time people narrate their lives and selves. Thus, narrative is a further central facet of our being-ness. Story is particularly pertinent in that it is this aspect that enables the ability to create and construct our unique experiences, interpretations, and identities. The centrality of narrative in identity and illness has been briefly outlined in chapter two. Furthermore, I comprehensively outlined the narrative self in Restorying the dying self (Wilson, 2002, p. 39-42) and so will not do so again in this thesis. That being said, however, it is important to emphasise that narrative (or story) plays a fundamental role
in the formulation of personal identities and interpretations about life, illness and dying, and, I would argue, the identities of social practices such as HPC. Narrativity functions by generating a construction, a process and a continuity of self-identity and can provide an account as to how identities are formulated. Taylor (cited in Kerby, 1991) believes that only narrative can offer “a coherent answer to the persistent questions concerning our self-identity” (p. 59). Let me reiterate, briefly, an explanation of narrative-selves

Stories provide a sense of continuity, or self-sameness, throughout life. However, the story also changes as the person has new experiences and as new events occur. The stories people tell about themselves shape how they understand and experience events, and events, in turn, also shape the self-story or narrative-identity. New events shape new self-stories and new self-stories lead to new actions and events. Life is an ongoing cycle of action and constructing and reconstructing self-stories (Rice & Ezzy, 1999, p. 26).

This storied facet of personhood is an in-process and always unfinished act. It is the common factor which bridges all of the facets of being that have been presented in this chapter. Stories are constructed in interaction with others: our social embeddedness. Stories are developed through dialogue: mediated in language. The people, language and meanings (interpretations) are all embedded within a particular culture or ‘world’. Stories always have a temporal dimension to them: from past experiences, or imagined futures. Yet, even though narrative is interwoven throughout each of the facets of ontology that I have outlined, stories are also the facet of being that most accounts for our uniqueness.

I have argued that the listening to stories at the end of life must be a crucial caring practice in hospice palliative care (Wilson, 2002). Belling (2004), in her ruminations of the ‘death of the narrator’, similarly argues that “one helpful response may be to approach the last stages of a lethal illness as an opportunity for the patient to author the last chapter of his or her life narrative” (p. 147) or to reconfigure all the chapters of one’s life into one kind of book. Balber (1995), too, believes that “listening and responding to stories becomes an act of genuinely enhancing a vulnerable self” at the end of life (p. 102). Finally, for Byock (1997), “stories are the only satisfying way I know of explaining the paradox that people can become stronger and more whole as physical weakness becomes overwhelming and life itself wanes” (p. 74). The
consideration, acknowledgement and attendance to stories at the end of life, as a facet of personhood, are crucial in so many ways. I proposed in the conclusion to my previous research study ‘an ethic of listening’; for as Frank (1995) asserts “one of our most difficult duties as human beings is to listen to the voices of those who suffer … this then becomes a fundamentally moral act” (p. 25).

4.5 Summary: Embedded personhood
This chapter presented several important facets to one’s being. These include our mediation of life and self through language; our interpretive nature; that we are more than reflectors or thinkers, but that we are also purposeful, active beings; that we are embedded in the world, our culture, in relationships and roles, in an ethical and spiritual landscape and in time. Each of these facets can be considered both ‘in common’ and unique. For example, all humans are storied beings though each one’s story is unique. For our relationship to, and experiences with, any of these facets of our being can be storied in multiple and diverse ways. To explain further, for a living-dying person whose primary identity is one of athlete, their body-relatedness will be of central importance to them. Thus, any disruption to this body-self relationship through a terminal illness will be interpreted in a unique way, in comparison to someone who has a different type of relationship with their body. The degree of ‘relatedness’, connectedness or influence to each of the facets of being outlined above will be different for each person who is dying; their experience and interpretations will therefore be different, according to what story or stories are being told (or not told).

4.6 Implications of disrupted personhood
In addition to presenting the above alternative and arguably richer account of ontology, some considerations of possible implications for the living-dying person have been included in this chapter. Our embeddedness in language might mean that a living-dying person’s experience and identity could be either creative (transformative) or constraining (diminishing), especially when we take into account the role and significance of dominant medical language. Human beings as interpretive beings include the recognition that any particular person’s interpretation of such things as pain, dying, or
identity could be confused or altered, adjusted or incomplete. Three dominant
interpretations – restitution, quest and chaotic narratives (Frank, 1995) – could be
narrated in the interpretation of the illness experience. Appreciating our embodiment;
our relationship between body and self, means that with the living-dying experience
comes a profound change in self. The relationship one has with one’s body is altered or
disrupted. There needs to be the recognition that we cannot separate a person from his
or her body and that any overt focus on body as object will affect the living-dying
person. Next, the significance of people as doers, or purposeful beings, means that one’s
ability to do is altered and this too will affect one’s sense of self. Our embeddedness in
our world, or culture, means that an appreciation of the available scripts provided by any
society will also shape the living-dying experience, especially if a living-dying person is
attempting to die outside of the dominant ‘way of dying’. We are not separate from the
world, but rather deeply connected to it. Only two of the HPC professionals articulated
this sense of embeddedness.

On the other hand, the facet of being that included the recognition of our bond to others,
our social relatedness, was much more familiar for the HPC professionals in this study.
Roles and relationships change in the living-dying experience and this can alter or
disrupt a person’s sense of self or indeed their experience of dying. Further, an
understanding that people are embedded in a moral world of strong evaluations means
the recognition of the importance of moral appraisals at the end of life; including the
possibilities and problematics of these appraisals. Time, as understood in personhood, is
a further central component as we are beings who come out of a past, are immersed in
the present moment, and consider or imagine a future self. Each of these temporal
understandings can be influenced in the dying experience, and hence have potential for
affecting a living-dying person’s sense of self. Finally, a narrative understanding of self,
the unique dimension of personhood, recognises that people story themselves and their
lives in different ways. A living-dying person’s story is profoundly altered, disrupted
and requires reconfiguration at the end of life. Caring practices that recognise the
centrality of stories are crucial. Stories are who we are.
Aside from these brief ruminations about the possible effects upon our facets of being in the living-dying experience, several authors, too, have postulated what could occur for the living-dying person. Isaacs (2005b) explains that a reality, such as illness or dying, can affect a person’s way of being in the world. It can impact on the persons meaningful sense of self, her relationships to other selves, and her sense of place and purpose in life. It can trouble one’s sense of well being. It can bring up a fundamental ontological experience of powerlessness. Self as doer is compromised. A person can become dislocated, vulnerable and naked. It may involve a profound dislocation in terms of the ill self’s comfortable being-in-space and being-in-time as well as the disruption of intimate, familial and social relationships. Illness can bring a dependency on others and experiences of relational and social vulnerability. Overall, it can profoundly disturb one’s sense of identity (p. 7).

In the same way, Callahan (1993a) understands that the core fear is “the sense that the self is losing its identity, its ‘I’ and ‘me’ are becoming harder and harder to locate” (p. 161). Similarly, Dowling Singh (1998) believes “our sense of self, our sense of identity, endures profound and relentless changes during the course of terminal illness and the dying process (p. 60). “The self is always profoundly threatened”, asserts Olsen (1997, p. 9). Exley (1999), too, notes the living-dying person lives with the challenge of “reassessing and reordering their self-identities … Discovering that one is dying means that one’s self-identity is likely to be irrevocably changed and also, often more importantly, damaged” (p. 250). No doubt, these authors all agree that with serious illness and the facing of one’s death, ‘I’ can become altered, lost, threatened, disturbed, damaged or assaulted (Wilson, 2002).

Correspondingly, it is of no surprise therefore that testimonies from living-dying people, such as the ones below, reflect the sorts of changes, disruptions, disturbances and assaults on one’s sense of self. These expressions capture the implications of these changes in their own words and connect back to the original quotation at the start of this chapter: “It may not be dying we fear so much, but the diminished self” (Broyard, cited in Frank, 1995, p. 39).

All of me is wrong (cited in Clark, 2000, p. 52).

I became frustrated at the shedding; this is not just the shedding of life, but of what formerly gave living significance: personal space, privacy, looks, career status, mobility, educational opportunities, health, projects that are important, parental involvement (cited in Kellehear & Ritchie, 2003, p. 122).

All that we have imagined ourselves to be is lost in dying. Our persona, our personal sense of history, our goals, and our ideas about reality melt away as we lie dying. We [those who are dying] wonder who it was who stares at them from the photographs of happier, healthier times … who am I now? It’s not you anymore (cited in Dowling Singh, 1998, p. 162).

My body changed and body image is a non-event really. It’s difficult to get used to not having any hair. It’s amazing how people treat you differently. I get angry because I’m still me, whether I’ve got hair or not (cited in Wilson, 2002, p. 61).

I was a very good nurse. But I had to give up work. I’m sorry that I had to give up work. Mainly because I then felt even less of a person. I’d love to be able to go back and work again and be a whole person again (cited in Wilson, 2002, p. 60).

The hardest part for me is I feel like I’m being seen in the past tense. Something that once was complete and important. And I used to be the energetic father, the loving husband, the best photographer in town. I can’t do all that anymore but I’m still me. I am still complete (cited in Kessler, 2000, p. 149).

Undoubtedly, the living-dying experience and one’s personhood is profoundly affected. Illness and dying strikes at the very heart of the ‘I am’. In addition, Kellehear (2007) points out that the voice of the dying has been silenced. We do not tend to hear the voice of the dying person anymore, as they “now encounter problems expressing themselves, problems that we have not witnessed in some twelve thousand years of settlement history” (Kellehear, 2007, p. 253). Indeed it was difficult to even locate the words from the living-dying above. With some of these possible implications inherent in the living-dying experience, including the recognition of the silencing of the voice of the living-dying person, I would like to conclude this chapter by briefly mentioning two broad possibilities of the ontological implications in the living-dying process: suffering (woundings) and opportunity (transformation and healing).
4.6.1 Ontological suffering: Woundings

One of the articulated goals of HPC practice, as presented in chapter five, is the relief of suffering. Clearly, with the implications of ontological changes for the living-dying person, suffering will be present. For, as Cassell (1991a; 1991b; 2005) explains, suffering is about “the distress brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person” (p. 24). Given what has been outlined above about personhood and the implications of changes to one’s personhood in the living-dying experience, this then translates into suffering for the living-dying person. This understanding of suffering in personhood, then, in turn alerts us to the inherent “frangibility of humans - for we are delicate, tender and fragile. Bodies may be fractured, hearts may be broken, selves may be shattered28 (Massey, 2000, p. 4). Just as our bodies are susceptible to disease and decay, so too are identities vulnerable to woundings. Massey (2000) explains that “the wounds will vary in kind, and in severity, and constitute a threat or an assault on the integrity of one’s identity” (p. 4).

Importantly, Cassell (1991b) contends that our first task is to acknowledge and recognise suffering and potential woundings. “To know the suffering of others demands an exhaustive understanding of what makes them who they are – an awareness of when they feel themselves whole, threatened, or disintegrated” (p. 26). Arguably, HPC professionals would need a richer account of personhood that what is currently understood by the modernist paradigm. Much of the articulations and understandings pertaining to personhood, both in the literature and from the HPC professionals in this study, was that of individualistic, thinking (mind) beings. This sits in tension with the philosophy of (total) care which aims to care for the ‘whole person’. This in turn would mean that HPC professionals would then need to seek to understand what it means to be a whole person, or disrupted or altered; that is, pay attention to the changes in personhood or identity. This might seem like a daunting task for some professionals, yet as Cassell (1991b) notes, “to know someone as a suffering individual does not require

28 Massey would like to acknowledge that the original founder of the concept of ‘shattered selves’ was Glass (1993) Shattered selves: Multiple personality in a postmodern world.
complete knowledge of the person; it is sufficient to know what is involved in the suffering” (Cassell, 1991b, p. 27). What can be involved in the suffering and woundings of living-dying people, I would suggest, are the potential implications of changes to the varying facets of being as outlined in this chapter. These facets of being give HPC professionals signposts to understanding suffering and woundings.

4.6.2 Ontological opportunities: Transformation and healing

With the woundings and sufferings of the living-dying experience also come profound opportunities for healing and transformation. When wounded, explains Massey (2000), “possible transformations and reconfigurations, especially identity reconfigurations” are possible (p. 7). In seeking “to preserve or enhance their threatened identities” living-dying people come to a time and place of opportunity (Massey, 2000, p. 8). Saunders (2003), too, noted this possibility when she wrote: “As their role is lost … as Ramsey lost his as a television producer … much of the integrity of the self seems to go too. Like many others, in his response to a totally new and extremely dependent situation, Ramsey found a new self” (p. 26). Even in the face of suffering through disruptions to self, a new self can be discovered, right up until the moment of death. Similarly, for Steve,

he didn’t set out thinking of his illness or impending death as an opportunity to grow as a person – indeed, the idea would have seemed ludicrous to him when he was well – but the prospect of dying so scared him that he was willing to try anything that might relieve the terror. Substantial personal growth often occurs in dying without agonizing soul-searching or questioning of one’s fundamental nature. Even as they are dying, most people retain the capacity for change or, more accurately, growth (Byock, 1997, p. 140).

This possibility for growth, as outlined in Byock’s (1997) book Dying well: Peace and possibilities at the end of life, reveals itself in opportunities for “nurturing, honouring, and celebrating the person departing” (p. 137). Byock (1997) calls them “the rich possibilities within dying” (p. 33) and writes that “in the very shadow of death one’s living experience can yet give rise to accomplishment – a new sense of self despite one’s impending demise” (p. 32/33). Dowling Singh (1998) would concur as she calls for the sorts of conditions “that nurture movement through the transformations of dying … which can include the living-dying persons’ restoration, alteration or reconstruction of
their sense of self” (p. 283). These conditions would be concerned with healing, or “making whole”, as Jennings (1997, p. 4) expresses. Even in the midst of dramatic changes to one’s sense of self, the demise of one’s physical body, and suffering, woundings and death, personal transformation and the potential for healing can occur. For, as Jennings (1997) explains, “life, even in this last chapter, has its own capacity for flourishing, its own integrity and intrinsic worth” (p. 4). Jennings (1997) fundamentally emphasises that the mission of hospice should be to facilitate healing in the sense of “sustaining the integrity of the self” despite the inevitable diminishments (p. 4).

4.7 Chapter summary

Any study into the ethics of a social practice requires critical, detailed and thorough investigations into what it means to be a person; ontology. The commencement of this chapter outlined the significant reasons for this. Fundamentally, HPC practice is concerned with the care and nurture of human beings, and thus must articulate, understand and acknowledge their meanings and assumptions of personhood. Our ontological understandings shape how we respond to others. Or, in other words, since ethics has as its central feature the well being of persons, “we need a richer understanding of self” (Isaacs, 2001, p. 12). This is often a neglected dimension in the study of ethics. Consequentially, Isaacs (2005a) asserts that applied ethics calls for this “reflection upon, a sensibility for, and an understanding of the nature of human beings” (p. 2).

Once this justification was presented, the recognition of the significance of time and place to our current understandings of personhood were noted. Coinciding with this recognition is the dominance of a modernist account of personhood; people as individualistic, autonomous, decision making and cognitive beings. The HPC professionals did, by and large, reflect and assume this modernist account of being. The limitations of this modernist account were noted, particularly in regards to what this account ignores, silences or devalues. That is, a modernist account of personhood decentralises other important facets of being. Further, this modernist self is incongruent with a philosophy of (total) care, as outlined in the previous chapter. It was concluded
that a modernist account was simply one understanding, and one that needed to be made transparent in literature and research, but one that ultimately required a reconceptualisation for the practice of HPC.

An alternative account of personhood was then thoroughly presented. That is, a human being who is both embodied and embedded (in language, time, relationships, world, moral and spiritual horizon); a person who is also a doer or creator, a narrator, and an interpreter. Each of these facets of being were explained and explored in light of the lived experience of the living-dying person. Of note, it was the social realm, or the embeddedness in relationships with others, that was most articulated by the HPC professionals. There is an imperative to develop a fuller understanding of relational embeddedness. This rich account of ontology presented in this chapter also included ruminations about the possible implications for personhood and identity in the living-dying experience, drawing on actual narratives from living-dying people. Finally, two broad ontological implications were suggested: suffering and opportunity. Ultimately, as Byock (1997) passionately expresses, “the separation between suffering and the sense of growth and transformation is but a membrane” (p. 246).

Overall, a modernist account of ontology is insufficient for the caring practices of HPC. The profession as a whole, including the research and literature corpus, need to articulate and understand a richer ontology, as presented in this chapter, for example, for the continuing development of the crucial philosophy of (total) care and a process of caring for the dying which fundamentally attends to the whole person, right up till the moment of their final breath. With an understanding and appreciation of an embedded personhood palliateurs can more thoroughly work towards the purpose of their practice. This purpose of the practice is the main focus of investigation in the next chapter of this thesis. According to a social practice framework all practices are aimed towards an end point. These are the teleological features that make up another further important element of the ethical dimension of HPC practice.
CHAPTER FIVE
Purpose: Wandering in the Wilderness

A palliative care nursing administrator commented that “it’s time to stop again and look exactly at what we are doing here … what are our goals?”

5. Introduction

The ethics of hospice palliative care, when understood through the lens of a social practice framework, requires a greater understanding of the purpose of this practice29. All social practices have this feature of being directed towards an end or ‘goods’. The notion of a common goal or desired good or end point is one of the fundamental ethical features of a social practice. These features are understood as the telos30. This chapter explores the teleological features of hospice palliative care practice.

5.1 Why telos?

The first important reason for examining this feature of the practice of HPC is that it provides justification for the “ways of seeing and ways of acting” in the profession (Isaacs, 1998). The profession needs to articulate and understand these teleological features for, as Dekkers (2001) writes, “the foundations of palliative care are not often explicitly addressed in terms of goals, be it goals as regulative ideals or as more concrete, attainable goals” (Dekkers, 2001, p. 117). It is these features that are the basis for the ethics of a practice (Ricoeur, cited in Widdershoven & Smits, 1996). It is “the teleological character of practices [that] is the foundation for moral obligations” (Widdershoven & Smits, 1996, p. 279). “To adopt the aims of palliative care is to adopt a moral standpoint”, assert Randall and Downie (1996, p. 1). Thus, the purpose of the practice is a central ethical consideration and one that will highly influence how HPC professionals carry out the care of the dying.

29 It is important to note that the understanding of a purpose is encapsulated under a variety of terms including telos, goals, objectives, outcomes, aims, goods, ends, hopes. These terms are used interchangeably in this chapter and are considered to mean the same thing.
30 Telos or teleological features are understood as a point toward which effort or movement is directed; the objective point or terminus that one is striving to reach; the end aimed at (OED, 2007).
A second important reason for examining the telos of HPC practice is that it bestows an identity on the practice which makes it known to the public and other professions (Isaacs, 1998). Clark, ten Have and Janssens (2002) agree in saying that “giving regular attention to the renewal of the goals of palliative care” is important for the maintenance of an identity (p. 53). It could be argued that the identity of HPC is currently vulnerable or unclear at this time, especially as a consequence of the mainstreaming of the profession, and needs strengthening through the consideration of the purpose of the practice.

Thus, the key questions critically explored in this chapter are what are the current understandings and articulations of the purpose of HPC practice and how have these changed over time; how many different understandings are there of the purpose; and is there any suggestion of an agreed or shared understanding of this purpose or purposes? In the conversations with HPC professionals I asked two types of questions in regard to the purpose of the practice. The first was a direct question - what do you understand to be the current purpose of the HPC profession? The second question was an indirect question - what are you hoping to achieve in your practice? In critically exploring this notion of a purpose of a practice, it was thought that having two types of questions would provide rich responses in terms of individual hopes and the professional’s broader understandings of the purpose of the practice. The examination of these two types of questions offers the foundation for the critical exploration of the teleological features of HPC practice. The storied accounts from the HPC professionals are interwoven with current literature on this topic.

5.2 Crucial telos literature

Crucial literature from the Pallium project examines the current position of the stated purposes of palliative care in the European context (Clark et al., 2002). These authors proposed that there are currently four goals

The metanarrative of palliative care across Europe consists of four specific goals: achievement of best quality of life for patients and families; relief of suffering; promotion of ‘good death’; and the prevention of euthanasia. These appear to be the overarching goals, held in common across many settings (p. 52).
However, even though these four goals are noticeable purposes of the practice of HPC, Clark et al. (2002) note problems with these, such as that they vary in explicitness, they are not given equal priority in differing settings, and they can “appear a weak platform” for the development of HPC (p. 52). Conclusively, Clark et al. (2002) argue that “there is no unanimity on the goals … that they [the goals] have become blurred” (p. 63). It seems that “palliateurs appear to lack internal unity and cohesion about the central purposes of their work” (Clark et al., 2002, p. 62). It has been my concern also, that the purpose of HPC has become somewhat confused, blurred, weakened or fragmented, and most likely not shared within the profession. Similar to the philosophy of (total) care it seems that what once was a common and shared understanding about what HPC practice strives to achieve, has now become unclear, as Clark et al. (2002) suggest. These authors ask a vitally important question: “whether the existence of a cohesive metanarrative is essential to the future well-being of palliative care and those it seeks to serve?” (Clark et al., 2002, p. 53).

Randall and Downie (1999) have also discussed the aims of palliative care in their ethics text. The standpoint of these authors, however, is that palliative care is an integral part of health care and therefore “its aims and scope should … fall within those of health care” (Randall & Downie, 1999, p. 16). What this means is that Randall and Downie link the purpose of HPC as the same as the aims of health care generally. Randall and Downie (1999) outline three aims in hospice palliative care

- Personal aims: “earning a living, having job security or expressing idealism” (p. 17);
- Intrinsic aim: “to bring about a ‘medical good’: the amelioration or sometimes cure of disease processes, the relief of suffering, the prolongation of life, the dressing of wounds and many others” (p. 17);
- Extrinsic aim: “what doctors and nurses may be able to do as a result of standing in special relationships with their patients: the promotion of the patient’s psychological good (emotional, relational and spiritual goods)” (p. 18).

It is interesting to note that Clark et al. (2002) argue that the secondary purposes of palliative care, such as those day to day activities related to the consolidation of palliative care within the mainstream health care arena (conferences, journals, the creation of an evidence-base, education programmes, funding), are given priority, and are subject to greater consensus than the primary, overarching goals (p. 62/63).
There are several criticisms of this articulation of the aims (purpose) of hospice palliative care. Like Clark et al. (2002) I too dismiss this explanation of the central goals of the practice as being overly simplistic and dualistic in nature. Clark et al. (2002) state that this formula for the aims of palliative care reinforces the mind-body dualism inherent in the medical model of health care and does not take into account the multidimensional and complex nature of people and the living-dying process. Furthermore, this understanding of the aims of hospice palliative care assumes a compatibility or sameness with the aims of all health care practices which is arguably unrealistic. For example, the valuing of dying-as-natural and an inevitable part of life is incongruent with an overt focus on cure and life prolongation which is inherent in health care. Randall and Downie (1999) fail to recognise the unique or distinct nature of hospice palliative care and simply bracket it with all health care; hence hospice palliative care must have the same purpose as health care.

Randall and Downie (1999) do qualify their discussion of the aims of palliative care by writing that these goals are “necessary for health care professionals, [but] they are not sufficient to ensure that each individual patient receives the care most appropriate” (p. 26, original italics). These above aims are more the ‘science’ of palliative care, write Randall and Downie (1999), which is about generalities, whereas the ‘art’ of palliative care is about particularities, and “finding the best course of action for each unique patient” (p. 26). This qualification offered by Randall and Downie raises the question of what then is the aim or purpose which pertains to the art of hospice palliative care practice? Interestingly, in Randall and Downies’ (2006) recent text these authors suggest a new way forward which dismisses the concept of quality of life as a central goal of the practice, and write that principles are no longer sufficient to guide practice. Rather, Randall and Downie (2006) still maintain that the practice of palliative care “should be consistent with the aims, values, and assumptions of health care generally” (p. 220) and that “the central aspect of palliative care is symptom control delivered humanely with adequate information” (p. 220).
With the insights and arguments of these two central texts now outlined, this chapter explores in more depth each of the differing purposes. This includes the goals of the relief of suffering, the promotion of the good death, and the achievement of the best quality of life\(^\text{32}\). In addition, the traditional goal of providing comfort is discussed firstly, and a brief inclusion of the goal of a peaceful death is warranted. Further teleological considerations that arose from the HPC professionals’ stories include the influence of individual choice on the goals of practice and an overwhelming focus on creating and sustaining a particular type of relationship as the central purpose\(^\text{33}\) of their work.

### 5.3 Aiming for comfort

Before exploring the three overarching goals of HPC, as outlined by Clark et al. (2002), it is important to note that in Saunders writings, thinking and practice the goal for her was that of attaining comfort in dying and death. Therefore, I would like to acknowledge this as the founding goal of the practice. This, however, no longer seems to be the prevailing goal of HPC practice. For the pioneers of the hospice movement, however, this was the primary focus of care. There can be no doubt that the original goal of hospice care, according to Saunders, was comfort rather than cure or palliation (Saunders, 1966, p. 225). Saunders (1967) explains this when she writes

> Care for the dying person should be directed no longer towards his (sic) cure, rehabilitation or even palliation but primarily at his (sic) comfort (p. 385).

The tradition of hospice care, therefore, believed that cure and palliation were acceptable for people with treatable illnesses, but not for dying people. For Saunders (1966-67) the correct goal of hospice care was comfort. A few of the HPC professionals mention this as the purpose of their practice

> I don’t think anyone would go into it [palliative care] without the purpose of really providing comfort. Isn’t that everyone’s aim? (Nina)

\(^{32}\) Please note that one of these goals, the prevention of euthanasia, is not included for consideration. The reasons for this were noted in the beginning of this thesis. Furthermore, none of the HPC professionals stated this as their aim of practice.

\(^{33}\) Please note that some of the goals are given greater consideration than others. There are limits to being able to explore each goal equally. For example, the goal of quality of life is given a great deal of attention, because this is arguably the most common, contemporary articulation of the aim of HPC practice.
The purpose of palliative care, for me, overtly, is to bring comfort. That could mean comforting in giving support and in the provision of allied health members or it could mean pain relief. To reduce that sense of burden that they may feel that they’re under. That to my mind brings comfort. This is my goal (Lisa).

The aim for anything you do is that they are going to be more comfortable. Because there’s no point doing something if the outcome is not going to be that they are more comfortable (Naomi).

It is interesting to note that Nina thinks that maybe the goal of comfort was the same for all HPC professionals. Unfortunately, Nina is not correct. Comfort as a concept, value or goal was minimally stated in the HPC professionals’ storied accounts and is rarely mentioned in the literature.

5.3.1 Community attitudes

Conversely, in a recent report entitled *Community attitudes towards palliative care* (AGDHA, 2006), the highest aim of HPC, as understood by the community, was the provision of comfort and pain relief for the terminally ill (p. 13). This report sets out that the community understood the aim of HPC to be about comfort (fifty two percent); pain relief (twenty three percent); quality of life (twenty percent); family support (nineteen percent); and dignity (seventeen percent). This serves to highlight that, for a certain percentage of Australians HPC is about comfort, whereas the providers of HPC tended to focus less on general descriptions, and more on specific elements of HPC such as emotional support and symptom relief. It would seem there is incongruency between the community and the HPC professionals’ understandings about the aims of HPC practice. Overall, according to the HPC professionals and scholars, it would seem that the goal of comfort does not hold a central place in the stated purpose of HPC practice anymore, as it once did. As Clark et al. (2002) argue “today’s practitioners have become diverted from the goals of the founders” (p. 62).
5.4 The achievement of a good death

A further traditional goal of HPC was the achievement of a good death. Yet again, like the goal of comfort, it does not seem to be the prevailing contemporary goal for the practice anymore as it was a concept barely mentioned by the HPC professionals. Initially, though, the good death was an ideal aim which was interwoven with the values of the hospice movement and provided the fundamental teleological dimension of the practice. In other words, the end point that professional caregivers strove for was the aim of a good death.

There has been a plethora of studies, both from the professional caregivers perspective, the patient’s and family member’s perspective and scholarly reflections, that have attempted to understand and articulate this evaluative goal. Clark and Seymour (1999) suggest that a new “societal formulation” of the good death came out of the critiques of medicalised dying in the 1950s and 1960s “in which personal choice and awareness of dying were central” (p. 19). Kellehear’s (1990) study of the good death in Australia emphasised five common features: awareness of dying, adjustments to and preparations for death, relinquishing of roles, responsibilities and duties, and the making of farewells with others. Kellehear (1990) asserted that for a good death to occur “the active and critical role that dying people played in the social management of their dying” needed to be optimal (p. 24).

Notably, the good death has been defined in various ways including the sense of dying painlessly by euthanasia or that of “adhering to a set of socially sanctioned modes of behaviour” (Clark & Seymour, 1999, p. 88). Australian research from hospice nurses’ perception of the good death found that if the patient is to have a good death nurses feel that they should: “ideally be involved; provide effective symptom control so that the patient may complete their living and die pain free; and work toward providing an

34 ‘Death’ in such concepts as the good death usually refers to one or more of three different and consecutive situations. These three situations are ‘the processes of dying’, ‘the event of death itself’ and ‘the state of death’, where the event of death is the passing over from the process of dying to the state of death (Dekkers, Sandman & Webb, 2002). Thus, when we speak of the good death, it could be referring to the processes leading up to actual death, or the moment of death itself. For some family members it might refer to the few hours leading up to the cessation of breath. These terms of dying and death are often defined differently according to different people, authors and situations.
environment where the patient may die peacefully and with dignity” (Wilkes, 1998, p. 118).

The good death has certainly been a contested notion, interpreted in various ways over the course of history. Hart, Sainsbury and Short (1998) believe our understandings of the good death are now, arguably, fragmented. In addition, it is a notion that is often not viewed as even appropriate in our pluralistic society. Finally, it needs to be recognised that the notion of the good death is a dynamic one, rather than a static notion, “more akin to a negotiation process [and] an ever-changing kaleidoscope of various types of goodness and of the play between good and bad factors” (Bradbury, cited in Masson, 2002, p. 193).

5.4.1 The good death helpful?

Aside from recognising these multi-faceted considerations and the external influence of individual choice in the goal of the achievement of a good death, it can now be seen that contemporary HPC professionals and scholars are questioning whether this notion of the good death is still relevant or helpful as a purpose of the practice. Often, these questions include whether the aim of a good death is enabling or constraining for living-dying people, families and friends and HPC professionals. Clark, ten Have and Janssens (2002) conclude that this notion of the good death “is increasingly abandoned as an orienting principle by the practitioners of modern palliative medicine [care]” (p. 59).

Overall, Clark et al. (2002) maintain that the attempt to achieve the good death “is a shaky edifice upon which to build a goal of palliative care” (p. 57). It would seem, like the goal of comfort, the notion of achieving a good death, as a goal for HPC practice, has also been abandoned by the HPC professionals in this inquiry. In the articulations of the HPC professionals, only one HPC professional mentioned the good death as the goal of her practice. Stacy directly spoke about it as the goal of her practice

I think that what we’re trying to achieve is a good death, but a good death means something different to everyone. It’s especially important so that the succeeding generations understand what dying can be about and it’s a learning process. Families come back and say “I don’t feel scared of dying now. I saw the way my mother died, in
the way she was supported and looked after, and I know that I can face it now”. So I aim for this good death outcome (Stacy).

Here, with Stacy’s comments, we can see that she is trying to make a broader impact on the community’s experience of dying through the practice of HPC. This was certainly what was hoped for by the original hospice movement. That is, with an awareness of death and the promotion of a good death, that people will then in turn not fear life’s ending. This was the broader goal of the movement; to change the face of how we evaluate dying and death. However, it speaks volumes that only one HPC professional out of thirty mentioned the term the good death. This concept, value and goal, which was initially embraced by the hospice movement, may have been discarded.

5.4.2 The ‘good enough’ death

McNamara agrees with this conclusion of the abandonment of the good death ideology in her study *Good enough death: An ethnography of hospice and palliative care* (1998b; 2001; 2004). In this study McNamara exposed that the valuing of individualism, choice and autonomy has changed the face of HPC, particularly the goal of the good death. As McNamara (2004) writes, “the good death ideology has become increasingly inappropriate in the current climate of patient autonomy and consumer choice” (p. 3). McNamara (1998b; 2001; 2004) believes that HPC professionals have adopted a compromised stance which she has termed – “the good enough death” (p. 3). Thus, interplay has developed between “the shared understanding of what constitutes a good death [versus] the locus of control and decision-making [with the living-dying person]” (McNamara, 2004, p. 4). McNamara (cited in Clark & Seymour, 1999) concludes that HPC workers have come to “embrace a more pragmatic and contingent notion of the ‘good enough’ death which gets as close as possible to the ideal goal of HPC practice and to the preferences of the deceased” (p. 94).

The above contentions and considerations, offered by McNamara, can be seen exemplified in the one other statement that mentioned the good death offered by Julie

There are all these expectations that are put on people and with them trying to force them into our mould of what we think is a good death and that’s just how you go about making a bad death [pause] by having all those expectations (Julie).
What Julie is saying is that HPC professionals’ expectations about a good death are largely problematic. What is most important is the living-dying person’s choice in the manner with which they die. Thus, the achievement of a good death, as understood by the profession, has reached its use by date in being helpful as a guiding purpose for the practice of HPC. Like the European context, the good death as a goal of HPC practice, “has largely been discarded” in the contemporary vision of the HPC profession (Clark et al., 2002, p. 58). HPC professionals, states McNamara (2004) have, rather, adopted “a compromised stance” (p. 930).

5.5 Peacefully dying
Rather than the evaluative goal of the good death, perhaps the concept of a peaceful death may be a suitable alternative. The aim of a peaceful death for HPC practice has an added advantage of being congruent with that of the practice of medicine. In an international study, The goals of medicine: Setting new priorities (Callahan, 1996), it was found that the pursuit of a peaceful death was seen as a duty of medicine in “creating those clinical circumstances in which a peaceful death is most likely” (p. S13). This goal of a peaceful death “is as old as humankind, but has been re-championed by Daniel Callahan” (Dekkers et al., 2002, p. 115). Callahan (1993b) outlines this peaceful death as

A death that is accepted and not unduly feared, a death that is not marked by excessive pain and suffering, and a death that takes place, so far as possible, in the presence of other people who are there to offer comfort, support and love (p. 36).

What is thought beneficial about this peaceful death goal is that it “more powerfully encapsulates the personal, medical, and social strands involved in dying” (Dekkers et al., 2002, p. 116). Furthermore, a peaceful death emphasises finding meaning in death; of making some sort of sense of mortality (Callahan, 1993a/b). Certainly, it can be acknowledged that this goal of a peaceful death is similar in many ways to the understandings of a good death, especially since it reinstates the importance of the acceptance of death and the minimisation of pain and suffering.
Perhaps the goal of a peaceful death may be more helpful as a clear purpose to the practice. From my experience, it is a concept that more people are in agreement with. However, again, like the good death, it was a concept barely mentioned by the HPC professionals. Kieran, a social worker, was clear about its importance

It’s so important for us to help people to die as peacefully as possible (Kieran).

Elaine also offered some comments related to this goal of a peaceful death

I like to think that at the end of the day, when a person dies, that it is important that it has been peaceful for them. Somewhere along the line, you can see that there may have been some inner peace. That they weren’t concerned about what they were leaving behind because they had talked about it, they’d done what they could, and they were comfortable with the past. I hope that I can assist with that and help them with that sense of peace (Elaine).

Finally, Naomi shares poignant reflections on peacefully dying

I know we’re all meant to rage against the dying of the night and dying peacefully and contently is not necessarily how everyone wants to die. But it’s whatever people want. That’s the way I’d like to die, at peace. And to have the sort of care that assists me with this (Naomi).

Naomi’s articulation has many facets to it, and demonstrates the struggles that HPC practitioners go through in articulating the goal of their practice. The first sentence about raging against dying expresses a societal tone, whereby one of the current, dominant scripts in Western society of how we are meant to die is understood as ‘raging’, ‘fighting’ or ‘battling’. The next part says that dying peacefully and contently is not necessarily a good death, thereby maintaining that each individual has his or her own choice in interpreting the good death, demonstrating that individual choice is an influential value. Finally, we have her own value stance of how to die in that she wishes for a peaceful death for herself. Here we can understand Naomi to be actually juggling in one quote the societal scripts, the priority of individual choice, and her own valued goal. What a difficult thing it is to have to be open to each of these interpretations and hold your own valued stance as well. Maybe this is one of the reasons why articulating a goal of the profession is so difficult. In summary, the ideal of a peaceful death may be a helpful one as it has links to the goals of medicine. Yet, like the goal of the achievement of a good death, the aim of a peaceful death in HPC practice did not play a
large role in the articulations and understandings of the HPC professionals in this inquiry.

5.6 The relief of suffering

If the goals of HPC practice are explicitly discussed at all, the relief of suffering and the promotion of best quality of life are usually mentioned (Dekkers, 2001). These are the next two goals that are considered in this chapter. The goal of the relief of suffering in dying and death has been a part of the hospice palliative care philosophy since its inception. As Clark et al. (2002; Saunders, 1961) explain “the language of suffering has formed part of the palliative care worldview from the early days” (p. 56). PCA (2006) recognises this goal when it states a living-dying person needs “to be as free as possible from unnecessary suffering (physical, emotional or spiritual)”. The WHO (2002) definition also includes the “prevention of suffering”. The relief of suffering, as a broad goal of HPC, is the one most favored by Clark et al. (2002). These authors conclude that attending to suffering is a more realistic goal for HPC than quality of life (Clark et al., 2002, p. 56).

5.6.1 An account of suffering

Cassell (1991a; 1991b; 2005) is one author who has extensively examined the concept of human suffering, particularly in relation to the goals of medicine. Cassell links suffering with his account of personhood, as outlined in chapter four, and understands suffering to arise when any element of personhood is threatened, or even perceived to be threatened. Cassell (1991a) explains

Suffering occurs when an impending destruction of the person is perceived; it [suffering] continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner … [thus] suffering extends beyond the physical. Suffering can be defined as the state of severe distress associated with events that threaten the intactness of a person … this can occur in relation to any aspect of the person (p. 33).

Adopting this eloquent understanding of suffering, and the required appreciation of personhood, it can be seen that the experience of dying and death provide the ultimate experience of threat to oneself. The condition (of dying) or the event (of death) threatens the intactness of self and therefore suffering will occur. This account of
suffering, offered by Cassell, also aligns itself with the philosophy of (total) care as well. Thus, it seems this would be a helpful goal for HPC in many ways: it is congruent with the goals of medicine; with the living-dying process; and with the philosophy that underpins hospice palliative care practice.

Unfortunately, Cassell largely stands alone in his reflections on suffering within the health care arena. Although listed as a goal of medical care, the education and understanding of this complex concept and experience is rarely attended to in medical and palliative training (Cassell, 1991a). Cherny (2004) agrees when he states that “the medical literature on the nature of suffering is sparse” (p. 7). Logically, therefore, Dekkers (2001) asks the question: How then can we know it’s been reached, as a goal? Dekkers (2001), in proposing an alternative goal linked to the metaphor of ‘coming home’, argues that the relief of suffering as a goal is not specific or concrete enough, is usually linked with the medical good or viewed in a medical way, and is understood as a negative goal or problem. This is linked to the modern ideal of the eradication of suffering in today’s contemporary society.

5.6.2 Suffering as a medical problem
Increasingly, with the growth of palliative medicine and the influence of medicine, the relief of suffering is viewed as a medical problem to be clinically solved. As Cherny (2004) writes, in the *Oxford Textbook of Palliative Medicine*, “the ability to formulate a response to the challenge of suffering requires a clinically relevant understanding of the nature of the *problem*” (Cherny, 2004, p. 7, authors italics). Indeed, this chapter in the Oxford textbook is even entitled ‘the problem of suffering’. Palliative literature now articulates a concern that suffering is being understood in a purely medical and problem-based way. For example, Kearney (1992) writes that

> If we sell out completely to the literalism of the medical model that such suffering is *only* a problem, we will be in danger of following a pattern which could significantly limit our scope for development and lead to our becoming ‘symptomatologists’, within just another specialty (p. 41, original italics).
In this quote Kearney is explaining the possible consequences of understanding suffering as a medical problem; as a problem to fix. This, Kearney suggests, might translate into the priority of pain and symptom management. This translation can already be seen in the contestation of the philosophy of (total) care, where the relief of physical pain and symptoms is placed foremost on the agenda of the priorities of practice. This understanding of suffering has also influenced the goals of HPC as examined further along in this chapter. One HPC professional responds by saying that we need to change the name of the practice to ‘symptom managers’. Ahmedzai (1994) is in agreement when he reflects that if suffering is understood as a problem that comes hand in hand with a medical response, this will “reinforce the focus on pain and symptom management, and will reinforce the notion of suffering as pathology” (p. 218). This would mean that there would be a “failure to recognise the positive and creative elements of suffering”, suggests Ahmedzai (1994, p. 218). We would miss the possibility of suffering being positive for the person. The possibility of suffering being something more than negative is captured in some of the HPC professionals’ storied accounts below. Indeed, Cassell was one of the first scholars to argue that the suffering person, rather than his or her symptoms, should be the focus of palliative care (Ohlen, 2002, p. 293). Furthermore, Frankl (cited in Byrock, 1994b) explains that “physical discomfort and deprivation are not necessarily sufficient to cause suffering” and that suffering often relates to an experienced loss of meaning and purpose (p. 9). We need to understand suffering from the perspective of the person’s life, the meaning he or she makes of their life, and as a human experience, rather than a bodily problem, with a corresponding ‘total’ response (Rodgers & Cowles, 1997).

5.6.3 Suffering as inevitable
What is important to note from the HPC professionals who took part in this investigation is that the relief of suffering was not overtly mentioned as a goal of care, but rather discussed generally throughout the interview process. These expressions of the role and understandings of suffering offer insights into the pitfalls of having the relief of suffering as the goal of HPC. Firstly, there was the acknowledgement of the inevitability of suffering in the course of living and dying. If the account of suffering
articulated by Cassell is accepted then the process of moving towards death will necessarily involve the threat of the end of self according to some religious and world views. Thus, the HPC professionals expected that suffering would be present for people. Their articulations portrayed the complex dance between acknowledging suffering, being realistic about the limits of relieving it, but still being committed to minimising it if possible

We always have patients who do die with some suffering, despite what we do. There’s always a certain amount of suffering that will have to be endured. But the minimisation of this as much as possible is important. I think we would have to be naïve to think that we can eliminate all suffering (Stacy)

It’s not about alleviating that suffering [pause] not getting rid of it, but it’s about acknowledging that it’s there and then minimising it if possible (Natalie).

Here we can hear that some of the HPC professionals have worked towards a process that understands that acknowledging suffering is important for the living-dying person, that a level of appreciation of the inevitability of it is required, but that there is the hope to minimise it if possible. This demonstrates a contingent stance whereby HPC professionals are realistic about what they can or cannot do about the relief of suffering for living-dying people.

5.6.4 Suffering as valuable

Secondly, as Ahmedzai (1994) alludes to above, there is a sense in the HPC professionals’ articulations of a value in suffering; that for some people suffering holds meaning or value in and of itself. Seeing value in suffering is not a popular notion in Western, modern cultures and is further confused by the differing positions of ‘value in suffering’ or ‘value in overcoming suffering’. For, as Cherny (2004) writes, “the potential for personal development and net positive gain in overcoming situations of adversity and suffering is widely recognised” (p. 8). Thus, it becomes more about overcoming suffering. Certainly, the Christian and Buddhist perspectives on suffering and dying both consider suffering to be an inevitable component of human life, “and both discern potential purpose in suffering” (Byrock, 1994b, p. 9). There were noticeable comments from the HPC professionals about the role of suffering in the living-dying person’s journey
My thinking is that it’s okay to suffer and that also in that suffering for some people is something that they want. They are not saying that they want the pain and suffering relieved necessarily. They just want to hear us say “yes, it must be extraordinarily painful”. It may be important for them to suffer. For some people there may be a measure to suffering and there may be value in that for them (Amy)

The scriptures teach a value in suffering and that you can use the scriptures to help people, to find meaning and purpose in suffering. Often we make judgments and assumptions about suffering, according to our medical culture (Tony)

Knowing that there is actually very little I can do in this situation and then trying to find some meaning in it [suffering]. It is an inevitable fact, so once again it’s about trying to find some meaning in that (Natasha)

Some people may benefit from suffering. It may be part of their spiritual or religious belief that suffering is necessary for them. It’s certainly not something that I ascribe to … that is I don’t see suffering as a necessary part of dying, but we are not going to be able to totally eradicate it in every case (Michael).

It can be heard in these expressions about suffering in the living-dying process that it is important to acknowledge suffering in a person’s life, and then the option or choice for people to find meaning, purpose and value in this. This is Cassell’s point also, when he talks about how we can address the relief of suffering

Meaning and transcendence offer two ways by which the suffering associated with destruction of a part of personhood is ameliorated. Assigning a meaning to the injurious condition often reduces or even resolves the suffering associated with it (cited in Callahan, 2002, p. 346).

5.6.5 Choice in suffering

The final theme in considering the place of suffering as a goal of HPC practice is the recognition of people doing their dying ‘in their own way’; that is the living-dying person’s choice to suffer, if this is a part of their journey for them. “It may not be the ideal care for everyone … if they want to suffer in silence, that’s what we have to put up with” (Jeffrey, cited in McNamara, 2001, p. 94). The HPC professionals in this study also stated this emphasis of choice in suffering

Often it is that sometimes people don’t mind suffering. It’s not up to us to say “you will not suffer”. They have a choice in their suffering. But we can say “we can help you with it if you want”. But you can’t do much. So I don’t think we’re there to stop the suffering (Fiona)

I think if the patient feels okay about suffering, for whatever reason, then that needs to be respected (Peter).
These quotes by Peter and Fiona represent the prioritising of individual choice in the living-dying process that so often pervades the articulations from the HPC professionals.

What can be noted from these articulations from those HPC professionals is that although suffering was discussed at differing points, and it was an important concept for them to reflect upon, it was not overtly mentioned as a goal of the profession. In addition, given the above reflections: confusion about it’s definition; being viewed as a medical problem to be clinically solved; the inevitability of suffering; the potential value in suffering; and the individual choice for people to suffer if they wish to, these all add up to the relief of suffering being a problematic goal for the profession. “It has become a contested territory in which competing definitions and emphases are at work”, writes Clark et al. (2002, p. 57). Ultimately, although these three European scholars favour the relief of suffering as a goal for HPC, they argue that the profession “appears remarkably unclear on its view of a central focus of its interventions: human suffering” (Clark et al., 2002, p. 57). Given these tensions, confusions and the inevitability of suffering it would seem that having this as an overarching goal for hospice palliative care practice would be fraught.

5.7 Achieving quality of life
A goal that is now recognised in the literature as the most common articulated purpose of the profession is the improvement of quality of life. Like the relief of suffering, on the surface of things it is an unproblematic goal that has now been widely accepted by the profession. This is largely due to the adoption of the WHO (2002) definition which states that the intention of palliative care is that it will “improve the quality of life of patients and their families” (p. 1). It would seem that this goal has become the overarching aim of HPC practice. It is suggested that the rise of this goal of quality of life was borne from the oft quoted statement by Saunders (2004)

You matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die (p. 19).
Hence, the new objective for HPC has been reformulated into concerns about the quality of living, up until you die. Stemming from the WHO definition, the majority of Australian definitions also include this as the goal of end of life care. The PCA (2006) definition reinforces that the “primary treatment goal of palliative care is quality of life” (p. 2). Parallel with this inclusion in definitions, and the adoption of this goal generally by the profession, is the increase in the number of articles about quality of life in the HPC literature. Randall and Downie (2006) note this increase, where “between 1996 and 2000 there were 12,749” articles on this complex concept (p. 25). Clark et al. (2002) would agree with the centrality of this goal of the improvement of quality of life. In their study they found that “there was nearly universal agreement that quality of life is the most important moral notion and overall goal in palliative care” (p. 55). “On this basis we might regard it as an absolutely explicit goal of palliative care”, write Clark et al. (2002, p. 55, original italics).

However, like attending to suffering, achieving quality of life comes with its share of difficulties and limitations. “It conceals many problems”, suggest Clark et al. (2002, p. 55). These problems include the difficulty in defining quality of life; the challenge of measuring or evaluating quality of life, and thus whether it has been achieved as a goal; that it is thought not to be a realistic aim for practice; and that there is more often than not debate between how the professionals and the living-dying person defines it. These types of difficulties with this goal are noted both in the literature and reinforced by the HPC professionals’ storied accounts.

5.7.1 What is quality of life?
Firstly, Randall and Downie (2006), in their critique of the philosophy of palliative care, ask the question: “Is there a clear and shared concept of quality of life, and if not, could one be developed?” (p. 26). Clinch, Dudgeon and Schipper (1998) found that there are competing definitions, and that it is especially important to consider, “extensive cultural variation” in its meaning (p. 94). Clark, ten Have and Janssens (2002) report that there is a “growing tendency to say nothing [about what quality of life means] or to allow quality of life to be what a person defines it to be” (p. 55). Randall and Downie’s (2006)
conclusion about this goal was that “there is not a shared conception, either in ordinary or in professional discourse” (p. 34). “Quality of life cannot be defined … is impossible to define … [and] attempts to define it should simply be abandoned”, assert Randall and Downie (2006, p. 29). A highly experienced palliative care specialist, Natasha, would most likely agree. She felt that achieving quality of life was the goal of her work, but

The more that I think about that [achieving quality of life], the more I realise that I don’t know what that’s about. Its rhetoric and almost twenty years on I’m beginning to see. I think what we’re actually trying to do, without using words … it’s so much deeply spiritual. Quality of life doesn’t capture that for me (Natasha).

Similarly, Jackie, another experienced palliateur, was dubious about its meaning

Quality of life [pause] that concept has gotten very ambiguous really, in what we mean by that. It came to us as a useful theory. If you take it in its face value, yes, I do respect that whatever we do we should make people’s life as best as we can (Jackie).

Twycross (2002) sums up the ultimate problematic nature of defining quality of life

Quality … you know what it is, yet you don’t know what it is. But that’s self-contradictory. But some things are better than others, that is, they have more quality. But when you try to say what the quality is, apart from the things that have it, it all goes poof! There’s nothing to talk about” (p. 273).

Thus it is argued that the goal of quality of life has been simply adopted and is now used in an unreflective, unarticulated and undefined way. This means, as Natasha alludes to, it is merely rhetoric. “There has been no commensurate increase in conceptual clarity on this subject”, declare Clark et al. (2002, p. 55).

5.7.2 Measuring quality of life

Although there have been a number of new articles and research projects that attempt to define, evaluate and measure quality of life, there is still difficulty in understanding what quality of life is and how it can be reached as a goal. Randall and Downie (2006) ask the question: “Can quality of life be assessed by measurement?” (p. 26). Clinch et al. (1998) cite this as a problem as well: “too much time and money has been spent on the development of instruments and assessment tools, the use of these in clinical settings and the interpretation or misinterpretation of evidence from these tools” (p. 120). Randall and Downie (2006) extensively review the literature and research and conclusively argue that it is not possible to assess quality of life (p. 26). If quality of
life is unable to be measured, as Randall and Downie (2006) claim, and HPC professionals “are not told how specifically this is going to be done [the achievement of quality of life]” then this is an entirely unhelpful goal of practice (p. 26).

5.7.3 Unrealistic as a goal

The third problem associated with the achievement of quality of life is that it is thought not to be realistic. This point of realism is alluded to by Sandman (2001, cited in Clark et al., 2002) who writes that there is a variation “in their [HPC professionals] degree of ambition about what might be achieved” (p. 55). This dubiousness or realism is articulated by Fiona in her statement about the goal of quality of life

Well, I suppose in theory it’s a good goal [quality of life], but I suppose it doesn’t irk me. I suppose we are optimising quality of life. We want them to have the best quality. But it doesn’t happen, a lot of the time (Fiona).

It would seem that achieving quality of life for some is an unrealistic goal to aim for. The achievement of quality of life for both living-dying people and their family is, for Randall and Downie (2006), a completely unrealistic aim. Furthermore, from my experience, quality of life is so often defined by living-dying people in terms of what is valued in contemporary Australian society: health, independence, employment and physical ability; that is; quality of life is appraised on values of life and self before becoming ill, and the dominant values of society. This is reinforced by Clark et al. (2002) who write

It [quality of life] appears likely to obsolesce as a salient concept. It seems too tied up with a particular social and economic era, too much a part of the machinery of western capitalist ideology, too loaded with overtones of consumption and consumerism (p. 56).

Thus, how can people understand ‘quality’ when it is measured against such overtones? If the profession is going to continue to hold quality of life up as the banner of what hospice palliative care is all about, I would suggest that HPC professionals would need to spend more time in conversations with living-dying people and their families discussing how their view of ‘quality’ can change. However, with the dominant story of dying and death as negative, finding ‘quality’, let alone measuring quality, for many people is extremely difficult.
5.7.4 Choice in quality of life

The final difficulty with this goal, as with the other overarching goals, involves the influence of the value of individual choice. What this translates into is that quality of life must be determined by the living-dying person. When quality of life is viewed as something that is solely defined and decided upon by the dying individual it leaves little room for active guidance by the HPC professionals to aim for. This is further complicated by the often invisible and unarticulated tension between what quality of life means for a HPC professional and what it means for the living-dying person; that is, that even though HPC professionals state that it must be up the living-dying person, they still hold opinions and values to the contrary. This tension between how it is understood by the HPC professionals and the living-dying person is apparent. With the prioritising of individual choice, yet again, the goal of the achievement of quality of life becomes problematic. How then can this be helpful as an overarching goal for the profession? Julie expresses her concern that the profession understands quality of life in a particular way and then ‘puts’ that onto a living-dying person

The aims can be used in a very paternalistic way. You know, quality of life can be put on the person (Julie).

Here, Julie’s concern is that the views and opinions of the HPC professionals, who hold a great deal of power and influence over the living-dying person, will be enforced. Anna holds more optimism in being able to find out what it means to the living-dying person and his or her family and then work towards this. Still there is the emphasis on it being about the person’s choice in what that means

For me it’s [the purpose] quality of life. But that’s not what I perceive or like it to be, but what the person and the family want it to be. If I know this person and I’m open and honest with those people, then we can reach the best quality of life they wish to achieve (Anna).

Peter goes so far as to suggest that terminal sedation, if this is part of the definition of quality of life for the living-dying person, needs to be carried out

The more time I spend here, the more I think it’s about quality of life [as a goal]. And that’s why I think that terminal sedation needs to be an individual choice, because if sedation helps the quality of life, while they are dying, then we need to respect that (Peter).
Finally, Emma is dubious that the living-dying person, who is in the throes of a terminal illness, would be unable to define what quality of life means for them.

We have these quality of life discussions and we talk about living our lives until we die and I think sometimes that’s easy to talk about … but trying to give people and families the opportunity to do that within the confines of their illness is incredibly difficult. It’s around their quality of life issues, so really [pause] and respecting their wishes for whatever they want to do. So it’s not easy, but I think that’s all encompassing for palliative care (Emma).

Therefore, it can be seen that even though these palliateurs acknowledge the achievement of quality of life as the goal of the profession, they each follow on with questions about ‘what does it mean’, ‘can we really achieve it’, ‘its simply up to them’ and, finally, ‘how can they possibly know what it means when they are so sick’.

Given these confusions, complexities and limitations, expressed both by the professionals and in the literature, it can be argued that this is an unhelpful telos for the practice. Randall and Downie (1999; 2006) believe that “ideally it should be discarded” (p. 49). Clark et al. (2002) concur stating “it will be a goal that will continue to lack precision” (p. 56). Twycross (2002) proposes that it is used in a “vague and undisciplined manner” (p. 276). Nord (cited in Clark et al., 2002) simply believes that “the use of the term has gone too far” (p. 56). Ultimately, Randall and Downie (2006) argue that “quality of life as a global concept should not be used as a goal of palliative care, and it follows that attempts to quantify it should be abandoned” (p. 48). The reason for this is that what can contribute to quality of life for living-dying people and their families largely lies outside of the realm of HPC professionals (Randall & Downie, 2006). Since there is no shared and coherent concept of quality of life, attempts to measure it are “bound to fail”, and “it should not be used as a goal for palliative care” (Randall & Downie, 2006, p. 48).
5.8 Aiming for pain management and symptom control: The external influence of biomedicine

A further articulated goal for the practice is that of pain management and symptom control. Given the confusions, limitations and complexities with the goals explored above, palliateurs aim for what they believe is achievable and within their scope. This goal of providing adequate pain management and symptom control goes hand in hand with the medicalisation of the practice and the influence of biomedicine. This goal may very well be adopted as the most realistic and clear one for the practice. This is reinforced by Breitbart (2006), the Editor-in-Chief of Palliative and Supportive Care, in his article about the goal of palliative care. For this article he asked HPC professionals what their goal was. The response was “immediate, simple, clear, and emphatic”, stated Breitbart (p. 2). Overwhelmingly, the professionals understood their main goal and obligation as “assuring that the patients under their care received adequate pain and symptom control. Nothing more, nothing less” (p. 2). This palliative care physician then asked the HPC professionals about existential concerns; helping with life completion; achieving a sense of peace, and they again responded swiftly with: “That’s not our job!” (p. 2). Breitbart was concerned about this change of goals and hoped that one day we move beyond this and have a “focus [that would] …extend beyond symptom control” (p. 2).

Similarly, the HPC professionals who took part in this inquiry mentioned this as the goal of their care:

The goal of palliative care … very often it’s seen purely as symptom management … and therefore if the patient doesn’t have symptoms, they don’t necessarily need specialist palliative care (Stacy)

With the goal of palliative care … we should start by changing its name for starters … symptoms managers, or extended care or symptomology … and I don’t mean to say that to minimise or hide the dying part of it. But the general public has never heard the word palliative. So trying to get away from the terminal care aspect of it … try and blend it with other normal clinical practice like … we are the symptom managers while they have treatment … so that’s why we really have to focus on this symptom management … it would demystify what we do (Martha)

I think it’s all become about good symptom control [laughing]. She says without hesitation. I’m afraid that’s it. There will be other things that we like to do, but those are the margins (Jackie)
It’s actually about helping people who are dying … so that encompasses, you know, sort of symptom management, relief of symptoms (Melanie).

Notice how Martha even wants to change the name of the practice to ‘symptom managers’. This is certainly not surprising given the explorations of the changes to the philosophy of (total) care and the external and internal influence of biomedicine. Couple this with the changing nature of the hospice palliative care team, being predominantly one of medical professionals (doctors and nurses). As Breitbart (2006) alludes to in his article, this goal of assessing and treating the physical pain and other symptoms of living-dying people is “clear, well-established, [and] evidence-based” (p. 2); in other words palliateurs have some level of competence and mastery over this as a goal. However, HPC professionals do not have the same level of confidence when it comes to assisting with suffering, quality of life, existential or spiritual concerns and the like. This goal of alleviating physical pain and other symptoms is aligned with a biomedical framework, however, and does not take into consideration the account of pain as articulated by Saunders or an understanding of suffering as outlined by Cassell. Thus, it can be seen that having this as a goal of HPC is a further indication of the creeping medicalisation of the profession and the loss of the original telos.

5.9 Dying my own way: The external influence of individualism and choice

What can be seen to be even more influential is the external, societal valuing of individualism and choice. It is this, I would argue, that has dismantled many of the HPC stated goals of practice, or the ability to define the ‘good’ that HPC serves. As mentioned above, the goal of a good death now has a variety of meanings, but most often nowadays it means: “the death an individual would choose if it was possible to choose” (Sahlberg-Blom et al., 2000, p. 296). Indeed, the postmodern good death (and dying) simply means dying ‘my own way’ (McNamara, 2001, p. 43). This pluralism of meanings in the goals of the good death, the relief of suffering and achieving quality of life have all been superseded in some ways by the valuing of individualism and choice.
McNamara (2004) reinforces this when she states that the practice of palliative care now follows the “individualistic ethic of choice” (p. 929). Indeed, it could be argued that this now is the goal of HPC professionals. Amy encapsulates this individualistic and choice aim when she says: “No set goal. Just be guided by them”. This articulation of the telos indicates the difficulty in having an overarching goal for practice, and the prioritising of being guided by the living-dying person. In effect what is being said by the professional is “no, I won’t do anything, say anything, or contribute anything. I will just be guided by the person, and then they will make up their own minds, and make their own choices, in how they die”. A key HPC professional in McNamara’s (2004) study said “Look, it’s really up to the patients and all we can do is accept that it may not be a good death, just a good enough one” (p. 8). Unfortunately, this viewpoint and valuing of individual choice does not take into account the reality that it is often the HPC professionals “who are called upon to facilitate the viable choices” which are available (McNamara, 2001, p. 43).

Callahan (2002) discusses the role of individualism in medicine within an aging population. Callahan (2002) explains that

> Individualism, and the classical political liberalism … on which it is based, rests upon the right of individuals to seek that which in their private judgment will bring them happiness. The only limit upon that right is that they may not do harm to others in seeking their personal self-fulfillment. The search for the good of human life, for its purposes and ends and meaning (if any), is left to the individual (Callahan, 2002, p. 344).

This valuing of individualism necessarily includes the promotion of pluralism and diversity which is also increasingly valued in modern societies. “Medicine should serve that diversity, which does not in any case admit of a single right answer about what people ought to want” (Callahan, 2002, p. 344). How difficult it is to be a professional in a social practice such as HPC, which once had a shared understanding of the ‘good’ or a clear telos, that now is either aiming for, or stating that, it is up to the living-dying person to choose. Randall and Downie (1999) note this as well in their criticisms of the problems of supremacy of patient autonomy. These authors note that autonomy (and individual choice) could come to be seen as the goal of health care, and so share my concern that this is indeed happening in hospice palliative care as well. In addition,
Callahan (2002) notes that individualism then equates to a “lack of direction” for both health care professionals and older people (p. 344), which is the very thing that is happening with the confluence of individualism, choice and the overarching goals of HPC, as noted above.

5.9.1 The limitations of individualism

There are problems with this so called unfettered individualism and choice. Firstly, medicine, and indeed hospice palliative care, is not able to provide every person what he or she may desire (Callahan, 2002). Furthermore, prioritising individual choice and autonomy would translate into whatever the living-dying person decides or chooses is necessarily right, such that professionals tend to think that doing what the patient wants is necessarily a benefit to the patient, and conversely that not doing what the patient requests is necessarily a harm to the patient … harm and benefit become totally subjective concepts (Randall & Downie, 1999, p. 282).

This, of course, assumes one knows and can articulate what one desires. Fundamentally, as Callahan (2002) poignantly asserts “the price we pay for our individualism in an aging [and dying] society is that our culture provides neither the elderly nor anyone else with a clear picture of what they should be able to hope for from society in their old age or of the way they might make social sense of their illnesses and eventual death” (p. 345). Hence, there is harm in the “implicit relativism of the diversity itself” (Callahan, 2002, p. 345). What can be understood by this is that individualism and choice promotes the upholding of diversity and pluralism, but deemphasises any common and shared understandings – a shared story - about how to die.

Further complexities with this question of individualism is that the living-dying person may state it to be their individual choice to die fighting their disease, but that this is actually a dominant story in Western societies about how to die, or the ‘good’ or right way to die. What this means is that in reality living-dying people are in fact choosing from a shared, societal story, but naming it as ‘their own way’. This important point ties into ontology; how we understand personhood and the argued embeddedness of people in social interconnections and how they interpret the good in living and dying.
McNamara (2001) argues that individual choice is rarely achieved because the discourses that promote individualism and patient choice are masked by certain aspects of choice. Put simply, the way that professionals respond to living-dying people are drawn from techniques and established practices. These techniques “are formulated within the context of biomedical, organisational and moral components” (McNamara, 2001, p. 99). In addition, HPC professionals respond to living-dying people, states McNamara (2001), according to their own personal values. This point is reinforced in chapter six. Hence, saying “I will simply be guided by them” is not possible. Individual choice about how to die will always be informed around notions of what society generally views as ‘a good death’ and the hospice palliative care context. Kellehear (1990) reinforces this understanding when he asserts:

Whatever the conscious reasons might be for the choices that are made (or are not made) and whatever the stated reasons for the variety of dying styles that will emerge, they will do so on the basis of value – in fact valued - cultural positions and attitudes (p. 58).

What this means is that although people believe or state that they are making autonomous choices when it comes to how to die, in actuality they are choosing from a particular array of choices that are socially constructed and socially sanctioned. For example, at the present time one of the dominant scripts for how to die is couched in battle metaphors. Therefore, many people may state they are making an autonomous choice in how they die, exemplified by battling, waging war against a disease, fighting and so forth, yet this is a socially sanctioned and commonly reinforced ‘way of dying’. Anyone who decides to not ‘battle’, or in other words, not continue to treat their disease, is often condemned. Certainly, as human beings we are still able to exercise our personal power and go beyond the boundaries of what society believes is the right and good way to die. Hunt (cited in McNamara, 2001) further reinforces this point in his reflections on the ‘rhetoric-reality gap’ concerning patient autonomy in HPC practice. Hunt argues that the individual is accepted as an autonomous actor only within the confines of his or her specific culture and time and that there is a gap between what is said and what can be done (cited in McNamara, 2001, p. 99).
5.9.2 Individual responsibility

McNamara (2001) cites several concerns with individualism and choice in HPC which has become “the moral and ethical imperative” (p. 94). This author outlines her concerns about this, which include that it “creates an emotion and moral weight of uncertainty” (p. 92). This often equates to individual responsibility, pressure and authority to control the events of living and dying. There is now the expectation of dying people to live well until they die and make their own choices in the process (McNamara, 2004). Is this something they wish for? There is certainly a “shifting of the locus of responsibility from the social collective to the individual who is dying” (McNamara, 2004, p. 934). Randall and Downie (1999) agree with this concern when they write that “professionals lose their sense of moral responsibility … [this] has effectively been passed to the patient” (p. 282). Indeed, I would argue that HPC has swung too far in opposition and reaction to paternalism. Paternalism equates to responsibility and control being with the professional and individualism, or autonomy, equates to a heftier responsibility with the living-dying person. Are not each equally problematic in the practice of HPC? David, a hospice home care doctor, asks this question

The issue of patient autonomy is an important one, but often the patient is working on a different line of thinking. They want their pain taken away, they don’t want to think about dying and all the while we are pumping team resources into trying to give them some control. Do they in fact want it? (cited in McNamara, 2004, p. 937).

Ultimately, McNamara (2001) sums up these concerns when she writes

While in principle the idea that everyone can construct their own scripts for dying holds appeal for members of a highly individualistic society, the rhetoric of a good enough death can mask less positive aspects of these scripts. Closer examination of the concept reveals that acceptance of the good enough ethic can shift the locus of responsibility from the social collective (and the professional carers) to the individual who is dying. If the death of the person who is terminally ill does not go well, the good enough ethic allows health professionals to rationalize the failures in terms of the dying person’s decisions rather than in terms of failures on the part of the organisation that manages the person’s death.

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Thinking about the dying process in this manner can minimise the necessity of reflection about the quality and the meaning of care (p. 51/52).

What McNamara is explaining is that there is now a move to individual responsibility lying with the living-dying person and that if something goes wrong it is easy to blame the person, rather than looking beyond to the profession, medicine, or society. It could be suggested that this is why continuing reflection and reevaluation of the goals of this practice have been largely unarticulated.

These above concerns about individual choice becoming the goal of HPC practice, the lack of direction (and goals) that comes out of a valuing of individualism, that professionals are the ones providing the array of choices, and that people are socially embedded in relationships, culture and time, equate to many limitations on individualism. Callahan (2002) argues that “individualism should, in sum, give way to a community-based and affirmed notion of the value of the aged in society and, with that, an acceptance of limits to health care for the aged … That requires a thick, not a thin, theory of the good” (p. 345). I would suggest that what is needed is recognition and valuing of individualism and a shared view of the good in dying. This requires HPC, as a profession, to embrace both the personal and the relational (or community) in the goals and practice. This would also include the important acknowledgment that it cannot be just ‘dying my own way’ because “terminally ill people rely on the care of health professionals and on the services provided within the health care system” (McNamara, 2001, p. 52). In addition, the growing frailty and dependence that is an inevitable part of the living-dying process, means that some people “must surrender part of their self-determination to others” (Sahlberg et al., 2000, p. 296) and that this is not a negative, but rather reinforces the value of community and relationships.
5.10 Summary of overarching goals
In summary, it has been argued that the original hospice goals of aiming for comfort and achieving the good death have largely been discarded. Furthermore, the two other well known goals of the relief of suffering and achieving quality of life have each been critically explored in terms of their limitations, confusions and complexities. Although quality of life was stated as a goal by several of the professionals interviewed they, in turn, also articulated their concerns and reservations about this goal. In addition, each of these goals has been externally influenced by biomedicine and society’s valuing of individualism and choice. Hence, new contemporary articulations of the telos for the practice include providing pain management and symptom control and ‘dying my own way’ (individual choice in dying). However, the first of these goals misses the original point of HPC which was to provide something distinctive from a purely medical approach to caring for the dying and does not sit comfortably with Saunter’s understanding of total pain and the importance of the philosophy of (total) care. The later goal of ‘dying my own way’ places the responsibility firmly on the shoulders of the living-dying person without acknowledging the dialogic nature of personhood and that living-dying people will in effect ‘choose’ what is available from societal scripts about the good in dying or how to die. Crucially, this goal, which centers on individualism and choice, dismisses the fact that there are always two people involved in HPC practice: the living-dying person and the professional care-giver embedded in particular contexts with their own complex dynamics. In summary, the original goals have been discarded; the dominant goals hold numerous complexities and limitations and have been largely influenced by either a plurality of meanings, biomedicine or individual choice. This in turn has prompted new articulations of the telos of HPC practice which favours a medical approach and emphasises the singular and dominant role of the living-dying person. This new choice oriented goal is certainly a central component of HPC practice as person-centered care is crucial to the practice. However, this extreme version of ‘it’s simply up to them’ as a goal does not take into account the dialogic nature of the caring relationship. Clearly, the ideal of a shared, commonly understood and helpful purpose for the practice is missing.
5.11 Telos as fractured and fragmented: Wandering in the wilderness

Indeed, the purpose of the practice of HPC is, arguably, fragmented. There does not seem to be a shared and common understanding of the goal, goods or aim of the practice. This insight harks back to the question originally posited by Clark et al. (2002) where they asked: Is the existence of a cohesive metanarrative essential to the future well-being of palliative care? (p. 53). Or, rather, is it sufficient that HPC has a diversity of goals? Can HPC, as a profession, survive without a shared appreciation of the purpose of its work? If the teleological features of the practice provide a justification for the ways of seeing and ways of acting, direction for the practice, and offer the profession a unique identity, what then happens to these elements if the telos is unarticulated, not shared, eroded or fragmented? Several comments from the HPC professionals go some way to express their ideas of fragmentation; or as one professional expresses it:

“wandering in the wilderness” (Ken)

The palliative care community in Brisbane is still very fragmented. There needs to be some sort of way to get them all working towards one common goal. But it’s hard (Emma)

In Brisbane, it’s too fractured. Everyone’s got their own agenda, everyone’s got their own, you know, “we’re special, we do it differently and we’re wonderful”. And they’re all just too busy to think about these things (Zoe)

I think that the palliative care profession is wandering in the wilderness at the moment. That it is being influenced by external forces. I think the focus of palliative care is still highly clinical, to its detriment. It is heavily weighted on service provision or the aim is to provide clinical services (Ken)

I think that the profession is struggling to provide a cohesive response to the palliative patient. The ideals are there [pause] but the constraints of working within a monolithic public health system that is overly endowed with administrators and lacking real insight into how to do it (Lisa)

The various models of palliative care have confused it [the purpose] (Stacy).

These comments express the concern of the ‘wandering in the wilderness’ metaphor when it comes to the purpose of the profession. Some even are skeptical that a shared goal can be found. This research inquiry, however, did find a shared goal. Although it was expressed as a hope, the response to the question of ‘what do you hope to achieve in your practice’ illuminated a possible shared and common purpose to HPC practice.
5.12 The centrality of relationship as purpose

What cannot be dismissed as a significant insight in this critical inquiry of the ethical dimension of hospice palliative care is the overwhelming response to the question of what did the palliateurs hope for in their practice; what did they wish to achieve. Nearly every HPC professional answered in a similar way to this question: the purpose was to create and maintain a relationship whereby they could assist the person on their path towards death. Interestingly, this fits neatly with an account of ethics as set out in the earlier chapters of this thesis. To reiterate this: engaged ethics is about “creating and sustaining relationships which mutually recognise the needs, interests and aspirations of all participants as ‘ends in themselves’” (Isaacs & Massey, 1994, p. 2). These storied accounts from the HPC professionals powerfully describe the purpose of their practice:

The purpose of palliative care to me is to assist the dying person and their families to go through the dying process in a way that they want to. So I guess it’s about propping them up. We can’t stop them dying. We’re not there to stop them dying. But it is to prop them up. It’s just to help them through it. I guess the literal meaning to palliate is to ease; to make things easier. I see that as the major focus. That is, my goal is to make things easier for the person and their family and I do this through my relationship with them (Fiona)

It’s actually about helping people who are dying live that very little time left. I guess just helping them, if that’s possible. So that’s a very broad thing. It’s normally just tiny little things. To help them feel a bit better (Melanie)

The purpose of palliative care for me is to assist someone to have a death (Anna)

The goal of palliative care to me is to provide a safe place and that takes in all kinds of things … not wanting to see them suffer and not just physical pain, but emotional and spiritual pain as well. A sense in the absolute sanctity of human life and not wanting to control what’s happening, but merely to be a vehicle to allow it to happen (Natasha)

I think it’s actually much more than just the end point. It’s when ever we meet them, wherever they might be. It’s an ongoing thing … whenever we come into contact with each other (Nina)

I’m hoping to achieve connection. You go in there, you try and be there as a person, as an equal. You show yourself to be vulnerable, you show that you don’t think you know everything, you show them that you value their opinions, that they’re important. All you need to be is someone who they can talk to about what’s happening, someone they can trust (Julie)

I work really hard at making sure that I’m still thinking that this is the first person … because I’ve been doing this for a while now. That the people I meet feel as if they’re the only people having this experience. So I work particularly hard to go there as a
personal friend and I’m very much guided by their situation. I’m really guided by the whole situation and being responsive to this (Amy)

I think the goal of practice is very situational. Whatever they want to have happen … would happen hopefully. The main thing is that I understood enough of what the person in my care needed or wanted and I do this by forming a relationship with them (Jackie)

I hope to establish a link; a therapeutic relationship. Then look at what their needs are … what their wants are (Peter)

I want to accomplish a relationship, that’s all. Then further goals are to provide that holistic symptom control. I like to assist them in improving the quality of the symptoms in all those four rooms [physical, social, emotional, spiritual]. What’s most important to me is the relationship. That they are being well supported and that they know who to call on or who to turn to (Jim)

I’m hoping most of all to build a relationship with this person that will build meaning and purpose into their life and to help their family through a very difficult time. My goal is “what do they want”? (Tony)

I wish to be able to connect with that person in a deep way so that I can get a sense of who they are and where they’re at and how I can support them to facilitate their dying (Gavin)

What I try to achieve is to develop some sort of relationship with the patient, because a lot of those therapeutic interventions come from that relationship. And then I simply work towards the goals that they saw were important to them (Emma)

Well, its trust really. Just to see who I am and let me get a sense of who you are. But just something to build upon that means we can work together. So that they feel like they are comfortable with me. So I think I am mostly trying to build that foundation of honesty between us. If they don’t feel comfortable articulating what their needs are to you, then you’ve failed from the very beginning. It’s human, very human … a human relationship. That’s what has always worked for me (Zoe)

I think responsiveness would be one of the things that I’d want to achieve. You see, I don’t need to arrive with a package of products called palliative care. I need to be responsive and I need to be able to offer that flexibility so that, you know, what one family needs on a particular day maybe different to what they needed yesterday, and will need tomorrow. I can only do this by developing a relationship with them (Ken)

My goal is to connect with the person and the family. Unless there is that sense of connection it’s difficult to get them to trust me, for me to make some sort of difference. So hopefully we are able to make a connection very quickly and then be able to make some sort of difference to their dying (Michael)

What I’m trying to do is perhaps trying to achieve the best outcome, however that’s done. I still think it’s a facilitating type of thing; helping facilitate what’s the best outcome for that person (Naomi)

I’m hoping as much as possible that they’ll allow me to work with them (Kieran)
I hope for a level of relationship, first off and to gain an understanding of what is happening for them. I feel like I am given great permission to go into very deep and intimate places, quite quickly. I hope for a real presence; really staying as witness. And witnessing for me is marking what is valuable, in the person, and in their experience. Every human life is beautifully reverent. So just noticing, witnessing, being observant (Gloria)

No one knows how to die. No one’s given a book about how to die. So everyone, it doesn’t matter who they are, needs a fellow human being to hold them in some way. And I suppose holding is the concept … holding in the many meanings of that word. And you try and hold that person as they are dying (Stacy)

I think it simply comes down to being responsive to people and helping them do whatever they need to do (Elizabeth)

To accompany people on what is a deeply spiritual journey (Natasha).

There can be little doubt that what HPC professionals aim for is to develop a special type of relationship that will help living-dying people towards death. To further emphasise these hopes for what the professionals wish to aim for I would like to reiterate the various expressions of this relational purpose

- Propping them up
- Making things easier
- Helping them
- Assisting them
- Providing a safe place
- To be a vehicle to allow it to happen
- Achieving a connection
- Establishing a link
- Being a personal friend
- Being responsive
- Guided by them
- Forming a relationship
- Working together
- Holding them
- Noticing; being observant
- Staying as witness
- A human relationship
- Helping facilitate
- To accompany
- Work with them
- Be there as a person

I notice that these expressions are congruent with Saunders original idea of ‘watch with me’. Saunders (2003) wrote “I think the one word ‘watch’ says many things on many different levels … It demands very close attention to his (sic) distress” (p. 21).
Watching, and the types of expressions above, all point towards a new articulation of the purpose of HPC practice: the creation and maintenance of a unique relationship to facilitate a person’s journey towards death.

5.12.1 Relationship literature
Interestingly, it is not a subject that is often discussed in the HPC literature, but one which is fundamental to the practice. Randall and Downie (1999) include a chapter entitled *The patient-carer relationship* in their ethics text. Randall and Downie (1999) write that “all palliative care is ultimately delivered through the common pathway of the patient-carer relationship. Therefore, the success of such care is dependent on the nature of that relationship” (p. 30). The *nature* of that relationship is then considered in this chapter, which focuses on the inequalities of power between the ‘patient’ and the ‘carer’. These considerations of power in hospice palliative care relationships are addressed in chapter six. More recently Randall and Downie (2006), in their critique of the philosophy of palliative care, have suggested that HPC professionals should be “friendly professionals” (p. 90), which requires “moral and emotional maturity, and the expression of this professional concern and friendship …” (p. 90). In alluding to the relationship that is typified by this ‘friendly professional’ Randall and Downie write that “Professionals can use their common humanity to comfort the patient, through companionship, in combination with giving advice based on the relevant professional knowledge of similar situations” (p. 176). The term ‘friendly professional’ comes from Brewin (cited in Randall & Downie, 2006), a medical doctor who writes

The ability of one person to lend strength to another is a mystery that nobody entirely understands. But, for my money, in medical situations – especially advanced cancer – just being natural and friendly has a lot to do with it. Professional friendship is not quite the same as ordinary friendship, but much that applies still holds true. A friend is warm and welcoming at each meeting. A friend pays small compliments. A friend has at least some idea of how the patient feels; some idea of what she has been going through; understands how her moods may vary. A friend listens; knows the value of a little praise; asks how she can help. A friend is just as ready to talk seriously as to joke or gossip. A really supportive friend doesn’t go over the top emotionally, but is always concerned; doesn’t stay too long; knows when to be silent; doesn’t ask too many questions (p. 177).
What must be considered, with this quote above, is that this is one person’s definition of friendship. In a confusing manner, however, Randall and Downie (2006) then go on to conclude this section of their critique with the statement that

a close personal relationship between patient and professional is potentially harmful to both, unachievable and not sustainable. It is morally undesirable. The requirement for the development of a close personal relationship between patient and professional should not be a part of the philosophy of palliative care, nor should the development of the client/counsellor relationship be advocated. It should be replaced by the idea of alleviating those problems within the context of the traditional professional/patient relationship, using ordinary human interaction, sensitive explanations and advice based on professional knowledge and experience, and friendly professional interest (p. 179).

It seems as though they are explaining a type of relationship that is more towards the professional, but with a dash of friendliness. A close, personal relationship is not recommended by Randall and Downie.

On the contrary, Olthuis (2007) believes fundamentally that “the relationship between patient and professional forms the basis of whole person care” and that any such aim to assist with the psychosocial and spiritual dimensions of a person’s journey towards death “requires a personal involvement of the professional” (p. 13). In his ethical explorations, Olthuis (2007) reflects on connection and contact: the two elements required in this close relationship (p. 75). He writes

In the relational mode connection, the nurse is listening, using connective and caring touch, and is present as ‘being with’ a patient who wants a connection with the nurse. The characterization that can be applied here is that of invitation or gift. The patients invite the nurse to enter into their world and to share their narratives. The nurse gives the caring or connective touch, silence and attention. In the contact mode the nurse is ‘listening’, using task-oriented touch, and is present as ‘being there’ for a patient who wants contact (Olthuis, 2007, p. 75, original italics).

This interpersonal relationship is one of “solicitude: concern for the other” (Olthuis, 2007, p. 77). Of solicitude, Olthuis (2007) explains, this “actualizes the dialectic of giving and receiving as a fundamental aspect of the ethical relationship between the self and the other” (p. 77). The conclusion to Olthuis’ (2007) reflections are that “such an interaction is essential when a good (ethical) relationship – centered on caring conversations in the sense of connection – is considered the corner stone of palliative
care” (p. 82) and that “good palliative care requires the personal involvement of the practitioner because the relationship between caregiver and care receiver is crucial” (p. 149). The term used by Olthuis (2007) to describe this relationship is one of covenant: “a durable bond based on trust” (p. 146). These reflections on relationship included in Olthuis’ study, however, are set in the assumption that the aim of HPC is the relief of suffering and the achievement of quality of life, rather than the relationship being the end in and of itself.

Schotsmans (2002) is another European author who has emphasised the relational in hospice palliative care. This author describes the practice of hospice palliative care as “a fully inter-human event” (Schotsmans, 2002, p. 126). With the growing emphasis on the principle of autonomy, and thereby the privileging of individualism and choice, Schotsmans (2002) argues that “there is very little space for the relational encounter between the patient, the caregiver and other human beings surrounding them … [and that] the relational approach, unfortunately, is almost totally absent” (p. 127). Further, Schotsmans (2002) asserts that focusing on individualism “can prevent us from seeing the wonder of being human in its multidimensionality” (p. 127). Or, in Buber’s words,

One can never be a human being on one’s own. As humans, we essentially stand in an open relationship, involved with the reality in which we live, with other humans to whom we owe our existence and who continue to surround us … If humans wish to be fully themselves, they stand in need of encounter with others and of being encountered by others (cited in Schotsmans, 2002, p. 128).

Ultimately, Schotsmans (2002) presents a relational approach to hospice palliative care, one that is an inter-human process, and one that is “a significant guide in developing an ethical foundation to the experience of palliative care as a relational challenge” (p. 138). This articulation of the relational foundation of hospice palliative care is further included in chapter six. Although Schotsmans reinforces this relational structure of the practice of end of life care he, too, does not articulate the creation and maintenance of relationship as a guiding purpose for the profession.
Mok and Chiu (2004) conducted a study into the nurse-patient relationship in palliative care. She writes that “during the process of dying, time is limited and the patient is vulnerable, making the patient-nurse relationship in palliative settings an interesting area for exploration” (Mok & Chiu, 2004, p. 476). May (cited in Mok & Chiu, 2004) describes this relationship as ‘pastoral’ and one which is “imbued with a moral value, which is an investment that undercuts its status as paid labour” (p. 476). Spross (cited in Mok & Chiu, 2004) describes the relationship as “one-sided intimacy” and that this level of intimacy makes it more like friendship (p. 476). In Mok and Chius’ (2004) study she found that

Nurse-patient relationships have evolved from a professional relationship that emphasizes their functions to a focus on mutual understanding, and that there is feeling and affection in these relationships. The former type of relationship involves fulfilling obligatory functions and expectations, while the latter is one of trust and connectedness. A trusting and connected relationship is one that involves concern and dedication, and has a high emotional component. The relationship capacities found in this study are consistent with those described in the nursing literature, which show that relating with other human beings is a caring process that involves values, intent, knowledge, commitment and actions (p. 481).

Mok and Chiu (2004) hopes that her study helps to show that “the formation of trusting relationships are necessary in providing optimum palliative care … and the complexity of the interactional processes that comprise these nurse-patient relationships” (p. 482). Thus, this is another author who understands relationship to be pivotal in the provision of HPC, but not as a goal for the profession.

5.12.2 A unique relationship

I was curious to understand more from the HPC professionals about the nature of this type of unique relationship. Therefore, when the HPC professionals expressed this goal for their practice, I asked them if they could explain what constituted this type of relationship. The themes that emerged from their articulations include: balancing interventions; ontological intimacy and trust; being both professional and personal; acceptance and non-judgment; and honest communication.
• Balancing interventions
I’m asked to give advice, but if they don’t want it that has to be respected (Nina)

I think we can make suggestions some times, but otherwise we honour whatever they want to do (Natasha)

A relationship would be a supporting one, but not an intrusive one. One that is required, but not dominating or overtly guiding. So that it still allows choice, but not demanding that this be done this way (Lisa).

• Ontological intimacy and trust

Building trust is the first thing. You can’t do any of this without trust. You create trust by being open and honest (Martha)

In palliative care you have to be willing to be involved … because it’s a very intimate time and very private time and being invited into that is very precious. You know, you can’t help but get involved (Frieda)

Obviously there is no way palliative care can function, I think, successfully unless we develop a close relationship. It’s different in palliative care … it is very open to the idea of forming very human relationships. I think other specialty areas don’t feel at ease with that as we do. We don’t mind if we shed a tear with our patient. We don’t mind if we’re suffering along with our patients and families. So I think we work the emotions with our patients very closely. It’s a much more intimate relationship. I think the empathy that we show will build the type of relationship that is very close. So trust, relationship, intimacy, is a given (Jim)

We are deeply involved, intimately with people (Lisa).

• Being both professional and personal

It’s still a professional relationship … but a friendship too … so that they can feel comfortable in talking about some difficult issues with you. I guess that sort of relationship where they feel comfortable in feeling that they can discuss stuff with you, that they may not be able to discuss with anyone else. When I say professional relationship this means that the person can identify that I have some skills too, that can assist them. Often it does end up as a friendship because that relationship may be ongoing with the family after the death of the patient. So, a professional relationship, but one that goes a little bit further (Emma)

I think all social roles and barriers are cut down here. That’s what helps people to be or deal with their own human mortality. And helps them realise that they will get through it. You get to know people straight away here (Kieran)

It’s [relationship] a whole package I think. It’s important that that person has confidence in me as someone who knows what they are doing … who has the knowledge. And trust is really important in this. I think this all happens on a professional level, as well as on a personal level. It’s about being open, honest, and respectful and an understanding of where they’re at (Melanie).
• Acceptance and non-judgment

What’s important in the relationship is of accepting the different belief systems that you are presented with and working hard not to be judgmental. You know, trying to accept the person and the situation the way that it is (Amy)

I use the basic humanistic approach of valuing people. You know those basic Christian philosophies of doing good. I try to put myself in their shoes, and try to be non critical, non judgmental and accepting (Martha)

I try to be able to interact in a non-judgmental way with people and value the things in people that are good about them. You put that judgmental-ness aside, and you are just there as yourself, for them, and you respect them and value them for who they are (Julie)

I’m more conscious of listening more and not being as judgmental (Frieda)

I try to look at situations with curiosity. It’s not about judging where someone else is coming from, but just respecting where they are (Kieran).

• Honest and open communication

You’ve got to be able to have honest communication in these relationships (Stacy)

I think honesty is really important in that honesty with ourselves as to whether we are feeling uncomfortable with what’s happening … and honesty with the people we are caring for, in that they are asking a question they want to know and we need to answer it as truthfully as we can … be honest to say I don’t know, or I can find out the answer maybe (Amy)

That we don’t hide things from patients … and I think that’s one of the most important things (being honest) we can do for people (Jennifer)

What I’m trying to achieve is having a foundation of honesty. Establish that foundation with the person. Well you can’t meet people’s needs if you don’t know what they are … and if they don’t feel comfortable articulating what that is to you, then you’ve failed from the beginning (Zoe).

Each of these elements of balancing interventions, ontological intimacy and trust, being both personal and professional, accepting and not judging, and communicating in an open and honest way, point to a particular type of relationship in hospice palliative care practice. Stacy, an experienced palliative care specialist, sums up the unique end of life caring relationship that typified her practice

Through conversation with the patient, they then know that I really care about where they’re coming from and then I can find out more about them. That’s how the relationship develops. So it’s about trust, honesty, open communication, their faith in me, availability, and that we respect other people’s relationships. It’s not just about a professional relationship. It’s trusting and caring and very human. There is also a lack
of physical boundaries sometimes. We do put our arms around people, we do kiss them, we do cuddle them, and we do hold them, when they are distressed. So it’s very human, whereas you probably wouldn’t get that from your oncologist. To me these relationships in palliative care … what we experience, watching and dealing with the whole thing, and supporting them … these relationships are very, very unique. And often what we learn from those relationships we can translate into new relationships that we have with people, and they help us. They form the basis and so it continues … layer upon layer of relationships. It is this relationship that informs how we look after people at the end of life (Stacy)

Let me reiterate Stacy’s words: relationships “forms the basis” and “informs how we look after people”. This sounds like an ultimate ‘good’ and a worthy purpose for the practice of HPC. For, as McNamara (2001) explains, “by focusing on social relationships, then, we can acknowledge the broader context and the complexity of the interactions that happen” in hospice palliative care practice (p. 91).

5.13 Towards a new telos
Given the above insights as articulated by HPC professionals, including insights gained from this critical inquiry, I propose a new articulation of the purpose of hospice palliative care

The purpose of hospice palliative care is to create and maintain unique relationships based on honesty, trust, professional skill, and ontological intimacy with which to facilitate a person’s journey towards death. This relationship between professional caregiver and living-dying person (and family) can focus upon considerations of the quality of living and dying, the meanings of suffering, assistance with comfort needs, and provision of information and skills as required. This responsive relationship is based on the fundamental beliefs and values of the philosophy of (total) care and an acknowledgement of the interdependent, vulnerable and fragile nature of the human condition.

In addition to this articulation I would like to draw upon Dekkers’ (2001) suggestion of utilising the power and flexibility of metaphor to assist with a helpful purpose for the practice. Dekkers (2001) claims that “the goal of palliative care can be metaphorically described as ‘the patient’s home coming’” (p. 119). At each new part of this thesis I have included the six differing interpretations of this ‘coming home’ metaphor as outlined by Dekkers36. These are

36 Please note that Dekkers proposed five differing meanings and I have included one more interpretation, that of total care, from Kellehear (2000c).
Dekkers (2001) explains that this metaphorical goal is “both more concrete and specific enough to cover the whole range of palliative care, palliative medicine and palliative treatment, whether the care is provided by professionals or lay-persons” (p. 124). This goal of helping them come home also “represents central human values and refers rather to the moral than to the medical-technical or care aspects of health care” (p. 122).

Finally, Dekkers (2001) refers to the assistance that this goal provides in developing a new “ars moriendi” (p. 123), or an art of dying, that is currently being neglected in the new forms of contemporary palliative care and palliative medicine.

By incorporating Dekkers’ (2001) metaphorical goal, and the storied accounts from the HPC professionals in this study, I have formulated a concise articulation of the purpose of HPC practice

The purpose of hospice palliative care is the creation and maintenance of unique relationships between professional caregiver and living-dying person (and family) with the aim of accompanying them home.

This purpose has the three ingredients of coming home (to understand metaphorically, not literally), the creation and maintenance of unique relationships and the concept of accompanying. The notion of accompanying was articulated by Natasha when she said that the purpose of her work was “to accompany people on what is a deeply spiritual journey”. The concept of accompanying, I believe, best captures the types of descriptors from the professionals (as listed on page 210) which included such intentions as creating a safe place, holding, witnessing, propping them up and so forth. In addition, the notion of accompanying signifies a journey towards home (death) with which one travels and that the palliateur is someone who travels beside and with the living-dying person. The literal meaning of accompany is “to add or conjoin; to unite oneself with; to keep company with; to combine; to convey, escort or attend to” (OED, 2007). This is what the purpose of end of life care is: to unite oneself with another, to journey with them, to
be a companion and attend to their needs, as the living-dying person moves towards home.

5.14 Chapter summary
With this exploration of the teleological features of hospice palliative care complete, several insights have been located. Firstly, the traditional goals of aiming for comfort and achieving the good death are now mainly discarded. Secondly, the overarching goals, which dominate the HPC literature, of relieving suffering and achieving best quality of life are diversely understood, thought of as not achievable, and influenced by biomedicine and the valuing of individualism and choice. Arguably, hospice palliative care, as a profession and in its literature, is wandering in the wilderness in terms of its stated and practiced goals of care. The telos dimension of the profession is fragmented, fractured and confused. However, there was an overwhelming response to the question of what was hoped to be achieved by the professionals, and this was a relationship. This goal of relationship can more readily incorporate the diverse experiences and meanings that both the living-dying person and the professional caregiver may hold. Thus, we have moved towards a new articulation of the purpose of the practice that includes this unique type of relationship, the concept of accompanying, and the metaphor of coming home.

I am proposing that the new telos for the profession of hospice palliative care be the creation and maintenance of a unique relationship between professional caregiver and living-dying person (and family) with the aim of accompanying them home. In addition, these unique relationships must be based on honesty, trust, professional skill, and human intimacy. This accompanying relationship can focus upon considerations of the quality of living and dying, the meaning of suffering, assisting with comfort needs, and providing information and skills as required. Each of these elements must be based on the fundamental beliefs and values of the philosophy of (total) care and an acknowledgement of the vulnerability and fragility of the human condition – we will all die. This goal of accompanying them home is further examined in the next chapter which explores the elements of the ethical frameworks articulated by the HPC.
professionals. These ethical frameworks for HPC include crucial values which underpin
the practice, the considerations of virtues, and the centrality of a relational ethic. A
distinctive ethical framework for HPC is provided which includes further important
considerations about this unique form of relationship at the end of life.
Part Three
The Roof

Coming Home: To A Spiritual Environment
Where is my God?
What am I connected to?
Where do I go once gone from this place?
Peace and love I share
Show me that you are willing to witness
To the connections that shape my life
To that which is the great mystery beyond.

Coming Home: To The Origins of Human Existence
Take me back to my origin, my source
Returning home to where I first came
Ashes to ashes
Dust to dust
Traveling back to the earth
Help me leave this home
So that I can find my home.
CHAPTER SIX
An ethical framework: A compass for practice

Ethical moments begin, come to be, stand for themselves, and fade away again. Like the forming of a beautiful bubble that soon breaks, the moment encapsulating the ethical claim of the other too is short lived. Yet, what we experience and understand in that moment, we carry with us into the next moment that awaits (Cameron, 2004, p. 61).

6. Introduction
An understanding of the ethical dimension of hospice palliative care requires a critical exploration of the ethical frameworks that the professionals bring to their practice and how these frameworks play a role in guiding them. These ethical frameworks have two components - the expressions about what constitutes hospice palliative care ethics and statements about what ethically guides them in their practice. This exploration of ethical frameworks of HPC is underpinned by the implicit question of: what is ethics? Nowadays it is understood that there are a plurality of meanings when it comes to understanding ethics (Kekes, 1990), although a modern, moral philosophical tradition is often a dominant understanding. These varying understandings and frameworks are a central component of the ethical dimension of hospice palliative care. This chapter sets forth the understandings and articulations from the professionals’ storied accounts pertaining to these ethical frameworks. In the first instance this includes important questions about the role or place of principles-based ethics (PBE), and, in particular, the principle of respect for autonomy. Secondly, a quantitative presentation of the values or ‘goods’ thought central in underpinning the practice are included and compared to values lists in the literature. Thirdly, a brief inclusion of the importance of virtue ethics is included. Finally, an exploration of the central understanding of the ethics of hospice palliative care is offered - a relational ethic.
6.1 Why ethical frameworks?

6.1.1 Taylor’s moral frameworks

Taylor\textsuperscript{37} (1989; cited in Abbey, 2000) writes about the features of moral life\textsuperscript{38}. He describes a moral framework as “a series of beliefs that gives overall shape and direction to a person’s values and moral outlooks” (p. 33). What's more, Taylor asserts, all people have an ethical framework, whether they are articulated or not, or realised or not. These frameworks give shape and meaning to individuals’ lives and provide answers, no matter how tacitly, to the existential questions that he [Taylor] believes face all individuals about the purpose, conduct and direction of their lives [practice]. One’s framework provides guidance about moral questions in the broad sense; that is, about what it is right to do \textit{vis-à-vis} others and about what it is good to be; about what is meaningful and rewarding for an individual (cited in Abbey, 2000, p. 34).

Consequently, these moral frameworks then influence our every action or non action, how we relate, what we view as important, what sort of person we are and wish to become and so forth, including how we care for living-dying people. Taylor (cited in Abbey, 2000) goes on to explain that these moral frameworks orientate us in a moral space. I thus understand the concept of an ethical framework as a type of compass which guides people in their lives and work. In other words, the ethical frameworks held by a HPC professional would guide them towards “what is the right thing to do [or not do], what goods should be pursued [or not pursued] and what is the right direction for their lives [in their practice] to take” (Taylor, cited in Abbey, 2000, p. 34). Ethical frameworks give professionals the guidance, however subtle they may be, to each and every act in their caring practices. Hence, it is of central importance to understand what comprises these ethical frameworks and how they might be helpful to the practice of HPC. This is preferred rather than simply assuming that ethics is about ethical issues, or that a principles-based approach is most appropriate, or that everyone has the same understanding of what HPC ethics is about.

\textsuperscript{37} I am using the term ethical frameworks interchangeably with Taylor’s writings about moral frameworks.

\textsuperscript{38} Moral life clearly includes occupational life (hospice palliative care practice).
6.1.2 Dominant moral philosophical frameworks

Arguably, a modern, moral philosophical approach to the doing and seeing of ethics is dominant. As presented in chapter two, there are of course limitations and assumptions in this approach, especially the main assumption that this is the only way to understand ethics. The moral philosophical tradition set out to assist in the ethics of health care and thus developed an understanding of, and an approach to, health care ethics called principlism. A thorough explanation of this approach was offered in chapter two, including some considerations of whether it is helpful or problematic as a dominant understanding of ethics for HPC practice. It seems, from the HPC literature at least, that this dominant principles-based approach was being applied to the profession of hospice palliative care as well, perhaps due to the increasing medicalisation of the profession. Or, perhaps, principlism is applied to HPC in the literature due to the fact that the profession had not, to date, articulated a distinctive ethical framework of its own. Here, therefore, are further reasons why gaining the understandings of the ethical frameworks from the HPC professionals is essential. It is also important to note that principlism, as an ethical framework, was developed not from the practice of health care or medicine, but rather externally from the practice of moral philosophy. In other words, the theories, ideas and principles from moral philosophy were placed upon the profession of health care.

6.1.3 An engaged ethics standpoint

In contrast to this dominant moral philosophical understanding of ethics, engaged ethics appreciates that the meaning of HPC ethics, and the ethical frameworks that are adopted and useful for the practice, are internal. In other words, if we are to seek to understand what HPC ethics is, and what guides professionals in their ethical practice, then the insights to these questions needs to come from within the practice itself. Therefore, for this inquiry, an understanding of HPC ethics was generated from the place of ethics in the practice. I wished to understand, directly from the HPC professionals, what they understood hospice palliative care ethics to be about and what ethical frameworks they held that were helpful in guiding their caring practices. This emphasis on gaining
understanding about what is ethics from within a social practice such as medicine is explained by Isaacs’ (1998)

I am proposing that the cognitive point of departure for understanding … [HPC] ethics is not generated from the place of ethics in the practice of philosophy, or any other external practice for that matter, but is generated from the place of ethics in the practice of medicine [HPC] (p. 4).

Therefore, to answer the question - what is hospice palliative care ethics? - I have turned to the professionals who carry out this practice for understanding and have placed their articulations foremost; for as Abbey (2000) maintains “any meaningful [understanding] of morality must … take into account the way individuals experience their moral lives” (p. 40). An engaged ethics approach acknowledges the importance of mapping the existing ethical frameworks from the professionals in the practice which are often not explicitly acknowledged or examined. Arguably, viewing the ethics of HPC from within the practice gives rise to a more “comprehensive and radically different conception of the ethical agenda” (Isaacs, 1998, p. 23). Given these above rationales, the contents of this chapter include the articulations and understandings of ethics in HPC practice, what guides HPC professionals in their ethical practice, and the considerations of the role of principlism in the ethics of HPC. These insights then in turn provide an explicit and distinctive ethical framework for hospice palliative care practice thereby “protect[ing] the moral frameworks of how we provide care to people who are dying” (MacLeod, 2003, p. 125).

6.2 The role of principles-based ethics (PBE)

A principles-based ethics framework did not figure heavily in the HPC professionals’ storied accounts. Although a considerable amount of the HPC literature has adopted, from biomedical ethics, this dominant ethical framework to explore and understand the ethics of hospice palliative care practice, this is not congruent with the articulations from the HPC professionals as to what they understand HPC ethics to be about. Before viewing the professionals’ accounts, this chapter presents some of the ‘for and against’ statements about PBE specifically from the HPC literature.
6.2.1 HPC literature: The adoption of PBE

The most vocal of those in agreement with the adoption of PBE for HPC practice is O’Hare (2004) who indicates that it is only through the “attention to medical ethical principles” that the “most holistic and productive supportive end of life care can be offered” (p. 86). O’Hare assertively continues this line of argument when he states that for those who are caring for people in the throes of terminal illness there is a need for these four principles to facilitate their (HPC professionals’) reasoning.

Although the employment of each principle of medical ethics offers guidelines for reflection on the most comprehensive and appropriate care, it is attention to autonomy, informed consent, and beneficence that promotes the most effective supportive care. Thus, it is the heightened attention to the perspective of autonomy for determining the goals of care, to the twin principles of nonmaleficence and beneficence for designing the manner of care … and to the obligation of confidentiality to preserve privacy and enhance candour in delivering care that is of critical importance (O’Hare, 2004, p. 87).

There can be little doubt about what this author’s position is in regard to the importance of principlism in understanding and guiding ethical end of life caring practices.

Dahlin (2004), too, takes the stance that “our first thoughts must focus on the primary values of health care: nonmaleficence, beneficence, autonomy and justice” (p. 3). This author was writing specifically about HPC ethics. Chrystal-Frances (2003) also assumes that these principles must be adhered to in practicing HPC. Similarly, Lesage and Portenoy (2001) maintain that the challenge of ethics in HPC is “to provide an intellectual and pragmatic framework for pursuing the values of autonomy, beneficence and justice” (p. 128). It does not stop there, as the list of authors who favour a biomedical, principles-based approach to ethics for HPC practice continues. Cimino (2003) writes that “the most practical approach is to diligently apply the principles of beneficence (benefits) and nonmaleficence (burdens) in everyday practice” (p. 17). Latimer (1998) believes that ethical HPC practitioners “will practice in accordance with the principles of biomedical ethics” (p. 1741). Goncalves (2003) asserts that “the basic principles of biomedical ethics should be respected in every medical action, regardless of whether it is curative or palliative” (p. 158). Clearly, there are numerous authors in the HPC literature who argue for the use of a PBE framework for the ethics of HPC; or,
in other words, this has become a popular framework for the ethics of end of life care. This may be due to the influence of biomedicine, the predominance of biomedical authors, little research into this area, or because of its apparent simplistic format.

6.2.2 HPC literature: PBE criticisms

However, just as there are strong proponents for the use of the PBE approach for HPC ethics, so, too, are there palliative care authors who oppose it. Those who do not agree with the usage of this principlist approach argue that it does not take into account the context and particularities of any given situation. Firstly, it is important to appreciate that there is currently an anti-principlist crisis in health care ethics more generally (Pellegrino, cited in Taboada & Bruera, 2001, p. 340). The problem is not necessarily with the principles themselves, “but the exclusive reliance on them and an instrumental rationality associated with them” (Massey, personal communication, 2004). Pellegrino (1993) states the main criticism of the principle approach is that of being “too abstract, too rationalistic, and too removed from the psychological milieu in which moral choices are actually made; principles ignore a person’s character, life story, cultural background, and gender” (p. 1161). This means that the four principles often do not take into account the circumstances or particularities of each given situation adequately.

Authors who agree with this argument include McNaughton and Rawlings (2000) who write

A grasp of moral principles is insufficient for a correct moral appreciation of a particular case … as well as an understanding of the correct moral principles, we need fine judgment, sensitivity and even something approaching a perceptual capacity to appreciate the saliencies of the circumstances in which we find ourselves (p. 256).

Equally, Dossetor (1997) echoes this argument when he writes “the dominance of principles in ethics is now being questioned because they fail to take contextual features or the meaning of relationships adequately into account” (p. 1689). Ten Have and Clark (2002) argue against principlism writing that “to believe that there is one universal tool [principlism] to resolve all moral issues and guide moral behaviour is absurd” (p. 239). Principlism, as an ethical framework, does not take into account “the personal
philosophies, politics, religions or moral theories of the persons involved” (ten Have & Clark, 2002, p. 239). Turner (2002) agrees with ten Have and Clark (2002), as she argues that principlism “neglects to attend to the existence of distinctive cultural models and social practices” (p. 297). Lastly, Roy (1997a) eloquently writes

An ethics that tries to resolve value conflicts in the care of the dying by reducing persons to principles is bound to fail. Apparently simple principles are forbiddingly complex because their meaning only emerges when they are read within a dying person’s clinical and personal biography (p. 4).

Therefore, the PBE approach to the ethics of end of life care, according to the above authors, fails to take into account the person, their values, the context and the nature of our very embeddedness in society.

A further argument leveled towards the usage of principles for HPC ethics is that often two or more of these principles can be in conflict. For example, Taboada and Bruera (2001) write, because in this system each principle is given equal weight, “this approach does not provide a clear answer as to which principle should be given priority, and priorities among principles can be established only when the detailed circumstances of a particular decision are known” (p. 340). Byock (1994a) similarly believes that ethical principles “frequently fail to reveal an unambiguous ‘right’ course of action” (p. 10). As general guides, explain ten Have and Clark (2002), “they leave considerable room for judgment” (p. 238). Randall and Downie (2006) have since changed their standpoint on the role of principlism in HPC and now assert that “professionals do not seem to use the principles in the resolution of cases” (p. 13).

Ten Have and Clark (2002) are clear in their concerns about the adoption of PBE for the practice of hospice palliative care. They conclude that principlism fails in hospice palliative care because as an ethical framework it

- Is inattentive to the particularities of the practical setting;
- Is necessarily abstract and are not therefore immediately relevant to the particular circumstances of the actual cases;
- Fail[s] to realise the importance of the concrete lived experience of professionals and their patients;
- Is inadequate when faced with the dilemmas of palliative care practice (p. 239).
Ten Have and Clark (2002) suggest that rather than principles for the ethics of end of life care, the actual experiences of the living-dying person and the professional caregivers need to be foremost, as well as the context in which they experience their “moral lives” (p. 239). This moral life includes

the roles they play, the relationships in which they participate, the expectations they have, and the values they cherish … these should all be taken into consideration when addressing [the ethics of hospice palliative care] (ten Have & Clark, 2002, p. 239).

The abstract, universal, principles-based approach is thought to be highly inappropriate by the authors of *The ethics of palliative care: European perspectives* (ten Have & Clark, 2002). Rather, this text focuses on contextual considerations, moral values and a relational ethic.

### 6.2.3 Principlism in HPC narratives

This thesis echoes the European assertion of the inappropriateness of PBE as a dominant ethical framework. This is because the principles, or this approach generally, was rarely mentioned in the articulations and understandings from the professionals. PBE did get expressed occasionally in the storied accounts

The ethics of palliative care [pause] I’m aware of bioethical frameworks and I think that they’ve been very useful in finding a generic expression. So we are beneficent, nonmaleficent and we do promote self-determination and those sorts of things … but I think end of life ethics are perhaps more sharply focused than the general bioethics framework. When I talk to people who are in palliative care and talk to them about things like beneficence, they’ll talk more in terms of compassion perhaps. One professional felt that compassion was a more accurate description of the ethical principle that compelled her to behave in certain ways (Ken).

This quote by Ken explains his ideas around the possible helpfulness of principlism, but that it is not an accurate ethical framework for HPC; that the ethics of HPC are distinctive, or “more sharply focused”. Emma is another HPC professional who mentioned the principles, and thought that they might be helpful as you “can tie a name to them”, except that when she spoke of these there was some confusion in her tone as she expressed this
When you think about ethics in the true sense of the term, you think of truth telling, and [pause] … oh, I can’t think of the terms … the sort of ethics that you got taught at university, the do no harm, all those sorts of things. So those things still should be tied into how people practice. I mean do no harm, as practitioners we’ve all seen issues happen within palliative care. People who have obviously some months to live and they are constantly having procedures. So, yes, I think those principles can be helpful in palliative care too. And they are principles that people can tie a name to, instead of having a bit of a nebulous thing (Emma).

Emma thinks that PBE could be helpful because it provides this coherent and simplistic framework, however, notice the wording of ‘should’; “those things (principles) still should be tied into how people practice”. It does not sound as if Emma believed this for herself, but rather it was a prescribed way of understanding and doing ethics in practice.

In addition to these two statements above, four other HPC professionals mentioned specifically the principle of nonmaleficence (doing no harm) as their understanding of HPC ethics

The ethics of palliative care … well, don’t do any harm. Obviously some treatments could be considered harmful (Nina)

The meaning of the ethical dimension of palliative care … for me is to do no harm and more and more treatments that cause more pain than good. We come in and say “look, don’t do any more, don’t do more harm” (Martha)

The ethics of palliative care … well an understanding that you do no harm. Do no harm is probably the primary thing for me (Peter)

That what you are doing isn’t going to cause them any harm or any harm to the family (Stacy).

It can be understood that what constitutes HPC ethics for these professionals are specifically statements about harm. Noticeably, the professionals’ specific understandings of harm are not voiced. This next statement by Michael alludes to the question of whether a biomedical ethical framework is compatible or helpful for hospice palliative care

I guess my initial thought is that the ethics of palliative care should be no different to the ethics of health care generally, but then when I start to think about it, I guess, there will be experiences particular to palliative care, where, for example, patients are offered interventions without being given full information about the effects and the options. It’s
my strong sense that often people are not fully informed in that sort of situation, which is unethical to me … its harmful (Michael).

Once again, Michael mentions harm as an important ethical consideration, but significantly points out that the ethics of hospice palliative care are somehow different from health care ethics because there are experiences that are unique in hospice palliative care.

What can be understood from these expressions is that for a few of the HPC professionals principles are mentioned as a part of their ethical frameworks, but that the principle of nonmaleficence is perhaps the most important one to consider for the context of hospice palliative care, however, what constituted harm was not described. The principles were viewed as helpful in terms of putting a name to something which is complex, as explained by pro-PBE authors in chapter two. On the other hand, there was no mention of the fact that these principles are often interpreted differently by people and in contexts. Also, Ken and Michael make the important point that the ethics of HPC is different or distinctive from standard biomedical or health care ethics. This particular point sets out the need for a distinctive ethical framework for HPC practice, rather than adopting a biomedical, principles-based ethical approach.

6.2.4 An ethical framework: Above all (or first) do no harm

It is worth pondering the place of the principle of nonmaleficence in the quotes above. Clearly, for several of the HPC professionals, the consideration of doing no harm is important in their ethical frameworks. This is also relevant considering that nonmaleficence was voted the seventh highest value to underpin the practice (See Section 6.9). This principle, write Beauchamp and Childress (2001), “asserts an obligation not to inflict harm on others … or to avoid the causation of harm” (p. 113; p. 3). What makes these considerations of harm even more interesting is that the quotes above, offered by the HPC professionals, express harm in a way as pertaining to others; it is usually the biomedical interventions, carried out by others, which seems to be a dominant understanding of harm in this context. This focus on harm could stem from the tradition of the hospice movement which argued that the care of the dying, according
to medical practices, was problematic or even harmful. Hence, by working side by side with health care professionals, HPC workers understand some medical treatments and interventions as harmful in that they may be futile in the face of dying. Futility refers “to a situation in which patients who are irreversibly dying have reached a point at which further treatment provides no physiological benefit or is hopeless” (Beauchamp & Childress, 2001, p. 133). Here, again, the influence of biomedicine which is “driven by the medical technical imperative to treat and where curative medicine is prioritised at the expense of individuals” can be observed (McNamara et al., 1994, p. 1505).

Noticeably, the HPC professionals did not discuss harm in terms of themselves, which further reinforces this sense of otherness or a type of ‘them and us’ position between the health care profession and the HPC profession, which further reinforces the distinctive nature of HPC practice. It needs to be remembered that hospice care “originated from a moral discomfort with modern medicine … with its curative orientation and over-treatment” (Hermsen, 2005, p. 8). This discomfort could still be evident today in the articulations of possible harm and with the notable inclusion of the principle of nonmaleficence in the ethical frameworks of HPC professionals.

Moreover, these articulations about harm could allude to a dominant ethical ‘issue’ that HPC professionals face everyday in their practice; that of coexisting side by side within a curative paradigm and having to be the professional group that stands for: ‘no more, he (or she) is dying’. Kate, a palliative care educator, summed up this concern when she stated

The way I probably see things happening … there will be an area of palliative treatment and an area of palliative care and it will start to go back into the hospitals and it’s not going to be palliative care. It will be palliative treatment and that’s going to be the tricky one for us as palliative care people now … to move in there and say ‘you’ve got to be able to stop’ and they’ll call it palliative treatment and they’ll treat them to death (Kate).

‘Treating them till death’ might well represent a dominant understanding of harm for the hospice palliative care profession. Therefore, nonmaleficence, as a principle, requires further examination and articulation, to appreciate and understand the differing constructions of what harm means for the HPC professionals. I would recommend HPC, as a profession, have further ethical conversations about what constitutes harm in the
care of the dying, how it is recognised and understood, what place it holds in their ethical frameworks, and how to respond to perceived harms in practice. In other words, there would be value in the further “specification” of this principle, in that this “general norm of doing no harm has to be specified for this particular context [HPC practice]”, as advised by Beauchamp (2007, p. 8).

6.3 The role of autonomy

“That’s my life … nobody has any right to tell me what to do with it”. This essentially captures the true voice of autonomy (Breier-Mackie, 2001, p. 517).

Aside from these understandings of the role of PBE in HPC ethics, a further research question linked to the place of principlism pertains to the centrality of the principle of respect for autonomy. I was curious to understand more about how important this principle was in guiding HPC practice or what place it had in the HPC professionals’ ethical frameworks. Noticeably, autonomy was viewed in a dubious way by the professionals, and largely not thought to be appropriate for the practice and context of hospice palliative care. However, there is an apparent contradiction in that HPC professionals still cited individualism, rights, and choice as important in their understandings of the ethics of HPC. Overall, it can be seen that both autonomy and the acknowledgement and valuing of relationships is important in an ethical framework for HPC practice, but that autonomy was, by and large, not privileged.

6.3.1 What is autonomy?

Respect for autonomy and patients’ rights hold a central place in health care practice generally (Keleher, 1997) and HPC literature has adopted autonomy as a central principle as well (Breier-Mackie, 2001; Dickenson, 1999; Hilden & Honkasalo, 2006; Jennings, 1997; Martin, 1998; McNamara, 2004; Miteff, 2001; Randall & Downie, 2006; Russon, 1997; Scott, 1999; Webb, 2000; Woods, 2002). Autonomy’s ancient origins lie in Greek political theory (Woods, 2002). It refers to the “autos (self) and nomos (governing, rules, or determination) nature of the citizens who made their own laws” (Woods, 2002, p. 146). It is rooted in the liberal moral and political tradition as a “symbol of resistance to the misuse of authority by professionals, institutions and
governments” (Pellegrino, 1994, p. 353). Autonomy can be simply described as ‘self-rule’, but can also be interpreted in various ways. Dworkin (1988; cited in Webb, 2005) writes

‘Autonomy’ is used in an exceedingly broad fashion. It is used sometimes as an equivalent of liberty … sometimes as an equivalent to self-rule or sovereignty, sometimes as identical with freedom of the will. It is equated with dignity, integrity, individuality, independence, responsibility, and self knowledge. It is identified with qualities of self-assertion, with critical reflection, with freedom from obligation, with absence of external causation, with knowledge of one’s own interests … It is related to actions, to beliefs, to reasons for acting, to rules, to the will of other persons, to thoughts, and to principles. About the only features held constant from one author to another are that autonomy is a feature of persons and that it is a desirable quality to have (p. 64).

Thus, as Dworkin explains, understandings of autonomy are varied. However, as the ontological explorations presented in chapter four outlined, autonomy is thought to be a feature of personhood (self-as-individual and self-as-mind), and thus implicitly ties into our understandings and assumptions of people as individualistic, cognitive and rational beings. Autonomy is also thought to be valuable as it is a principle that has been “championed by ethicists … as a central if not the most important ethical principle” (Woods, 2002, p. 146, original italics). It holds a central place in biomedical ethics and “in the literature of hospice care” (Scott, 1999, p. 144).

6.3.2 Autonomy literature

In fact, Pellegrino argues that “in the western world, the concept of autonomy has lately become ‘a moral absolute’” (cited in Hilden & Honkasalo, 2006, p. 47). This privileging of autonomy is noticeable in the HPC ethics literature as well. Jennings (1997) writes about the ‘goods’ of hospice care and cites respect for the rights and autonomy of the dying person as being an important ethical concept. In this way, Jennings asserts, hospice “certainly shares a core value now influential throughout the entire health system” (p. 3). Autonomy represents the right to die your own death, in your own way. Indeed, Jennings (1997) believes that hospice “must be individually oriented because the patient must be treated as a subject, an active participant … in the process of his or her own care” (p. 5).
Certainly with the emphasis on patient-centered or person-centered care autonomy needs to play a role in end of life caring practices. In endeavouring to maintain a person’s sense of dignity, Miteff (2001) writes that “one way to achieve this is through advocating and protecting the dying person’s autonomy” (p. 4). Similarly, Breier-Mackie (2001) states that “patient autonomy has been promoted significantly in declaring the moral and legal right of competent individuals to make decisions about the course of their dying” (p. 512). A Finnish study found that palliateurs consider patient autonomy “to be a central principle in end of life care” (Hilden & Honkasalo, 2006, p. 41). Certainly, Farsides (1998) believes that the philosophy of (total) care “advocates both implicitly and explicitly that serious respect be shown to patient autonomy” (p. 149). In addition, Scott (1999) proposes that in remaining true to the hospice ideals “patient involvement, patient autonomy, and patient empowerment” must be met (p. 139). Indeed, McNamara (2004) has found that the hospice ideal of a good death has now been “increasingly inappropriate in the current climate of patient autonomy and consumer choice” (p. 929). As noted previously, autonomy, and the interlinking concepts of individualism, a person-centered approach, and freedom of choice all play a role in influencing the philosophy of (total) care and the goals of HPC practice.

6.3.3 HPC narratives of autonomy

Yet even though the HPC literature promotes the important place of autonomy in the ethical practice of end of life care only a few of the HPC professionals’ narratives spoke of autonomy in their articulations of their ethical frameworks. What is interesting to note is that the HPC professionals did not refer to the terminology of autonomy, but rather more often used similar concepts such as individual, decision-making, informed, information, rights and choice

Ethics is about allowing an individual to make decisions, by providing information so that they can make an accurate decision and then the right to make a decision (Nina)

It’s about their right to make whatever decisions they want to make (Amy)

The ethics of palliative care to me is ensuring that the patient and family are truly informed … so appropriate information giving is very ethical. They then have the right to choose which pathway they wish to take (Jim)
I think the ethics is about being upfront with people and giving them choices of treatment … so that everyone understands and can make choices based on the knowledge that is available. So basically, informing people and letting them know what the risks are and that sort of thing … and their right to make a decision based on that (Kieran).

Consequently, this presents a paradox where concepts such as choice and individual decision making are thought important in the ethics of HPC, yet, conversely, autonomy was viewed in a dubious way. This dubiousness about the role of autonomy in HPC practice is represented by it being rated twenty-third on the list of central values underpinning the practice (See Section 6.9, Table 7, p. 251). This is a noticeable difference when compared to the European Pallium study where the HPC professionals ranked autonomy as seventh (Janssens et al., 2002, p. 78, Section 6.8, Table 6, p. 249).

In other words, there is a noticeable difference between the rankings of autonomy in this study compared to the European Pallium study. Something about the concept or principle of autonomy is problematic for the HPC professionals here in Queensland, even though the paradox mentioned is evident. Some of the articulations that relate to the perceived problematics or dubiousness of autonomy for hospice palliative care include

- It’s a nice ideal, but I think in reality [pause] the theory tells us to respect a person’s right to autonomy, but in practice can we really do this? How far can we give people … can you respect absolute autonomy? We don’t live in isolation (Jackie)

- I don’t think autonomy is appropriate for palliative care. I think it’s more about respect for people and respect for interactions. Autonomy doesn’t allow for that interconnection. Autonomy is the opposite of relationships. So I prefer respect and valuing the person as a guiding principle. Autonomy has become distorted and lost its meaning. It’s been perverted in our modern kind of culture (Julie)

- I think autonomy is a double-edged sword sometimes and perhaps pervading the health care arena too much. And we haven’t had the conversations needed about what autonomy means in palliative care. I think it’s a fantastic ethical principle, but in a setting of palliative care and dying patients, I don’t think so. There are significant relationships that impact heavily on the care of that person as they die (Jim)

- We try not to let the patient’s autonomy destroy the family and visa versa. I think in palliative care, with the family as the unit of care, there is huge confusion about this. I think in society you can never be totally autonomous. The patient, just like us professionals, still has responsibilities to their families and to society as well (Jennifer)
The principle of autonomy is important. Where the patient’s coming from and what they particularly want. But at the same time you need to listen to the family, because they are the ones who will be left. So it’s trying to balance that (Stacy).

The HPC professionals above were concerned about the role of autonomy for hospice palliative care and, for varying reasons, thought that it did not fit for end of life caring practices, and thus was not an integral part of their ethical frameworks.

6.3.4 Criticisms of autonomy

The time has come for those within palliative care to question the importance of patient autonomy within their philosophy of care (Farsides, 1998, p. 151).

6.3.4.1 The opposite of relationships

The dominant critique, both in the HPC literature and in the narratives above, pertains to the assumption of self-as-individuals. For the HPC professionals an appreciation of people as being interconnected with significant others was thought not to fit, or be congruent with, the privileging of the principle of autonomy. Saunders (1994) explains this point when she writes, “people belong to each other, they are persons in relation” (p. 779). The HPC professionals above emphasised this point: that people are relational; that autonomy is the opposite of relationships; and that we do not live in isolation from each other.

The HPC professionals are not alone in stipulating their concerns about the predominance of autonomy. Several HPC and ethics authors, too, emphasise this point. Pellegrino and Thomasma (1988) explain that professional caregivers and patients “are existentially bound to each other in a way that makes moral atomism and absolute decisional autonomy unrealistic and undesirable goals for both parties” (p. 14). Farsides (1998) simply makes the point that we do not make decisions alone. The principle of autonomy neglects the reality that decision making among humans in an interpersonal transaction. The feminist author, Sherwin (1992a), critiques the priority that is accorded to autonomy, writing that ethical models based on the image of ahistorical, self-sufficient, atom-like individuals are simply not credible to most women … most women experience the world as a complex web of interdependent relationships, where responsible caring for others is implicit in their moral lives. The abstract reasoning of
morality on the rights of independent agents is inadequate for the moral reality in which they live (p. 47).

Hence, as Julie succinctly states, autonomy is the opposite of relationships. Chan (2004) alerts us to the problematics of a liberal autonomous perspective within Asian cultures, where people describe themselves in terms of connections to others. “Individuals are bound together by ties of concern and caring, empathy and reciprocity. Care, compassion and responsibility for others are the capacities that define us as moral agents”, writes Chan (2004, p. 95). The fundamental assumption is that human beings are separate, independent people who fear dependence (the dominant, Western, liberal ethic), rather than appreciating that people are intimately connected, who fear separation and abandonment (Chan, 2004, p. 95).

6.3.4.2 Family-centered care

This is an especially an important point when the family-centered approach to HPC practice is considered. For, as Woods, Beaver and Luker (2000) discovered in their study of the ethical implications of users’ views of palliative care services, “it is apparent that an ethical framework that focuses on individual patient autonomy poses a problem in a context where the family or carer is as significant” (p. 325). McNamara (2004) also notices this contradiction when she reflects on the “ideological weight given to the ethic of individuality and personal autonomy within palliative care communities is also somewhat perplexing given the emphasis upon the family as the ‘unit of care’ and the team approach to professional caregiving” (p. 932). In addition, the social situation and interdependency involved in the living-dying process will affect “the development of capacities necessary for autonomy” (Stoljar, 2007, p. 16). The decisions that a living-dying person make “are not entirely an individual matter because other family members will be affected [and involved] in this process … the patient-centered approach of the liberal model indeed ignores the fact that the interests of family members are connected” (Chan, 2004, p. 96).
The position that HPC philosophy and practice is family centred means that the 
“autonomy-centric view seems inadequate to the task of dealing with ethical” practice 
(Woods, 2002, p. 161). Woods believes that there are good reasons to limit the priority 
of autonomy in HPC, whilst at the same time not denying its importance. Finally, 
Saunders (1994) agrees in that she believes that “autonomy has to be considered not 
only in what is feasible but also in the context of family, of society as a whole and with 
what the carers and professionals concerned can reasonably offer” (p. 779). Hence, 
autonomy must be considered in light of the interconnectedness and interdependence of 
living-dying people with family, friends, and professional caregivers, and within society; 
in other words, a human being’s embedded nature.

The individualistic, atomistic and detached view of personhood is a modernist 
production, as argued in chapter four, and one that does not necessarily fit with the lived 
reality of living-dying people. As Candib (2002) points out “in many cultures individual 
autonomy is not the central core of identity” (p. 219). The prioritising of the principle of 
autonomy has come hand in hand with a dominant view of personhood that negates a 
person’s embedded position in relationships, culture, language and time. Whenever we 
reflect on a choice or decision, believing that we are exercising free will, we will be 
drawing on what is available to us from the contexts of family, relationships and culture. 
Our facets of being are intertwined and

we are all not only deeply enmeshed in social relations and cultural patterns, we 
are also defined by such relations … Standard models of autonomy under-
emphasize the deep identity-constituting connections we have with gender, race, 
culture, and religion, among other things (Stanford Encyclopaedia of Philosophy, 
2005, p. 10).

An alternative view of personhood, indeed a richer ontology, acknowledges this 
embedded nature of human beings and refutes the dominant construction of people as 
being solely autonomous individuals. Hence, for HPC practice, with its emphasis on 
‘family as unit of care’ and an interdisciplinary approach to care, the principle of 
autonomy is highly problematic. For, ultimately, “many of the factors that influence the 
experience of dying are social: “the social location of the person and their access to 
power; cultural understandings of dying and death; the political and economic
organisation of medicine and health care; and the moral dimension of shared decision making” (McNamara, 1998a, p. 181).

**6.3.4.3 Vulnerability and dependency**

The lived reality of the living-dying experience also impacts upon the applicability of the ethical principle of autonomy in HPC ethical frameworks and practice. Scott (1999) emphasises this point when she writes “I also suggest that within the context of palliative care too strident a call for autonomy of the patient may lead to underestimating the vulnerability of patients” (p. 145). Scott suggests that there is a need to lessen “the largely vacuous focus on autonomy that seems at the present time to be in danger of arising in the field of palliative care” (p. 146). Her reason for this is that autonomy is necessarily limited by the living-dying person’s experience of illness, disease, treatments and dependency (Scott, 1999). Jennings (1997), too, notes that the promotion of autonomy in the hospice context “is too abstract from the reality of the patient’s medical and psychological situation’ (p. 5). In other words, the abstract ideology of exercising individual autonomy is impacted by the process of living and dying with a terminal illness. Pellegrino and Thomasma (1988), in their critique of the prioritising of autonomy, write that

> The primary characteristics of serious illness alter personal wholeness to a profound degree. It also changes some of our assumptions about the operation of personal autonomy in the one who is ill. The effects of illness and disease on personal autonomy limit self-determination to variable degrees (p. 15-16).

The lived experience of illness, medical treatments, and suffering mean that the exercise of autonomy could prove difficult. It is at times such as the end of life where we would, it is hoped, be drawing upon the guidance and support of others in crucial decision making processes. This includes the HPC professionals who play a central role in providing specific information, based on professional skill and knowledge, to facilitate a shared, relational decision making process; one that does not prioritise autonomy. For, as van Eys (1991) simply states “to be a patient is to be out of control. To be a patient is to be dependent” (p. 28). There is a need to fetter this use of autonomy in the end stages of life so as to not “abandon the patient to a vacuous freedom of choice” (Carson, 1995, p. 105).
6.3.5 An ethical framework: Autonomy-in-relation

Ultimately, what needs to be acknowledged is that “autonomy is developed, enunciated, and ultimately exercised in the embrace of others” (O’Neill, 2001, p. 1921). These critiques of autonomy in the end of life context point to a dubiousness about the role of this principle in an ethical framework for HPC practice. Rather, Candib (2002) suggests that we need to “step back from the unexamined practice of privileging individual autonomy … and offer steps toward a collaborative construction of conversations with patients and families” (p. 213). It is not that autonomy is not an important consideration in HPC practice, but rather that both autonomy and relationship need to be taken into consideration in ethical end of life caring practices. Perhaps autonomy is important for the very reason that people do live in relationships. Overall, as Beauchamp and Childress (2001) recommend, the principle of respect for autonomy needs to be interpreted or specified for the context of hospice palliative care. Autonomy needs to have a different meaning in hospice palliative care practice than it does in acute care settings (Jennings, 1997).

Jennings recommends that “if the concept of autonomy is to function as a moral compass for caregivers in hospice, it must somehow be linked with notions of dependency and relationship much more so than it normally has been in broader discussions of medical ethics” (p. 5). HPC, as a profession, needs to rework the dominant understanding of autonomy and “move towards autonomy-in-relation … a situated autonomy that recognises the family context of autonomy … [this would mean that] decisions will flow not from one’s separateness as an individual but from one’s connectedness as a family member” (Candib, 2002, p. 223). Keller (1997) defines relational autonomy in three parts

- Self-governance
- Being able critically to reflect on whether one can take responsibility for an action while being true to oneself
- The ability to learn and use this skill among friends and other social contacts (an intersubjective, relational exchange) (p. 154).
Hence, HPC professionals need to conceive autonomy in relational and engaged ways. This is because “our human existence is autonomous within the totality of mutual relationships” (Bondolfi, 2002, p. 47). Autonomy cannot exist without recognition of our human solidarity and our lived realities of embeddedness. What is required is an understanding that both autonomy and the acknowledgement “that some of the choices we make will quite appropriately be guided by others” is needed (Farsides, 1998, p. 148). The living-dying process should be regarded “as a sharing process, the last journey that the patient (sic) makes together with her (sic) significant others” (Chan, 2004, p. 98).

6.4 Summary of principlism

To summarise the first section of this chapter it is argued that, although a principles-based approach to the understanding of ethics is often presented in the HPC literature as the dominant approach, it did not figure heavily in the articulations of ethical frameworks by the professionals in this study. It was a relatively minor response when considered in the light of the following presentation of the values, virtues and relational articulations inherent in the HPC professionals’ ethical frameworks. This thesis takes the same position as the European Pallium authors who argue that principlism is inadequate for hospice palliative care ethics. Even though there were some initial expressions of helpfulness about principlism, it was generally thought inappropriate for HPC practice. The reasoning behind this was that end of life caring practices were viewed as somehow different from other health care practices and, therefore, needed a distinctive ethical framework. That being said, there was a noticeable inclusion of the principle of doing no harm (non-maleficence). Yet this was in relation to the perceived harms done by others in terms of curative treatments and medical interventions. This insight points to a need to examine further the meanings and implications of the principle of nonmaleficence in the context of HPC practice.
The principle of respect for autonomy, too, was mentioned infrequently and there was a sense of dubiousness about the place of autonomy in the HPC setting. It was not thought to be an appropriate ethical concept in light of the relational and social nature of human beings, the family-centred focus, a team approach to care, and the lived reality of dying as vulnerable and dependent. By way of a paradox, the concepts of individualism, rights, and freedom of choice were voiced as crucial in ethical practice, and so it must be surmised that autonomy does have a place in the caring practices and ethical frameworks of HPC. Therefore, it was proposed that an autonomy-in-relation approach needs to be considered and developed, which would provide for a broader understanding of the concept of autonomy, adapted for the particularity of HPC practice. Indeed, “more research into the relevance of autonomy … in everyday practice is necessary” (Janssens et al., 2002, p. 84). I propose that HPC, as a profession, is keenly aware of the socially embedded nature of personhood, as is promoted in the philosophy of (total) care, and that this does not fit with the dominant construction of autonomy. Overall, it must be noted that autonomy was not a privileged concept in the ethical frameworks of these HPC professionals. Perhaps, like the changes within applied ethics, these insights contribute to “the end of principlism”, as argued by Emanuel (1995, p. 37). For, as Gastmans (2002) reflects,

> Within this ethical framework [principlism], hardly any attention is given to basic ethical intuitions or to the attitudes of the caregivers … such ethics overlooks the fact that human beings go through a whole process of care, during which they, in close interaction with caregivers and members of their family, continually have to make minor and major decisions. Such a process of care situates itself within a well defined relational, institutional and social context (p. 82).

6.5 An ethical framework: Values

Unlike principles, values play a major role in the ethical frameworks of HPC professionals. Values were articulated both as a meaning of the ethics of HPC and as central guiding notions. This central role of values in HPC is also recognised in the literature. Schotsmans (cited in Hermsen, 2005) indicates that “palliative care is said to have a surplus value compared to other health care practices” (p. 159) and that we need

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39 I am using the terms values and goods interchangeably throughout this chapter.
“critical ethical analysis to sustain them” (Janssens et al., 2002, p. 84). Jennings (1997) affirms this when he writes “hospice reflects its own systematic set of values” and that this “value-based heritage” requires further reflection and analysis, as it has been “curiously underdeveloped” (p. 1/2). It is for these reasons that a specific focus in this study included the articulation of the central values that underpin ethical practice for the HPC professionals. This was done, in part, to ascertain whether these values had changed over time and if so what values are now crucial. In addition, I wished to compare these values to the PCA core values and the Pallium project’s findings. However, no matter which values are considered important, simply noting that values were central and distinctive in the ethical framework for HPC is a significant insight. Any ethical framework for HPC practice must include a value-base.

6.5.1 Values as distinctions of worth
Taylor (1989; cited in Abbey, 2000) considers values to be a central feature of moral life, moral identity and moral frameworks; he often refers to them as distinctions of worth or strong evaluations. This notion of strong evaluations involves the qualitative distinctions we make between different actions, or feelings, or modes of life, as being in some way morally higher or lower, noble or base, admirable or contemptible … are central to our moral thinking and ineradicable from it (Taylor, 1989, p. 42; cited in Abbey, 2000, p. 18).

Strong does not mean that they are forceful or powerful, but rather Taylor is trying to capture the quality of values (Abbey, 2000). These strongly valued goods are ranked higher or lower according to which are most worthy or desirable. Taylor points out that “I simply mean that one is operating with a sense that some desires, goals, aspirations are qualitatively higher than others” (cited in Abbey, 2000, p. 20). These qualitative distinctions of worth are viewed as central in understanding and guiding ethical practice.

In this inquiry I asked the HPC professionals to rank the three most important values which underpinned HPC practice, thereby asking them to prioritise what was “more worthy, more valuable, more meaningful or more importuning than others” (Abbey, 2000, p. 17). This was crucial in that
individuals are [not] always cognizant of the fact that they order or evaluate their desires in this hierarchical way … evaluation in this context is closer to an intuitive judgment or response than to the outcome of a reasoned, reflected process (Abbey, 2000, p. 19).

These valued goods or strong evaluations often “exist as part of the tacit background of their understandings” (Abbey, 2000, p. 21). One of the intentions of this study, as mentioned in the introductory chapter, was the objective of articulation, which was to bring this tacit background to the fore. This would, in turn, strengthen the value-based platform that is unique to HPC practice.

6.5.2 The Pallium project
The Pallium project also made an explicit examination of the moral values which underpinned palliative care (Janssens et al., 2002). These researchers found that these values “are under debate” (ten Have & Clark, 2002, p. 7) and that we require “a moral language that is different from standard medical ethical notions such as autonomy, informed consent and beneficence” (Hermsen, 2005, p. 156). The Pallium project surveyed two thousand one hundred and seventy-four European delegates of the EAPC (European Association for Palliative Care) to investigate the moral values that palliative care workers thought were an integral part of the practice. The majority of respondents held the view that palliative care implies a specific set of values different from other health care practices (Janssens et al., 2002, p. 77). They were asked to rank these values in order of importance. The findings of this survey are set out below.

6.6 Understanding HPC ethics as values
Before examining what the specific values were, however, it is important to understand that values were, for some of the HPC professionals, an important response to the question of what is HPC ethics

The ethics of palliative care is just … what it’s tied to is the values around the practice (Emma)

It’s about practicing palliative care the way I live my life. Practicing it in being true to my own values and my own values determine the ethics by which I practice (Natasha)
I think we are deep, moral creatures, so I think it’s mainly about my personal values (Naomi)

I’m guided by Christian values. That doesn’t mean that I’m committed by a doctrine of Christianity, but I do align very closely with the values of caring for others and the values of life … I suppose this is what most guides me in my work (Jackie)

The ethics for me are … basic humanistic approach of valuing people. My sense of values impact upon my work. The values that I see that are very relevant to how I live my life (Martha)

It’s about using certain personal judgments based on my own values, I guess (Amy)

Ethical practice, for me, is about … I think of the values that I’ve been bought up to believe are important (Kate)

What guides my practice are the values of the service, right down to our individual values. And I would like to think that we had considered those sorts of things before we work in the area. And also a service would have those values of the practice clearly enunciated (Emma).

It can be noted from these articulations that a direct interpretation of the meaning of HPC ethics is that of values. Notably, these were often stated as personal values and, as Emma explained, these values need to have been reflected upon or enunciated somehow. Thus, it can be appreciated that values play a major role in the understanding of ethics, in guiding practice, and in the ethical frameworks of HPC.

6.7 Original values

Hence, with this awareness that values play a central role in understanding and guiding ethical end of life caring practices, this section of the chapter now presents the specific values of HPC. This includes the original values of the hospice movement, the stated PCA values, the findings of the Pallium study, and the specific ranking of the values according to the HPC professionals involved in this study. McNamara (1998; 2004) suggests that the original ideological framework which promoted the good death included the values of an open awareness of dying, honest or open communication, and a gradual acceptance of death. These values were promoted as the central underpinnings of the original hospice movement which came about through a dissatisfaction with care of living-dying people in medical institutions and insights from eminent researchers such as Glaser and Strauss (1965; 1968), Kubler-Ross (1969) and, of course, Saunders. Of
note, however, McNamara’s (2004) study found that this ideology, and its important values, has become “increasingly inappropriate in the current climate of patient autonomy and consumer choice” (p. 929). In other words, external, societal values of individualism and choice, McNamara asserts, have superseded the original values of hospice care.

Conversely, Jennings (1997), as previously mentioned, believes that there are three different values that inspire the hospice movement: “palliation and the relief of suffering, enhancing individual control and autonomy at the end of life, and the value of healing or maintaining meaning and personal integrity in the dying process” (p. 1). This author asserts that the traditional values are “in need of continuing clarification and examination” (p. 2). In addition, Jennings (1997) argues that

What is required for this final flourishing [in the living-dying process] are human goods that go beyond freedom from pain and freedom from outside interference; as necessary as the goods of palliation and autonomy are, they are not sufficient to create a good living near death, they are not sufficient to promote the human good at the end of life … The ethics of hospice must look beyond palliation and autonomy. What it seeks is threefold: (1) sustaining relationships, (2) sustaining the integrity of the self, and (3) achieving an appropriate closure to one’s life through reconciliation with one’s past, one’s self-identity, and with others. These three goals can be summed up in a single word: healing. The root meaning of healing is ‘making whole’. The mission of hospice is to facilitate healing in this sense (p. 4).

What Jennings is explaining is that the ethics of HPC needs to prioritise the value of total or whole person care through the promotion of healing at the end of life. This is the ultimate value, according to Jennings.

6.8 Contemporary values

Jennings reflections on the values of hospice care were proposed in the late nineteen nineties around about the same time as Palliative Care Australia (PCA) was conducting its own examination of the core values of the practice. These core values were articulated “in consultation with the palliative care community” that resulted in the 3rd Edition of the Standards for the Provision of Palliative Care” (PCA, 1999, p. 3). The latest update of the core values of hospice palliative care are presented in the Standards
for Providing Quality Palliative Care for all Australians (2005). PCA explains that the standards are based on a number of core values - dignity, empowerment, compassion, equity, respect, advocacy, excellence and accountability (PCA, 2005, p. 13). As pointed out in the introduction, the processes for locating these core values are unknown to me, except that it was done via consultation with the palliative care community. Notably, the recent additions to this list of core values reflect corresponding values in the health care context; in other words, values such as empowerment, advocacy, excellence and accountability reflect similar stated values in the health care arena.

The Pallium project provides us with the next list of core values for the profession. As mentioned above, a large number of European HPC professionals were surveyed to ascertain what moral values they believed underpinned the practice. Janssens et al. (2002, p. 78) provide the findings of this study.

Table Six: Pallium project moral values

<table>
<thead>
<tr>
<th>Number</th>
<th>Moral Values</th>
<th>Per Cent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Quality of life</td>
<td>97.5</td>
</tr>
<tr>
<td>2</td>
<td>Human dignity</td>
<td>92.7</td>
</tr>
<tr>
<td>3</td>
<td>Acceptance of human mortality</td>
<td>92.7</td>
</tr>
<tr>
<td>4</td>
<td>Total care</td>
<td>91.3</td>
</tr>
<tr>
<td>5</td>
<td>Nonmaleficence</td>
<td>84.3</td>
</tr>
<tr>
<td>6</td>
<td>Authenticity</td>
<td>84.1</td>
</tr>
<tr>
<td>7</td>
<td>Autonomy</td>
<td>81.0</td>
</tr>
<tr>
<td>8</td>
<td>Empathy</td>
<td>80.7</td>
</tr>
<tr>
<td>9</td>
<td>Beneficence</td>
<td>78.2</td>
</tr>
<tr>
<td>10</td>
<td>Hope</td>
<td>74.7</td>
</tr>
<tr>
<td>11</td>
<td>Solidarity</td>
<td>64.9</td>
</tr>
<tr>
<td>12</td>
<td>Compassion</td>
<td>64.7</td>
</tr>
<tr>
<td>13</td>
<td>Prudence</td>
<td>64.2</td>
</tr>
<tr>
<td>14</td>
<td>Holism</td>
<td>63.1</td>
</tr>
<tr>
<td>15</td>
<td>Justice</td>
<td>61.9</td>
</tr>
<tr>
<td>16</td>
<td>Love</td>
<td>50.7</td>
</tr>
<tr>
<td>17</td>
<td>Sympathy</td>
<td>40.8</td>
</tr>
<tr>
<td>18</td>
<td>Sanctity of life</td>
<td>30.7</td>
</tr>
</tbody>
</table>
As can be seen, the value ranked the highest in this European study is that of quality of life. Furthermore, the original values of hospice care – that of acceptance of human mortality and total care – are also ranked high on the list of important moral values for the European HPC professionals. This translates into an understanding that the original values have not eroded, but are still intact and viewed as crucial. Secondly, it can be noted that the four principles of biomedical ethics are ranked and are valued, even though not as highly.

These European researchers concluded that in light of quality of life, holistic care and acceptance of death all being highly regarded values of hospice palliative care, it became clear to them that the supposed processes of the medicalisation of the practice “touches at the heart of palliative care” (Janssens et al., 2002, p. 82). Yet interestingly, even though most of the professionals in this European study do adhere to a set of values that are unique to the profession of hospice palliative care, they also thought that the integration of palliative care into the mainstream of health care (eighty four percent agreed that HPC should be integrated) did not necessarily “mean that the hospice philosophy [and original values are] are going to be neutralised” (Janssens et al., 2002, p. 84). This can be interpreted to mean that “adherence to a specific set of values of palliative care can go together with integration into the mainstream health care system” (Janssens et al., 2002, p. 80). I would argue, however, that if this is to be the case the profession of HPC would need to reflect upon, maintain and protect this unique values-base of HPC practice whilst being immersed in the biomedical context.

6.9 Values from the HPC professionals
With the presentation of previously articulated values complete, this section now reveals the specific values that were chosen to be the significant ‘goods’ of HPC practice here in Queensland. By way of assisting with the identification of values, a set of values cards were provided to the HPC professionals. This set of values cards incorporated the original hospice values, the European survey values, the PCA stated core values and others were added during the process of interviewing, as explained in chapter two. These specific values were presented in table five (pp. 86/87). The professionals were
asked to prioritise three values in line with Taylor’s idea of ranking according to strong evaluations. This was difficult for some as they believed that the majority of the values were equally important. That being said, I still requested them to prioritise three. The table below outlines the particular values chosen and the ranking of them.

**Table Seven: Queensland HPC professionals’ values**

<table>
<thead>
<tr>
<th>Number</th>
<th>Values</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Acceptance and awareness of human mortality (dying-as-natural)</td>
<td>73</td>
</tr>
<tr>
<td>2</td>
<td>Total care (whole person care)</td>
<td>60</td>
</tr>
<tr>
<td>3</td>
<td>Open and honest communication</td>
<td>47</td>
</tr>
<tr>
<td>4</td>
<td>Compass</td>
<td>47</td>
</tr>
<tr>
<td>5</td>
<td>Information and knowledge (education)</td>
<td>40</td>
</tr>
<tr>
<td>6</td>
<td>Nonmaleficence (do no harm)</td>
<td>30</td>
</tr>
<tr>
<td>7</td>
<td>Advocacy</td>
<td>30</td>
</tr>
<tr>
<td>8</td>
<td>Justice</td>
<td>27</td>
</tr>
<tr>
<td>9</td>
<td>Dignity</td>
<td>23</td>
</tr>
<tr>
<td>10</td>
<td>Relationships</td>
<td>23</td>
</tr>
<tr>
<td>11</td>
<td>Respect</td>
<td>23</td>
</tr>
<tr>
<td>12</td>
<td>Authenticity</td>
<td>23</td>
</tr>
<tr>
<td>13</td>
<td>Hope</td>
<td>20</td>
</tr>
<tr>
<td>14</td>
<td>Empowerment</td>
<td>20</td>
</tr>
<tr>
<td>15</td>
<td>Quality of life</td>
<td>17</td>
</tr>
<tr>
<td>16</td>
<td>Caring</td>
<td>13</td>
</tr>
<tr>
<td>17</td>
<td>Acceptance and non-judgment</td>
<td>13</td>
</tr>
<tr>
<td>18</td>
<td>Love</td>
<td>13</td>
</tr>
<tr>
<td>19</td>
<td>Comfort</td>
<td>13</td>
</tr>
<tr>
<td>20</td>
<td>Empathy</td>
<td>13</td>
</tr>
<tr>
<td>21</td>
<td>Relief of suffering</td>
<td>10</td>
</tr>
<tr>
<td>22</td>
<td>Accountability</td>
<td>10</td>
</tr>
<tr>
<td>23</td>
<td>Autonomy</td>
<td>3</td>
</tr>
</tbody>
</table>

40 Please note that some HPC professionals still choose more than three values cards. There were a total of 178 values picked by 30 HPC professionals. This means an average of 5.9 responses per person. The percentage indicates the HPC professionals who listed a particular value as crucial to underpinning the practice.
What can be understood from this quantitative investigation of values is that acceptance of human mortality\(^{41}\) (seventy three percent) and total or whole person care (sixty percent) were the highest ranked values. Third on the list was open and honest communication at forty seven percent. Therefore, these responses show that the original values of the hospice movement are still considered of highest worth and have not been eroded. The prioritising of these three values corresponds with the values-based heritage of the original hospice mission. As mentioned by Jennings (1997) it is healing, or the adherence to total or whole person care, that provides for the ultimate value platform from which to practice, coupled with the appreciation of dying as a natural and normal part of life. In addition, compassion, as the fourth highest ranked value at forty seven percent, also corresponds with the original stance of caring at the end of life, as Saunders often emphasised the place of compassionate caring. These four main values must play a major role in the ethical frameworks for HPC practice. This is further reinforced by the insights from the understandings and articulations of the philosophy of (total) care, as presented in chapter three. Ultimately, the original hospice values have not withered with time.

This is the case for the European context as well, as acceptance of human mortality and total care were both prioritised as the third and fourth highest values of the profession. A noticeable difference between the two studies is that the Queensland HPC professionals ranked quality of life considerably lower at only seventeen percent. From this insight is can be presumed that quality of life is not seen to be a dominant good for the HPC professionals in the Queensland context, unlike their European counterparts. A further difference pertains to honest and open communication, an original value of the hospice movement, which was ranked third in this study, but not mentioned at all by the Europeans. The value of nonmaleficence is ranked similarly in both studies, being fifth for the Europeans and sixth for the Queensland context. This again reinforces the centrality of this principle and the call for further examination of the meaning of this principle for HPC practice. A further difference between the two rankings of values

\(^{41}\) Please note I am using the language of ‘acceptance of human mortality’ and ‘dying-as-natural’ interchangeably throughout this thesis.
concerns the principle of respect for autonomy, where the Queensland context ranked it last at three percent, whereas the Europeans ranked it seventh at eighty one percent. This is a noticeable difference and fits with the dubiousness portrayed by the professionals of this study about the concept of autonomy in HPC. A further interesting difference between the two inquiries is the valuing of information and knowledge. This was ranked as a highly important ‘good’ of the practice by the Queensland HPC professionals, being mentioned as valuable by forty percent of the professionals, but again not mentioned by the European study. The reasons for the increasing value of information and knowledge in the field of HPC are varied and could include

- A Western societal valuing of information;
- The assumption that with knowledge comes power and control;
- A predominant understanding of the role of HPC as information-provider and its link to empowerment;
- Legal protocols and processes concerning informed consent;
- Being responsive to a cohort of people who highly value knowledge and information;
- Linked with a dominant, modernist understanding of personhood (self-as-mind).

Whatever the reason or reasons may be, this valuing of information and knowledge needs to be recognised and further investigated as to how it is currently being provided, how helpful this is and how best to provide this aspect of HPC practice.

A comparison between the stated PCA list of core values and the findings of this study was also thought important. This table below offers such a comparison.

**Table Eight: Comparison of PCA and HPC professionals’ values**

<table>
<thead>
<tr>
<th>PCA Values</th>
<th>HPC Professionals Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compassion</td>
<td>Ranked 4&lt;sup&gt;th&lt;/sup&gt; (47%)</td>
</tr>
<tr>
<td>Advocacy</td>
<td>Ranked 7&lt;sup&gt;th&lt;/sup&gt; (30%)</td>
</tr>
<tr>
<td>Equity</td>
<td>Ranked 8&lt;sup&gt;th&lt;/sup&gt; (27%)</td>
</tr>
<tr>
<td>Dignity</td>
<td>Ranked 9&lt;sup&gt;th&lt;/sup&gt; (23%)</td>
</tr>
<tr>
<td>Respect</td>
<td>Ranked 11&lt;sup&gt;th&lt;/sup&gt; (23%)</td>
</tr>
<tr>
<td>Empowerment</td>
<td>Ranked 14&lt;sup&gt;th&lt;/sup&gt; (20%)</td>
</tr>
<tr>
<td>Accountability</td>
<td>Ranked 22&lt;sup&gt;nd&lt;/sup&gt; (10%)</td>
</tr>
<tr>
<td>Excellence</td>
<td>Not ranked</td>
</tr>
</tbody>
</table>
What can be noted from this comparison is that values such as excellence, accountability and empowerment, although important values, were not prioritised by the HPC professionals in this study. However, the other stated PCA values (compassion, equity, advocacy, dignity and respect) were certainly ranked higher by the HPC professionals in this study. Curiously, it is these very values of excellence, accountability and empowerment that have been recently added to the PCA list in 2005, and these, arguably, have been transferred across from a health care context. It would seem that the HPC professionals in this study did not find these to be core values for HPC practice.

What are clearly missing from the PCA core values are the prioritising of acceptance of human mortality, open and honest communication and total care. These are certainly included as part of a definition of the practice by PCA, but have not been included as core values. I would suggest that this needs to be altered and these three top values need to be included and acknowledged in any documentation offered by PCA.

What can be summarised from this presentation of the core values of HPC in this study is that there are both similarities and differences between the Queensland and European findings, notably the prioritising (or not) of quality of life and the place of autonomy. Yet, aside from these notable differences much of the ranking of values is reasonably similar. Secondly, the PCA values, in the main, correspond with the Queensland professionals’ rankings. However, it is argued that a much more explicit mention of the three top values need to be incorporated into the list of core values for the profession, as listed in the ‘Standards for providing quality palliative care’. It is these three values which play the main role in the values-base platform for this social practice. Next, it is understood that the original hospice values are still the central goods of end of life care. These three dominant values of acceptance of human mortality, total care, and open and honest communication are still considered crucial and valuable to end-of-life caring practices and must be protected and promoted. This is especially important given the erosion of total care, as outlined in chapter three. Finally, I am proposing that because acceptance of human mortality is ranked as the foremost good in HPC practice this then translates into a distinctive ethical context for the profession. This central good, therefore, warrants further consideration.
6.10 Acceptance of human mortality: Dying as natural and valuable

I guess for us in palliative care that acceptance of human mortality underlies everything we do … if you don’t have that … well you don’t do palliative care (Michael).

It is an acceptance (or acknowledgement) of human mortality, as the most mentioned and highest prioritised value, that plays a central role in the distinctive ethical framework of hospice palliative care. To explain further, when the other values of HPC are considered it could be said that most of them can be seen to be important in health care as well. For example, the health care arena would most likely incorporate the values of compassion, holism, good communication, advocacy and so forth. Yet, the number one value of acceptance of human mortality is wholly unique to hospice palliative care. It is not a value that is prioritised or practiced in other health care settings. This value speaks of the fundamental ethical basis and intention of the hospice movement – to provide a place for people to die, to speak of dying, to seek value in the dying process and to shift the societal attitude of denying or fearing death. Thus, this ultimate valuing of dying-as-natural translates into a unique ethical culture for HPC. The HPC profession is declaring through the prioritising of this value: Here is a place where you can talk about dying and death, where you can prepare for death, and where we can understand both the value and the suffering inherent in the living-dying process, and perhaps find meaning in death, and even reduce the fear associated with this great unknown journey.

Consequently, HPC professionals bring knowledge, skills, qualities, attitudes, and the stance of acknowledging the limits to human mortality, to help people on this inevitable journey towards death. Throughout the conversations with the HPC professionals this worth of dying-as-natural, not as illness or failure, was repeated. I include some of the articulations from the HPC professionals of the centrality and importance of this value in their practice

We really seem to accept mortality and we are usually the ones that say ‘oh, for god’s sake stop doing all this treatment’, and accept the fact that this person is dying (Martha).

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42 I certainly appreciate, however, that judgments about whether or when a person is dying are fraught and difficult.
I think that most palliative care people have … can do it [accept that people are dying] well, because they’ve already confronted their own mortality. I think we have to be able to do that (Stacy)

We try to bring it back to being a part of life, something that we can deal with, that we can come together as a community, as a family, and deal with it in an open way, rather than putting it over there. I think our society’s attitudes to human mortality are unhealthy and destructive … everybody dies (Julie)

You just know its there [death] … that doesn’t mean that I want that … but it is a part of life … it is going to happen (Natalie)

We tippy-toe around this too much. We don’t bring it to the fore enough. I think sometimes we do dying people an injustice, because I think on the whole they are very aware that they are dying. They’ve put the house in order … they may not want to talk about it. So I think if you don’t have that acknowledgement of dying, you can miss out on that opportunity to say some of those precious things. And I think we have a central role to play in being proactive about getting out in the community and talking more about death and dying (Frieda)

If we put as much attention in people dying as we do when they are born they’d be a lot better off (Jackie)

I’d like to go back to people realising that we are going to die one day and there is definitely a need for us to understand this inevitability. Palliative care can help with this. I don’t want to die, but I am going to. Death doesn’t frighten me anymore (Anna)

I think we accept that people are going to die and given this fact we focus on how we can facilitate this death for them, and for the family (Peter)

It’s funny really. I’ve been working in palliative care for many years now. I don’t think I’ve felt that way for a long time [accepting death] and then it just sort of happens. I woke up one morning and it didn’t bother me anymore. To me it’s another important stage of life … a natural thing (Elizabeth)

It’s so important … essential really … to do palliative care well you must have an acknowledgment, or some part of an acceptance, of death. Once you view it as a natural and normal thing then you lose all of that fear about yourself and what you are doing (Jennifer)

Don’t mention the ‘d’ word [laughing], but that’s what palliative care is all about. The whole reason it came about was to make people more aware … to support people in their dying. There has to be discussions around death and it doesn’t have to be morbid. Death is a natural process, but it’s a very difficult process. We need to acknowledge this (Kate)

Our role in palliative care should be around community development … try and make sure that people see that death is a part of life and take away that fear (Emma)

The hospice philosophy is all about accepting the reality of death … that’s the core thing … that people are not always able to be cured (David)
We’ve lost sight of the fact that we do have to die. Yes, you need to have it [acceptance of human mortality]. You certainly need to be conscious of your own mortality. I don’t think you can really help others very effectively if your basic fears and anxieties haven’t been worked through. I don’t think you can live properly unless you accept dying (Naomi)

I didn’t originally pick that card [acceptance of human mortality] because I feel that we should all just have it … it should be a given in palliative care (Lisa).

Understanding that dying is a part of life, that it is a natural and normal process and that it need not be denied or feared, were all expressions regularly mentioned by the HPC professionals in this study. For many, this quite simply was what hospice palliative care is all about. Clearly, it is the central ethical underpinning of end of life caring practices, whether it was spoken of in terms of an intention or a purpose, as part of their practice, as something which is highly valued, as the ultimate ‘good’ of the practice, or simply as a concept to be discussed.

Thus, it can be argued, like total care, an acceptance of human mortality as a core value is still firmly in place from the original hospice movement. Saunders (1994) emphasised this value when she wrote that there needs to be a “readiness to accept that all of us will eventually die and recognition [whilst providing HPC] that this time has now come” (p. 782). Yet, although acceptance of human mortality was, and still is, a central value of HPC practice it is also, like total care, being influenced by biomedicine, particularly with the movement of HPC practice into mainstream health care and the proposed medicalisation of the practice. As Janssens et al.(2002) note, more often now palliateurs will “have to find a way to keep doing justice to their innermost motivations [valuing dying-as-natural] in the context of institutions that are a part of mainstream health care systems” (p. 84). For this stance of openness and inevitability of dying does not sit comfortably in a highly technical, curative medical system.
6.10.1 The mainstreaming of HPC: Incommensurable values

We have to ask ourselves whether medicine is to remain a humanitarian and respected profession or a new but depersonalized science in the service of prolonging life rather than diminishing human suffering (Kubler-Ross, 1969, p. 10).

With the mainstreaming of HPC, this practice now sits immersed in a biomedical sphere which values and aims for the curing of diseases, the treating of physical symptoms and the prolongation of life. How then can HPC practice, which includes the valuing of an acceptance and awareness of dying, sit within this health care context? This is clearly a point of tension and difficulty when it is considered that HPC practice more often nowadays is being carried out in these health care contexts. Randall and Downie (2006) make this point when they write that “the third aim of health care, that of prolongation of life, becomes very problematic in the context of palliative care” (p. 97). In other words, understanding, accepting and valuing dying-as-natural sits in tension with an overt focus on life prolongation.

Thus, these two ‘goods’ of dying-as-natural and life prolongation are likely to be incommensurable values when HPC practice is provided in biomedical contexts. Certainly, they may be able to be reconciled in practice by sensitive practitioners. Interestingly, when referring to this quandary, Randall and Downie (2006) assert that the aim of prolonging life needs to be included in the WHO definition of palliative care “since this aim is indisputably intrinsic to health care” (p. 100). What these authors are arguing is that the aim of prolonging life should now be a part of the philosophy and practice of hospice palliative care as they view this practice as being a part of health care. Indeed, for one HPC professional in this study, this change has already occurred.

43 What must be noted here with Randall & Downie’s assertions is that the outline of the goals of medicine presented by them differs from those outlined by Hanson & Callahan (1999) and Callahan (1996). In Olthuis’ (2007) text he draws on Hanson & Callahan’s (1999) four goals which are: (1) the prevention of disease and injury and the promotion and maintenance of health, (2) the relief of pain and suffering caused by maladies, (3) the care and cure of those with a malady, and the care of those who cannot be cured, and (4) the avoidance of premature death and the pursuit of a peaceful death. Olthuis then states that because of these goals palliative care therefore is an integral part of medicine. Certainly we could assume that the achievement of a peaceful death has been a part of medicine since antiquity as Callahan would suggest, however, I would argue that there is a powerful and overt focus on cure, as suggested by Randall & Downie, and that this is in conflict with the aims of hospice palliative care or that life prolongation is starting to influence the practice of HPC. It would seem that the goals of medicine, too, are complex and under debate.
But we hope that maybe … that hopefully with good palliative care people do sometimes live a bit longer … that we can prolong how long they live … and that’s changed a bit (Nina).

Notably, this HPC professional was working within a large acute care hospital setting.

Anna, a palliative care nurse from McNamara’s (2001) study, believed that many healthcare professionals who purport to offer palliative care now provide “a watered down version” of what HPC is supposed to be about (p. 130). Anna believes that the ideals or philosophy of palliative care were not transferring well, but that it was the clinical skills which were the focus of educational processes. The dilemma for this HPC professional was that “it is still a frequent occurrence that we get people who have been treated until days, if not hours, of death from those very units who propose that they offer palliative care” (McNamara, 2001, p. 130). Hence, even with this prioritising of dying-as-natural the mainstreaming of HPC may equate to an overriding or erosion of this central value. Ultimately, McNamara (2001) asserts, with the movement of palliative care into the mainstream health care system “there is a very real possibility that the founding ideals of the hospice movement [which include acceptance and awareness of dying] may be lost in the process” (p. 129).

6.10.2 The medicalisation of HPC: Masking of dying
What goes hand in hand with the mainstreaming of HPC is the increasing medicalisation of the profession, as outlined in both the introduction and chapter three of this thesis. This increasing medicalisation also affects the valuing of acceptance of human mortality. Just like the practice of total care, this openness and valuing of dying and death is also in danger of being superseded or eroded by the powerful influence of biomedicine. Already occurring signs of this erosion include

- The language of dying and death is used less and has been replaced by terms such as life-limiting illness in the PCA Standards (2005);
- There is a noticeable increase in providing treatments, either for palliation or prolongation, in HPC including palliative chemotherapy and palliative radiotherapy;
- There has been a shift in focus from the question of dying well to the problem of living well (McNamara, 2004, p. 936);
• The suggestion of including life prolongation in the aims of hospice palliative care by Randall and Downie (2006) and the inclusion of “may positively influence the course of the illness” in the WHO definition.

McNamara (2001) has been vocal in this supposition that with the medicalisation of HPC comes a “masking of dying” (p. 121). She explains that the “focusing on the medical responses to the pain associated with dying, in some way mask or cover the actual process of dying” (p. 121). McNamara believes that this ‘refocus’ on the medical aspects of dying now being practiced in HPC “pushes the phenomenon of death away through technology and pretence” (p. 121). Overall, she believes that this broader approach to palliative care provided for in biomedical contexts “may not include an acceptance and an openness to dying and death” (McNamara, 2001, p. 130).

What this translates into is that with the mainstreaming of HPC, and the proposed medicalisation of this practice, the aim and valuing of life prolongation is encroaching into the practice of caring for the dying. Most likely the original founders of hospice care would not be pleased about this in that life prolonging measures were rarely provided. Randall and Downie (2006) outline three reasons why this was the case

1. Such measures were seen as yielding little benefit in the face of inevitable death
2. The technology involved was considered to make death less dignified and to prolong the dying phase of the illness attached to tubes and machines;
3. The provision of such treatment was thought to discourage acceptance of the inevitable approach of death, and acceptance was thought to be the attitude associated with least emotional suffering for the patient (p. 101).

With the outline of these reasons one could ask are not these reasons still appropriate and relevant in 2008. Do technology, tests and treatments not seem futile and undignified in the face of dying? Does not the approach of ‘treatment-until-death’ still seem undignified? However, I do acknowledge the incredible difficulties involved in this complex question of - when is a person actively dying? This complexity includes our overt Western assumptions that medicine will cure all diseases. Certainly, it is understandable nowadays that medicine “finds it harder and harder to locate the line between living and dying, and thus to know when to stop treatment” (Callahan, 1993a,
Therefore, “balancing technical interventions with a humanistic, caring approach to patients lies at the heart of palliative care” (Olthuis & Dekkers, 2003a, p. 193).

6.10.3 Sustaining acceptance of human mortality
Arguably, HPC as a social practice needs to maintain this valuing and prioritising of acceptance of human mortality. Hospice palliative care was set up, and needs to continue to be viewed, as a distinctive practice designed specifically for people recognised as living-and-dying. Within this viewpoint is that prolonging life and offering overt treatments is not the focus or value of HPC, but rather it is recognising that someone is dying, their disease is no longer curable, and that “it differs from most in approaching every person anew, as a unique emotional, social and spiritual whole” (Saunders, 2007, p. 1). In other words, the profession needs to maintain, sustain and protect this ultimate good of understanding and appreciating that dying is a natural, normal and valuable part of life. If our health care system continues to prioritise an overt focus on treatment and curing this might translate into death being “moved out of nature into the realm of human responsibility” (p. 64) and, hence, the assumption that death can be eradicated will continue to grow. Callahan (1993a) asserts that there needs to be a shift in “the presumption to treat … [so to] enhance a conscious and socially engaged death” (p. 202).

6.10.4 Death education
In order to sustain this value HPC educational programs must provide death education. Currently, death education is only superficially addressed (Sheldon, 1998) or not addressed at all. This was the monumental task which Kubler-Ross faced in the 1960s in health care institutions. In the end, Kubler-Ross (1969) discovered that “it has been most helpful in making the students aware of the necessity of considering death as a real possibility, not only for others but also for themselves” (p. 23). More recently, Kellehear’s (1999a) health promotion framework for palliative care has reinvigorated the priority of death education. Kellehear (1999a) explains that death education can serve useful functions for both the living-dying person and the professional caregiver. Death education “provides a forum for the dissemination and discussion of death-related
issues – such as social preparations for death, philosophical, existential, or religious (that is, spiritual) discussions about death, or information and education about grief and loss” (p. 21). Through these educational processes, it is hoped that professional caregivers and living-dying people alike, can come to understand their attitudes to dying and death and how these have been formed, as well as being able to understand dying as both a negative and positive (valuable) experience.

The value of dying seems almost an oxymoron in these modern times, yet the HPC professionals in this study often expressed ideas about the value inherent in the living-dying process. This came in the form of notions such as opportunity, preciousness, time, and healing. To finish off this section of the value of acceptance of human mortality I present a short poem, which has been composed from the HPC professionals’ storied accounts, which speaks of what value can be gained with the recognition and acknowledgement that one is dying.

It’s a special time,
Which holds an abiding sense of value.
The opportunity to say the things that need to be said
Of doing the things that need to be done,
Meaningfully facilitating precious opportunities
Showing them how to grab hold of these.

This dying time,
What would you do with this knowledge of finite time?
It’s a special experience,
This time is really precious.
Reliving the good times and the bad
Reflecting on the journey of life.

Making that a meaningful and valuable time,
Right throughout your involvement with them.
We need to come back to the realisation,
That it’s a time to enable us to grow in wisdom and love.
Yes, that peace and those possibilities at the end of life.

From these expressions, locating the value in the living-dying process is a significant element in ethical HPC practice. In summarising this section on values, HPC professionals do adhere to a specific set of values and these values are unique to the context of end of life care. In particular, the values of total care, acceptance of human
mortality, and honest and open communication all being ranked highest means that the original hospice values are still alive and well in contemporary hospice palliative care services. However, working both within and alongside a biomedical domain with its overt focus on life prolongation and curative treatments equates with a possible difficulty in maintaining this stance of dying-as-natural and normal, and the valuing of the dying process in and of itself. Hence, further education and ethical reflection is required to maintain, sustain and protect this highest good in hospice palliative care practice and indeed for the other original hospice values as well. What is also important to consider in this presentation of the values of HPC is that they are closely bound up with a person’s identity: for “our identity is defined by certain evaluations which are inseparable from ourselves” (Taylor, cited in Abbey, 2000, p. 24). Therefore, considerations of identity need to be included in an ethical framework for HPC practice as well.

6.11 An ethical framework: Virtues

Ethical practice in hospice palliative care is closely interwoven with who a person is - his or her self-identity and who others believe you are. A facet of one’s identity is a person’s qualities or dispositions. An engaged ethics approach fosters an understanding of this role and development of self dispositions44 in the ethics agenda. Isaacs (2005c) explains that

> Rather than adopting a stance towards the other that is detached, neutral and objectifying (which is a stance adopted by the modernist self), the good self of an engaged being-in-the-world seeks to acknowledge attachments and interconnectedness, seeks to be both responsive and responsible, and seeks, therefore, to cultivate attitudes and dispositions that are open, humble, respectful and caring (p. 6).

This cultivation of attitudes, dispositions and virtues equates to a further component of the ethical framework for HPC practice and can be explored through a virtue ethics perspective. As Olthuis (2007) asserts, “people who are involved in palliative care on a daily basis act, either implicitly or explicitly, from a specific moral attitude. This moral attitude is defined in general terms as ‘the motivation and commitment to act in the

44 I am using the terms virtues, dispositions, qualities, and at times attitudes, interchangeably.
interest of other people”” (p. 3). This section, therefore, presents the storied accounts of the HPC professionals in terms of the expressions that pertain to HPC ethics as “tied up with who I am” (Olthuis, 2007, p. 135). This includes a brief explanation of virtue ethics, some inclusion of Olthuis’ study into the moral attitude of palliative care professionals, and an exploration of the particular virtue of compassion.

6.11.1 Virtue ethics

This emphasis on self-identity and the attitudes, dispositions or qualities that HPC professionals bring to their practice can be considered through the understandings of virtue ethics. This particular understanding of, and approach to, ethics has undergone a considerable revival of late (Slote, 2000). Olthuis explains that virtue ethics (1) “relates good behaviour to the kind of person someone is, and (2) offers insight into the way in which the qualities that are a prerequisite for such behaviour can be (further) developed” (p. 109). It is an ancient ethical theory that asks the questions of who are we to be, or how are we to act, and “as such should be of great import to persons who profess publicly, as members of their discipline, to be worthy of trust” (Austin, 2007, p. 54). Moral virtues, also known as qualities or dispositions, “inform the entirety of our life”, and call upon us to develop our human capabilities, explains Austin (2007, p. 56). MacIntyre (cited in Austin, 2007) particularly reinforces the importance that key moral virtues, such as courage, justice and honesty, play in social practices.

Olthuis (2007), too, reinforces the importance of moral virtues, “assuming an inseparable connection between virtue on the one hand and practice, motivation, emotion and practical wisdom on the other” and that these virtues “arise from practice and education and make a person likely to perform particular actions as a matter of habit” (p. 109/110). Thus, moral virtues like compassion and honesty, which are the goods that form the platform of ethical end of life care, are developed “as they [HPC professionals] live their lives” (p. 110). This virtue ethics approach “offers a meaningful (rather than idealistic) way to understand and develop ethical practice” (Austin, 2007, p. 56) and, thus, must be included in an ethical framework of HPC practice.
6.11.2 HPC ethics as who we are

As explained in an account of personhood according to an embedded perspective, distinctions of worth or central moral values are inextricably linked to questions of identity. This moral identity is explored by Taylor (1988) who explains that “being a self is existing in a space of issues, to do with how one ought to be, or how one measures up against what is good, what is right, what is really worth doing” (p. 298). In addition, our ethical frameworks, writes Taylor (cited in Abbey, 2000) include this question of who or “what is it good to be” (p. 34). The main point being made is that ethical end of life caring practices and the ethical frameworks professionals bring to their practice have much to do with the personal identity of the caregiver. This inseparability between who we are and the ethics of HPC practice was reinforced in the storied accounts from the professionals

I think it’s because I actually believe that my code of ethics within my life is how I live my life. This is more important. It’s got to come from within the person, to guide me in my work (Nina)

My practice is more guided by just who I am and how I live my life, and how I relate to people. Because of who I am, this is how I work (Julie)

What makes me is the journey I’ve had, my personal experiences. So that makes me who I am and I can’t change who I am and this is how I work (Anna)

It’s something about how you live your daily life. I would hope that I act out there [in her work] as I do with my family (Jennifer).

What can be heard in these expressions is: this is who I am, this is how I live my life, and this is how I ethically practice HPC - these three elements are interconnected. Or, in other words, there is no boundary between the personal and the professional. End of life caring practices are typified by a human to human encounter. Saunders (2003) reinforces this when she states that “there has always been a human as well as a professional basis that is fundamental to the work that we do” (p. 36). Kubler-Ross (cited in Youk, 2004), too, made this point when she said that people who cared for the living-dying needed “courage to not be in the professional role, but to be a human being … but we were told we must not get close, not get involved, keep your distance, but I knew this was wrong”. The HPC professionals in this study too reinforced this stance of being authentic, of being a human being, rather than simply another professional.
I don’t want to be their health professional. I want to be Anna, because this is their last journey (Anna)

You can’t divorce who you are with how you are with another person (Michael)

I think that’s a part of working in palliative care. That people aren’t afraid to show themselves and to show that they are vulnerable, which is good (Zoe)

This is so critical in the relationship with people, that … you know … the last thing I would want when you are dying is bull shit … someone to come in and not be authentically who they are (Gavin)

For me that’s the bottom line of everything that we do … it’s about me, being who I am, so that people can also be who they are … its probably about ‘as you are’ (Wendy)

Authenticity is important in terms of being real … its not about putting on an act, or acting in a role … so the more authentic I am in being who I am, the more likely I am able to help people and they know that you’re not hiding anything (Kieran).

This stance of being human, of being authentic, of being someone with particular moral virtues translates into ontological intimacy and trusting relationships. This differs from other professional caregivers who may prefer an objective, neutral stance in relation to their patients. HPC professionals seem to be saying that at this time of life, to be able to help people on their journey towards death and create and sustain the type of relationship that is meaningful and helpful, a much more ‘human face’ is required. This does not mean, however, that professionalism, skill and knowledge is not important, but that simply there is much more of an emphasis on showing ourselves as who we are.

6.11.3 Moral attitude and development

Olthuis (2007), therefore, argues “that the performance of palliative care professionals is closely interwoven with the people that they are, [and that this] is something that goes to the heart of the moral attitude of these professionals” (p. 135). The attitude of a HPC professional towards the living-dying person “is always a moral attitude which reflects the personal motivation and commitment of someone to act in the interest of other people” (Olthuis & Dekkers, 2003b, p. 929, original italics). This is not simply something that we do, but speaks fundamentally about the way we are. In other words, this moral attitude is inherently connected to the kind of person someone is (Olthuis & Dekkers, 2003b). It is this moral attitude, and the virtues associated with it, that is a
further crucial element in the ethical framework for HPC and, as such, needs development and reflection. Randall and Downie (1999) make this point when they write that caring practices “should be the products (sic) not just of a technical, scientific mind, but of a humane and compassionate one. That is why it is important for the professional to be more than just that; to be a morally developed person” (p. 14). This willingness to develop and grow as a person was also evident in the storied accounts of the HPC professionals as well

It’s just an ideal way of being able to benefit people and being able to develop yourself. I think I’ve become much more accepting of the fact that you can’t really change things. You just go there and do what you can; be yourself and often you find that works. It’s a real opportunity to develop yourself and think about what you value (Julie)

If you actually listen to what they teach you, you must be changed by it. I think it’s quite a long journey and they [HPC professionals] need preparedness on their part to be changed by it. Not to actually come thinking either that they have the answers or that they will in fact find the answers, but being open to being changed by it. You just have to continue to be open, to being changed and learning (Natasha).

I’ve certainly learnt to be a lot more patient and understanding. I’m sure I’ve learnt to be more tolerant of people’s differences (Naomi).

The HPC professionals here are saying that they believe that openness to learning, changing, and growing is essential in ethical end of life caring practices. Olthuis (2007) believes that this moral development can be assisted by phronesis, a virtue ethics concept, that should be considered as a capacity that motivates appropriate action in particular situations. It is a quality that enables someone to deliberate about what is good or bad for a human being in a particular situation and, as a consequence, enables the deliberator to act appropriately. Phronesis is not a feeling about what is good, nor just a capacity to make a good choice. It is, rather, a habitual disposition to act well (Olthuis & Dekkers, 2003a, p. 196).

Phronesis is usually translated into practical wisdom and is something that we learn “from experience set within a community” (Austin, 2007, p. 59). Practical wisdom and reflection, not only on one’s practice, but also in practice and for practice, is an essential part of the ethics of HPC.
6.11.4 Compassion: The most central motivating force

This moral development is especially important when the core values of HPC include such a virtue as compassion. A brief look at the notion of compassion is warranted given that it is the fourth value listed as crucial to the practice of HPC and an oft mentioned concept in the interviews with the HPC professionals in this study. Compassion, I believe, is an often misunderstood concept and practice, with competing definitions. Cassell (1991b) writes that the roots of the word compassion mean to suffer with another, yet “it appears impossible truly to know that another suffers” (p. 25). Randall and Downie (1999) similarly explain that compassion is “suffering with someone … and that the capacity to identify with the feelings of others is the natural basis of compassion” (p. 14). These authors go on to explain that compassion has three elements to it:

- an affective aspect (we feel with others)
- a cognitive aspect (we have insight into the situation of others)
- a conative aspect (we are moved to act on behalf of others; our volition or desire to act) (p. 14).

These three elements of compassion can be heard in the HPC professionals’ storied accounts, where they spoke at length about this important value, concept and virtue:

Compassion is about a feeling. It’s also about empathy because it’s about words and feelings. Empathy is picking up the feelings, but you may not necessarily act compassionately. So there is an element of feeling and an element of acting upon it. But if you always deliver compassionate care then I think you’re working from a very good base (Stacy)

Well you know what the definition of compassion is. It’s to acknowledge someone’s suffering and then to help minimise it if possible. Well that’s my definition anyway (Natalie)

I think compassion is about trying to understand each other, where we’re coming from, what our hopes and wishes are … our fears are (Peter)

Compassion is that sense of trying to understand the essence of the suffering for them and therefore to make some sense of it. It’s something that I feel quite deeply and it’s about not wanting others to suffer … and for me sometimes it’s a matter of making sense of that for myself (Natasha)

I think compassion is about a fellow feeling. It’s the feeling with what another person is going through and having the ability to identity with it … having some sense that what you are going through I can identify with because I’m a human being too. So … the
feeling with another person and that then becomes a motive to do something about it … to be there … to care (David)

I see compassion as quite a strong act. I think it’s an act of great application … an act of endurance. Compassion is an elemental component of end of life care. Compassion to me is simply the most central motivating force. That has certainly been triggered by, and grown out of, my life experience and refined by personal reflection and development (Ken)

Compassion I think … it comes down to everything … it’s about acceptance I think (Naomi)

One would hope that all people have that as a basis in this profession. You might struggle with some people, but instinctively you have to find the good in them (Lisa)

Compassion’s huge … it’s a biggie! I mean compassion to me is the Dalai Lama – he’s my role model. You’ve got to use compassion much more to come from where they’re coming from … to respect them and who they are … to talk about their suffering (Kieran)

Well I mean, I think I say everyday that I’m paid to love … that my work is really about loving … compassion is linked to this. Compassion is about where love and action meet … so to me it’s a stance (Gloria).

Hence, it can be heard that compassion is linked with understanding suffering, about acceptance of the person, about feeling with another person, and closely connected with notions of love as well. Certainly, there is often a struggle to articulate what compassion did mean for them. Sometimes, it seems that compassion is misunderstood simply as care. What can be heard, without any doubt, is the central place it holds in the practice of HPC.

Sogyal Rinpoche (1992), the author of The Tibetan Book of Living and Dying, would likely agree with this centrality of compassion in end of life caring practices, as he writes that “caring for the dying could perhaps be summed up in two words: love and compassion” (p. 187). Bradshaw (cited in Olthuis & Dekkers, 2003b) also reinforces that “the quintessential heart of palliative care is the kind of compassionate people involved in it” (p. 930). Sogyal Rinpoche (1992) outlines the Buddhist perspective on compassion
It is not simply a sense of sympathy or caring for the person suffering, not simply a warmth of heart towards the person before you, or a sharp clarity of recognition of their needs and pain, it is also a sustained and practical determination to do whatever is possible and necessary to help alleviate their suffering. Compassion is not true compassion unless it is active (p. 187).

Here, too, we can hear the importance of both the recognition and acknowledgement of what a person might be going through, but also the importance of acting on this (compassion-in-action). Kellehear (2005), in his text *Compassionate cities*, explains that compassion has a quality of both “attitude and action” and that it is derives from two Latin words: ‘cum’ meaning together, and ‘patior’ meaning to suffer (p. 41). It can be understood that compassion then is about a sharing with another’s suffering and the action that corresponds with this sharing⁴⁵. To note, this fits in with the notion of accompanying as there is a sense of ‘togetherness’ in this virtue of compassion. In other words, what is essential as an ‘accompanier’ to the living-dying person is compassion. No doubt, compassion is a complex concept and a difficult virtue (act) to develop, I would suggest. Still, even with these complexities, there is no doubt that there is an agreement on its importance in end of life care.

As a consequence, further education processes are needed to assist HPC workers with the development of this virtue. For, as Olthuis and Dekkers (2003b) suggest, palliateurs “must retain the capacity to feel, deeply, the suffering they encounter without being overwhelmed or incapacitated by it” (p. 933). Just like any professional training conducted in drug information, new symptom control procedures and the like, workshops in the understanding and development of compassion are needed. This would also need to include, I would suggest, the task of learning how to be compassionate with oneself as well.

⁴⁵ I would like to point out, however, that the action component of compassion can be either active or passive. In other words, I have been concerned to see many caregivers over time trying to actively and often aggressively alter someone’s suffering. This can be highly problematic at times. On the other hand, sitting with suffering, listening to it, helping someone make meaning of it is more of a passive response to compassion which may be more appropriate at times.
In summary, who we are in terms of qualities or dispositions, also plays an important role in the ethical framework for HPC practice. To note, the HPC professionals spoke eloquently about the ethics of practice as being about ‘authentically being who they are’. This necessarily includes such qualities, and the corresponding actions, of being compassionate, honest and trustworthy. A virtue ethics perspective can assist in this area and is a further understanding of ethics which holds a valuable contribution to the ethics of HPC. This needs to be further recognised and integrated into HPC education processes. Unfortunately, as Olthuis and Dekkers (2003b) confirm, “there is little empirical understanding of the relationship between the education of palliative care givers, the practice of palliative care and the personal qualities or moral attitudes that are needed in care for the dying (p. 932). This domain of the moral or ethical attitudes and dispositions required in the practice of HPC has been largely neglected. Perhaps, as Woods et al. (2000) suggest, the greatest challenge to the profession is “that of how to nurture such highly valued virtues” (p. 325). For our virtues, which encompasses the development of our human capacities, are sorely required at this crucial time of life, especially when it is understood that these virtues are “essentially relational” (Austin, 2007, p. 55) and it is this domain (relational) which plays the last and most fundamental role in the ethical framework for HPC.

6.12 An ethical framework: Relational
The most frequently mentioned component of an ethical framework for HPC practice pertains to the relational. This meant that the majority of HPC professionals cited in their narrative accounts relational expressions of their understanding of ethics and what guided them in their daily ethical practice. For a majority of the HPC professionals ethics is about how they treat others; the other mainly pertained to the living-dying person. ‘Treating others’ emphasises and centralises relationships. In turn, these relationships and the ‘treating of others’ in these relationships, are ethical. The ‘how’ component was repeatedly explained via the golden rule ethic of do unto others as you would wish for yourself, or a familial ethic of treating others as I would do for my own family. This prioritising of a relational understanding of ethics fits with Frank’s assertion that “social relationships may represent an equally and sometimes more
compelling framework for bioethics [applied ethics] than individual rights” (cited in McNamara, 2001, p. 91).

An engaged ethics viewpoint, too, emphasises this ‘ethics as relationships’ as it reinforces the purpose of ethics to be about “creating and sustaining relationships which mutually recognise the needs, interests and aspirations of all participants as ‘ends in themselves’” (Isaacs & Massey, 1994, p. 2). This relational understanding of ethics, and its corresponding guidance, also links in with the dominant articulation of the purpose or hopes of the practice, which is the development and maintenance of unique relationships. Schotsmans (2002) offers some reflections on the centrality of a relational approach to palliative care which incorporates relational philosophical writings. Schotsmans (2002) believes that for too long Anglo-American ethics “creates the impression that there is very little space for the relational encounter between the patient, the caregiver and other human beings” (p. 127). This relational understanding of HPC ethics is “almost totally absent”, asserts Schotsmans (2002, p. 127).

The insights discovered in this inquiry argue for overriding a one-dimensional focus to stress that the relational must be central in understanding ethics, in any development of a distinctive ethical framework for the profession, and in the teaching, research and practice of ethical HPC. The final section of this chapter presents the HPC professionals’ articulations of a relational ethic, some philosophical writings pertaining to relational ethics and the nature of the type of ethical relationship in HPC practice. This description of an ethical relationship for HPC practice commenced in the previous chapter when considering the purpose of the practice and continues through to the end of this chapter. It is important to note that no account of an ethical relationship is complete – this is one small part of a conversation about what constitutes ethical relationships in HPC practice.
6.13 Narratives of relational ethics

A relational ethic must be central for HPC ethics. Some of the initial articulations which incorporate this understanding of ethics include:

- Fundamentally, it [HPC ethics] is about respect, towards others, and self. The fundamental ethic is an ethic of respect of others (David).

- For me ethics would be, generally, about how I treat them as human beings, worthy of respect (Amy).

- Well I think it’s just about respect … respecting and valuing that other person and where they are in their life and their life story (Julie).

- I guess it just generally comes back to how I treat others … and showing my respect of them (Natalie).

- It’s really about having those best intentions for another person. I mean a strong feeling of not wanting to hurt or harm them in anyway (Amy).

- So when you talk about the ethics of palliative care, for me, my success or failure as a practitioner really rests on my ability to understand the other person and to honour and treat that person for who they are (Natasha).

- What drives me is that person … that person in front of me … what do they want or need? Sometimes this is quite demanding, I mean, to be saying “whatever you want, we will try to provide” … that sense of altruism. And that’s my guiding light (Elaine).

It can be heard in these articulations and understandings that ethics is about how the HPC professionals treat others: it is relational. In addition, concepts such as understanding, honouring, valuing, and of treating a person as worthy of respect attempt to explain what this relational ethic means.

6.13.1 The golden rule and a familial ethic

What were noticeably repeated in these relational understandings were statements pertaining to the ‘how’ of thinking and acting ethically towards others. These statements included an emphasis on treating others as I would wish to have myself treated (the golden rule ethic) and treating others as if they were family (a familial ethic). These articulations were significantly repeated in the HPC professionals’ narrative accounts:

- I think the ethics [of HPC] is about being honest and upfront with people. I’ve always had a strong feeling that it’s so important to treat people the way you’d like to be treated yourself, basic though it sounds, that’s what guides me (Kieran).
I keep it very simple and it’s a case of what sort of care would I like to be provided to me and that’s the type of care that I actually provide to other people. It’s very easy for me. To me you’re mine and if that was my mother what would I like people to do for her. Therefore that would be the level of care that I would give to their mother (Zoe)

I mean it’s a really old thing to do, but I’ve always believed that you treat people as if they were a member of your own family. If you treat people like that you will always, well hopefully, not become too paternalistic and you will give them as much compassion as they need. Do unto others, as you’d have them do unto you. It’s an old saying, but it’s how you live (Nina)

When someone comes into the hospice I think “what care can we give them” and it always comes back to me, whether it be an older person or a younger one, that that could be a member of my family and I’ve always said that I would like to give them the same sort of care that I would like for any member of my family. I hope that in having that in the back of my head, then the decisions that I made will be the right one’s for those people. This has made me feel that I want to do the best for any person that I can (Frieda)

I guess I wouldn’t do to somebody else what I wouldn’t like to have done to me and that’s probably the most basic, personal philosophy that guides me in my work (Peter)

I just sort of practice how I would want my parents, or my sister, or my brother to be looked after. That’s probably how I guide my practice. It’s about how I would want to be looked after (Emma)

It’s me as a person, what I would want … So treating people as you would really want your sister to be treated, or yourself. So as close as you can to being in their shoes, I suppose (Fiona)

Family is very important to me. I’m guided by communities getting together … of humanism. I’m guided in the human aspects of care and the power that that can give to each of us … of being with … that’s what guides me (Jim)

It’s just about humaneness for me. It’s about valuing humans and how we treat each other. I would want to be treated the way I want to be treated, and I will treat others accordingly (Kate).

These expressions about treating others in the way in which I would want to be treated stem from an ethical notion called the golden rule. The golden rule ethic, writes Gensler (1996), requires that “we treat others as we want to be treated” and is an ethical concept that has been prominent among the different cultures and religions of the world for the last 2500 years (p. 93): Buddha said: “Hurt not others in ways that you yourself would find hurtful” and Jesus said: “Do to others whatever you would have them do to you” (Gensler, 1996, p. 105). This is perhaps a commonly utilised ethical understanding that provides important guidance in practice.
Unfortunately, ethical practice is much more complex than this rule implies. Although it certainly could be helpful, it also has its share of limitations. Firstly, the HPC professional would need to imagine him or herself in the exact place of the other person. Gensler (1996) explains this when he writes “we need to be able to imagine ourselves, vividly and accurately, in the other person’s place” (p. 106, original italics). This could certainly be rather difficult, if not impossible, given that the other person is someone who is dying; an experience which the HPC professional would have witnessed, but never gone through themself. Secondly, we would also need to understand or know what effect our actions have on the lives of the other (Gensler, 1996). Needless to say these possible effects could be numerous and unpredictable.

I would add to this list of limitations by including that this golden rule ethic does not adequately take into account diversity. For example, the way that I would want to be treated as someone who is dying would most likely be different to another person’s desires. How open can we be in discovering how someone else wishes to be treated if we are focused upon ‘this is how I wish to be treated’? Hence, for a HPC professional to say that I would treat others at this time in a way that I would want to be treated myself could translate into a self-centred approach; one that does not take into account differences between people. On the other hand, it is certainly an ethical concept which embraces a commonality or solidarity between humans, appreciating that we would all wish to be treated with respect, dignity and care. However, again, how I understand or ‘see’ respect and how someone else does could be quite different. Certainly, Gensler (1996) agrees that “it isn’t an infallible guide … it doesn’t give all the answers. It only prescribes consistency” (p. 105). Ken, too, believed that the golden rule had its share of limitations as well, believing that we needed to go beyond this common understanding of ethics.

Whilst I would ascribe to that [do unto others principle], I don’t experience it as enough to guide me. One of the reasons for that is because try as I might to put myself in the shoes of a dying person, I simply cannot know. So I think as a general rule it’s entirely appropriate, but that I can’t know what others are experiencing makes it problematic. We need to move beyond this basic level and be a bit more sophisticated than that (Ken).
6.14 Proximity stance: Near or far?

To critically reflect upon these relational expressions – the ethical nature of HPC relationships - I am utilising a ‘proximity stance’ on a near-far continuum. This continuum takes into account how ontologically near or far, or separate or connected we consider ourselves to be to each other in such a relationship. I suspect that when HPC professionals speak of the golden rule or the familial ethic, of treating the living-dying person as if they were treating themselves or one of their family members, they are attempting to bring this person nearer or closer, thereby assisting with the development and maintenance of the unique relationship hoped for. Perhaps, as understood by the articulations of the type of relationships HPC professionals are hoping for, as expressed in the previous chapter, the ontological intimacy, trust and honesty requires professionals to become conceptually, spatially and ethically closer somehow. Hence, guidance such as the golden rule and the familial ethic may bring them closer to the living-dying person.

This near or closer stance is in contrast to the far stance on the continuum. This far stance is understood through the oft heard explanations of being professional: maintaining distance, keeping your boundaries, being neutral or objective. This is a very common understanding of health care relationships, which was referred to above by Elisabeth Kubler-Ross (“we were told to remain distant”). However, in HPC practice Kubler-Ross (cited in Youk, 2004) emphasised that there was a need to be a human being and of not being so distant from the living-dying person. Frank (2005c) writes that there is a need in palliative care practice “to avoid the stance of distance from patients that is adopted by many nurses” (p. 295). In other words, HPC professionals do not wish to occupy the far stance on the continuum and so are attempting to become closer to the living-dying person by imagining them as a family member, or even as themselves.
There are, however, issues to be avoided by going too far to the extreme on the near end of the continuum. In considering the ‘too near stance’ Frank (2005c) would most likely caution HPC professionals about “merging” in that the aim is not to get “caught between getting too close to … [the] patient and remaining too distant” (p. 297). It is vitally important that we do not get ‘too near’ in that the danger is one of ‘she becomes me, and me becomes she’. This then would most likely translate into ‘I will treat you as I would wish to be treated myself’, or ‘I know what’s best for you now’, because I am you. It is ethically vital that the living-dying person retains their “mutual otherness” (Frank, 2005c, p. 295). This too near stance often emerges in statements levelled at HPC professionals as being too involved or of overstepping the boundaries. This concern is certainly voiced and evident in hospice palliative care practice today.

Utmost in end of life caring practices is finding a delicate balance on the proximity stance that is neither too close nor too far. To explain further, in first meeting with a living-dying person they are a stranger, hence they are distant from the HPC professional. In seeking to establish a relationship of ontological intimacy, the HPC professional attempts to alter the relationship to a closer or nearer one, proximally speaking. Gaining this closeness is sought by thinking of the living-dying person as a family member or as themself. In other words, the HPC professional is trying to negate distance or strangeness, and seeking familiarity. The professionals are implicitly saying - ‘If I think of this person as a member of my family, then I am more likely to be able to act compassionately, gain intimacy and trust, and be with them in their suffering’.

The essential components of the unique relationship in HPC practice require this nearness that perhaps the familial ethic can guide them towards. Yet again, the familial ethic, as with the golden rule, has its share of problems. I have certainly witnessed some of the harms that family members do to each other. It is an ethic, like any, which has its limitations. Like the golden rule, how can I possibly know that this person would be like my mother in wanting certain things? I have had extensive opportunities to understand and learn from my mother what it is she prefers, values and desires, but not the same opportunities with the living-dying person in front of me. That being said,
however, I believe that the value of the familial ethic is that it equates to an intentionality to become nearer or closer to the living-dying person, and thus to find that intimacy and trust that is critical in end of life caring practices.

Overall, neither a stance of too far (distance) nor one of too near (merging) is helpful in end of life caring practices. In being proximally too far the HPC professional is more likely to be distant, cold and impersonal. In being proximally too near, the danger is of merging or being too close to the living-dying person so that her pain becomes my pain, or my way of wanting to be cared for becomes what I believe the living-dying person would necessarily want. Frank Brennan (cited in Wakely, 2008), a well known palliative care physician, appreciates this concern when he writes

> To become so powerfully involved that we are unable to meet with the next patient because we’re inconsolable, that is the other end of the spectrum. We lie somewhere in between. But the other important thing is to constantly remind myself that this is not my family, this is not my father dying. This is not my death. So however close or empathetic we become, we also need to realise that this is unique to that person and that family (p. 22).

Ideally, a proximity stance of in-between these two extremes is required for ethical relationships in HPC practice.

### 6.15 HPC ethical relationships: Close and connected

The proximity stance of connectedness and in-between takes into account both relationships and the uniqueness of the ‘I’ (the other). Thus, there is both ‘I’ and ‘We’. This would mean that the HPC professional would not be too near or merge, as Frank refers to it, thereby assuming that what the living-dying person wants or needs would be the same as for myself. On the other hand, the HPC professionals would not be too far and take a professional stance of objectivity or neutrality which would most likely prevent ontological intimacy. The in-between stance would rather require professional caregivers to retain the ‘otherness’ of the living-dying person\(^{46}\). This type of ethical relationship is extensively ruminated upon by the European philosopher, Emmanuel Levinas (1985; Davis, 1996; Cameron, 2004; Critchley & Bernasconi, 2002) and further

\(^{46}\) The living-dying person, or family/friends, is referred to as the other.
considered by Frank (2004; 2005c). Schotsmans (2002), too, utilises Levinas in his chapter on a relational approach to palliative care. Each of these authors is utilised in this following section to outline an account of an ethical relationship for hospice palliative care practice.

6.15.1 Levinas: The face of the other
Levinas understands the ethical in a broad way, “where ethical experiences and relationships occur before the foundation of ethics in the sense of … established principles, rules or codes” (Davis, 1996, p. 48). Levinas’ gaze firmly focuses on ethical relationships. The complexity of Levinas’ ethical-relational thoughts are that he attempts to understand the self and the other in ways in which both are preserved as independent and self-sufficient, but at the same time in relation with one another (Davis, 1996). Thus, there is both self (I) and relationship (We), rather than a dualistic either/or understanding - there is only self (as emphasised in the principles of autonomy) or there is only relationship. This is certainly a difficult task, as Davis explains

This is more difficult than it might appear, since it is in the nature of the relation to bring the other into the self’s sphere of familiarity, thus making it intelligible from the perspective of the self and reducing its true otherness (p. 41).

From Davis’ explanation it can be understood that the HPC professionals are trying to “bring the other into the self’s sphere of familiarity”. Yet, in doing so, whilst appreciating the possible helpfulness of this, the danger is that we reduce the otherness or uniqueness of the living-dying person. They then become me.

6.15.2 Alterity: The uniqueness of the other
Levinas suggests, rather, that we need to preserve the other as other. For if we do not do so we are much more likely to see the other as ourselves. The other

must not become an object of knowledge or experience, because knowledge is always my knowledge, experience always my experience; the object is encountered only in so far as it exists for me, and immediately its alterity is diminished (Davis, 1996, p. 41, original italics).

This is the pitfall in being guided by both the golden rule and a familial ethic in that the HPC professionals would most likely draw upon their own knowledge, experiences and
understandings and may believe this to be the same for the other. This in turn would diminish the uniqueness or alterity of the other. Alterity must be maintained; because as Levinas explains: tout autre est tout autre, which translated means “every other is wholly other” (Davis, 1996, p. 130).

Alterity, or the face of the other, is the key term in all of Levinas’ work. The other is simply the other person, whom ever that may be. It is the respect for alterity which is Levinas’ moral imperative. Levinas believes that to infringe on the other person’s alterity – their otherness that precedes any attributes – is to commit violence against the other. Symbolic violence comprises the often subtle ways that alterity is challenged and violated (Davis, 1996, p. 115).

This respect for alterity translates into not “pronouncing final words about another” or indeed assuming that the living-dying person would want to be treated in a way in which I myself would, or in a way that my mother would. Any silencing of the other would be “unethical insofar as it fails to acknowledge the concrete other person from whom the concrete ethical imperative sounds” (Davis, 1996, p. 130). Unlike the golden rule ethic, a Levinasian ethic shifts the focus to the other from whom the original summons to responsibility emanates. Thus, HPC professionals need to start from a position of not-knowing and then seek to understand the other.

6.15.3 The ‘strangeness’ of the other
This intention of seeking to understand starts upon first seeing ‘the face’. Levinas says that, by virtue of just seeing another’s face, we are summoned to responsibility by the other. Face, however, does not merely pertain to some physical arrangement of the eyes, nose and mouth, rather “to see the other’s face is to recognise the other as needing me and to feel chosen in the primacy of my obligation to meet that need” (Davis, 1996, p. 48). Levinas directly explains his use of the face

I define face precisely by these traits beyond vision or confusion with the vision of the face. One can say once more: the face … is like a being’s exposure to death; the without-defence, the nudity and the misery of the other. It is also the commandment to take the other upon oneself, not to let him (sic) alone … If you conceive of the face as the object of a photographer, of course you are dealing with an object like any other object. But if you encounter the face, responsibility
arises in the strangeness of the other and in his (sic) misery. The face offers itself to your compassion and to your obligation (cited in Davis, 1996, p. 48).

Thus, it is the ‘strangeness’ of the other, upon seeing his or her face, rather than his or her familiarity, that is foremost in Levinas’ ethical-relational explanations. He cautions us against the “fusion of consciousness”, for “he (sic) remains that which I – closed up in myself – am not” (Davis, 1996, p. 50). This fusion of consciousness parallels Frank’s understandings of merging. Ironically, therefore, in seeking to become closer - to gain ontological intimacy – there is a need to ‘see’ this person as stranger so to start from a point of not-knowing (I would not know or assume what he or she wants or thinks).

There is a great need to retain the unique and distinctive sense of personhood, whilst at the same time also understand the interconnection between beings and develop a responsive relationship. Here the notion of a boundary between people can be incorporated which translates into ‘you are you in all your uniqueness such that I am I in all of my uniqueness’. Yet this boundary must always be permeable; not fixed. It must be understood that “no firm boundary separates self and other … the boundaries of our selves are more permeable than real” (Frank, 2004, p. 46/47). Hence, this concept of boundary must be mutable and include both connection and otherness.

6.15.4 The space in-between

Frank (2005c), in drawing upon the work of Levinas, describes this ethical relationship which is close, but not merging, as in-between. In his writings about a renewal of generosity in health care practices Frank discusses the processes of generosity through dialogue which finds a balance on the proximity stance. He recommends that we need to get into this space in-between, “because balance requires that both voices be there, neither self-sufficient nor merged” (p. 295). As mentioned, this requires that delicate balance of neither too distant, nor too close. Bauman (1993) would most likely concur with Frank’s suggestions in that he reinforces this notion that we, as human beings, are separate from each other; but that “at best we are with each other” (p. 70, original italics). This separateness, or gap as Bauman refers to it as, may be bridged in various ways. As Isaacs (2005c) suggests “we are connected to the other, and the other displays
A subjectivity that invites us to open ourselves in response” (p. 2). This in-between proximity stance typifies ethical engagement - this is accompanying.

6.15.5 Dialogue as critical

We acknowledge, or we do not acknowledge, that the very possibility of our self and thoughts has always depended on others. We enter into dialogue, or not. There is no choice except to enter into dialogue, because the self has its origin and its ongoing existence only in that realm (Critchley & Bernasconi, 2002, p. 45).

This ethical relationship of accompanying must place dialogue as central. For Levinas, this relation to the other, what he calls the “original relation”, takes place in the concrete situation of speech (cited in Critchley & Bernasconi, 2002, p. 15). In other words, this face-to-face relationship with the other is always linguistic. As Critchley and Bernasconi (2002) write,

The face is not something I see, but something I speak to [or with]. Furthermore, in speaking or calling or listening to the other, I am not reflecting upon them, but I am actively and existentially engaged in a non-subsumptive relation, where I focus on the particular individual in front of me … this leads to a significant insight … it is the relation which is ethical, not an ethics that is instantiated in relations (p. 15-16).

In aiming for this ethical relationship, as proposed by Levinas, Frank and Schotsmans, dialogical connection is a must. In aiming to sustain otherness, or alterity, we must speak with each other, for the “assimilation of the other into my voice, or submerging myself in the other … terminates dialogue by violating alterity” (Critchley & Bernasconi, 2002, p. 116). The danger, therefore, becomes one of ‘speaking for the other’. This translates into ‘I know best what you need, desire or wish for in this dying time’. Hence, in speaking for the other there is the real danger of falling back into the type of paternalistic practices of the past.

An example of this speaking for the other was noticeable in Zoe’s explanation about her role as patient advocate

What I see as my chief role as a nurse in palliative care is as a patient advocate. I try to be the voice of the people who don’t know what they want or what they want to do (Zoe).
With an ethical relationship of accompanying the HPC professional’s role would be one of assisting the living-dying person to discover, for themselves, what they want or what they want to do, rather than speaking for them. Certainly there may be circumstances where speaking for the other is justified and their may be times where not speaking for the other may be irresponsible. Yet, with the increasing professionalisation of HPC, and the rising levels of specialist expertise, there is a real danger of taking this ‘advocacy’ role too far by speaking for the living-dying person, rather than with. The living-dying person’s voice is crucial, but often absent or silenced. Schotsman (2002) notes “how frequently and how easily people speak about the dying, but how little the voice and the reality of the dying person is heard and represented” (p. 131). An ethical relationship requires that we converse with each other – “speaking with someone, not about them; entering a space between I and you, in which we remain other, alter, but in which we each offer ourselves to be changed by the other” (Frank, 2004, p. 126).

6.15.6 Levinasian HPC practice

In drawing together these elements of a Levinasian relational ethic and translating these into ‘A Relational Ethic of Accompanying’, a HPC relational trajectory may look something like this

**Table Nine: Levinasian ethical relationships**

<table>
<thead>
<tr>
<th>Experience</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seeing the face of the other.</td>
<td>The HPC professional meets with the living-dying person for the first time.</td>
</tr>
<tr>
<td>Without being asked I become summoned to responsibility upon seeing the face of the other.</td>
<td>I must respond to create an ethical relationship. I enact response-ability.</td>
</tr>
<tr>
<td>Seeing the face often begins with the empathic imagination of how the other feels.</td>
<td>The HPC professional commences a relationship by assessing and understanding the pain, symptoms or suffering of the living-dying person.</td>
</tr>
<tr>
<td>An attempt is made to become closer or familiar with the other.</td>
<td>I think to myself that this is my mother in that bed, or that I would feel terrible with that kind of pain if it was me.</td>
</tr>
<tr>
<td>Empathy risks symbolic violence or the diminishment of alterity.</td>
<td>The HPC professional feels for this living-dying person and seeks to reassure him/her that they will be feeling better soon, more comfortable; the HPC professional will start medications and pain and other symptoms will soon be under control.</td>
</tr>
</tbody>
</table>
Empathy tends towards unification; either my projecting what would make me feel better onto you, or my fusing with your suffering.

The golden rule would guide the HPC professional to think this intervention would be something that would make me feel better (or indeed has done so for other living-dying people in the past), and so this will necessarily work for this person as well. Or, maybe the HPC professional thinks that this person is just like my mother and this is what my mother would want or need.

Or, on the other hand, like the palliative nurse in Frank’s (2004) text, the HPC professional will start to take on the suffering of the living-dying person themselves, and hence, they will be preoccupied with doing all they can to alleviate the suffering, with the possibility of becoming miserable themselves, or of inappropriately ‘treating them until death’, offering futile treatments and medications.

RATHER

Alterity is the opposite of unification with the other; seeing the face requires respect for alterity.

The HPC professional would commence a dialogue with the living-dying person to seek to understand what is happening for them, to hear their story, to appreciate their meaning of pain and suffering. A conversation would occur in which the HPC professional would seek to take a position of not-knowing, and to try, as much as possible, to put prior knowledge, experiences, understandings and assumptions aside so as to seek to understand the living-dying person as a unique being with their own stories and interpretations.

I must recognise that there are aspects of your suffering that I can never imagine and that I can never touch.

The HPC professional takes on a position of not-knowing when it comes to the other’s unique experience of living and dying. For this stance, humility and genuine curiosity is required. This does not mean that professional skill is not required, but that comes in further along the conversation. Professional expertise could also relate to how we communicate. A proximity stance of in-between is maintained.
6.16 Powerful beings

Before summing up this relational ethic for HPC a consideration of power needs to be included. Unfortunately, there is not the scope to consider power in all of its complexity as it is a concept that deserves more attention. I am mindful that the flow of power is present in all of the elements thus far presented in this account of ethical relationships in end of life care. For in seeking to listen to the voice of the other, in developing an in-between proximity stance, and in achieving a position of not-knowing, reflections of power need to be included47.

Power takes many different forms and shapes, but its centrality is obvious, for as Isaacs (2005c) states “a power to be and to become … is at the core of what it is to be a human self” (p. 4). Isaacs (2005c) elaborates by explaining that

Through such power we exercise choice, achieve goals, realise aspirations and create ourselves. However, the cultivation and exercise of this power in a way that might fulfill us is not straightforward. Within ourselves we may experience deep contradictions. The power within to grow can be turned inwards and become a force for self-destruction. Similarly that power can be a force directed towards the enhancement of others, or can be used to destroy others. And reciprocally, that power to grow can be nurtured and sustained by others, or blunted, frustrated or destroyed by them (p. 4).

In HPC ethical relationships it is ideal to direct our flow of personal power for the enhancement of the other. This “flow of power”, as Isaacs (2005c) suggests, needs to be “channeled in ways which permit or support human growth and flourishing” (p. 6).

Needless to say, in ethical end of life caring relationships, which must acknowledge the vulnerable and possible powerlessness of the living-dying person, the HPC professional needs to “channel the power to be by promoting nutrient (power for) and integrative power (power with)” (Isaacs, 2005c, p. 6; May, 1974). There is a need to recognise this flow of power in ethical engagements and to shape them to achieve positive outcomes “where all selves may be nurtured and flourished” (Isaacs, 2005c, p. 7). This point is crucial in the understanding that living-dying people, although at the end of their lives, still too, have the opportunity to grow, transform and flourish.

47 I do not de-value the importance of considerations of power in applied ethics, but simply was not able to include a full exploration of the concept within the scope of this thesis.
In *The Healer’s Power*, Brody (1992) provides excellent guidance on what HPC professionals could consider about the use of power in ethical relationships. Firstly, Brody (1992) suggests three guidelines that can be considered helpful

- Realism: being aware of the true consequences of one’s acts or omissions
- Accountability: being ready and able to give an explanation of one’s use of power; this eventually leads to broader participation in decisions
- Purposiveness: having a specific end toward which the power is directed, rather than simply drifting along with it because it is there or employing power merely for its own sake (p. 42).

Brody defines these three guidelines as owned power, shared power and aimed power, explaining that

we can have the highest degree of confidence that the healer’s power is being used ethically and responsibly when that power can be described as owned power, shared power, and aimed power (p. 43).

These three types of power can be translated into HPC practice and relationships. HPC professionals would, at the very outset, understand and be aware of the powerful positions they hold; Brody refers to this as an acknowledgement of power. HPC professionals would then also ‘share’ their power by reflecting on, and conversing with others, about their use of power, including in their relationship with living-dying people. Finally, the use of power would be directed or aimed towards a good. This is an important point, especially in light of the telos of HPC. It would mean that the power that a HPC professional held would be directed towards the maintenance and creation of the unique relationship needed to accompany the living-dying person towards death. This is certainly not as clear cut as this, as often the goods are different, competing and unarticulated.

Overall, the ethical ideal is that of a shared power approach. This is certainly not an easy process, however, as it often rests on the perceived, imagined or constructed power that any given person has. For example, are all living-dying people powerless and all HPC professionals powerful? I would suggest that regardless of position, experience, age and gender we all have differing perceptions, both within ourselves or viewed by others, of being powerful people. I raised the possibility once that a particular living-
dying person I was with was quite powerful. This was met with skepticism by several professionals around me at the time. The assumption was that with a failing, dying, out of control, diseased body no person could possibly feel powerful. I would suggest that our own sense of personal power, in whatever position, context or time we find ourselves in, changes from vulnerability to strength on any given day.

With these different perceptions of personal power in mind, Brody (1992) proposes some general guidelines for the ethical employment of power: a power sharing approach.

I have adapted Brodys’ explanations to fit the HPC context.

1. The HPC professional should employ all her power to try to effect a good outcome for the living-dying person. Good outcome is determined in conversations with each other;
2. The HPC professional should try whenever practicable to share her power by informing the living-dying person, in so far as he or she wishes, about the nature of the disease and possible courses of action;
3. The HPC professional should be alert to the sense of powerlessness often accompanying the living-dying trajectory and be prepared to respond to it in several ways;
4. The HPC professional should support and encourage the living-dying person’s own exercise of power;
5. The HPC professional should regard the relationship as a primary therapeutic tool. His or her means of seeking a good outcome should be designed not merely to resolve the problem of the moment, but also to cement and reinforce a mode of relating with the living-dying person that encourages his or her full and active participation over time (or his or her flourishing before cessation of life).

(Brody, 1992, p. 65, modified).

Again, let me reiterate this above point: power needs to be employed in a way that best maximises the ethical engagement between the HPC professional and living-dying person, including his or her family, as Brody refers to in this last recommendation. Power sharing is the ultimate aim in an ethical framework for HPC practice.
6.17 Summary: A relational ethic of accompanying (REA)

In approaching the living-dying person as other, as unique, within his or her own biography, meanings and interpretations, HPC professionals locate how best to accompany this person on their journey towards death. If the HPC professional ‘merges’ with the living-dying other and views him or her as themselves, then “everything ends … [this is understood as] absolute death: the state of being unheard, unrecognized, unremembered” (Bahktin, cited in Frank, 2004, p. 47). When HPC professionals seek to ethically care for the other at the end of life, to accompany them towards death, all of these elements outlined in this account of an ethical relationship for HPC practice need to be carefully considered. A HPC professional will spend considerable time learning about the technical aspects of his or her role. Similarly, I would suggest that, equally, HPC professionals need to spend time reflecting on, and discussing their ethical relationships that make up the fundamental part of their practice. It is not enough simply to assume that ‘I must treat this person as I would wish to be treated myself’. The relationship between professional caregiver and living-dying person needs to be ethically and practically reflected upon. The table below sets out a summary of the key considerations of an ethical relationship in end of life caring practices.
<table>
<thead>
<tr>
<th>Relationally Too Near</th>
<th>Relationally Connected and In-Between</th>
<th>Relationally Too Far</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A relationship of …</strong></td>
<td><strong>A relationship of …</strong></td>
<td><strong>A relationship of …</strong></td>
</tr>
<tr>
<td><strong>Merging</strong>: Who you are is who I am (fusion of</td>
<td><strong>Inbetween</strong>: entering a space between you and I (emphasising both relationship and self)</td>
<td><strong>Remaining too far</strong>: a stance of objectivity and rationality; no intimacy</td>
</tr>
<tr>
<td>consciousness)</td>
<td><strong>Retaining and sustaining otherness</strong> (alterity and uniqueness)</td>
<td><strong>Maintaining professional distance</strong></td>
</tr>
<tr>
<td><strong>Sameness</strong>: treating others as I would wish to be</td>
<td><strong>A proximity of closeness</strong> (neither too near or too far)</td>
<td><strong>Knowing</strong>: I know what your experience is, I know what you need, I know what is</td>
</tr>
<tr>
<td>treated myself (golden rule)</td>
<td><strong>Language</strong>: seeking to understand the other through conversation and story</td>
<td>best for you (expertise and paternalism)</td>
</tr>
<tr>
<td><strong>Familiar</strong>: treating others as if they were your</td>
<td><strong>A stance of not-knowing and curiosity</strong>: I cannot know what you experience or know</td>
<td><strong>Fixed boundaries</strong>: understanding that there are fixed boundaries between beings</td>
</tr>
<tr>
<td>family (familial ethic)</td>
<td><strong>A stance of engagement</strong>: I am with you</td>
<td>and not overstepping these (no interconnectedness)</td>
</tr>
<tr>
<td><strong>A stance of knowing</strong>: what I know and experience is</td>
<td><strong>Appreciating interconnectedness</strong> between human beings (inter-human event)</td>
<td><strong>Non-affect</strong>: no emotion reactions; not supposed to be moved</td>
</tr>
<tr>
<td>the same as what you know and experience</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Unification</strong>: projecting what would make me feel</td>
<td></td>
<td></td>
</tr>
<tr>
<td>better onto you or my fusing with your suffering</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table Ten: An account of ethical HPC relationships
In striving to locate this relationship of in-between HPC professionals are more able to accompany living-dying people in an ethical manner towards death. Anecdotally, I recently spoke to a palliative care nurse who was being chastised about becoming too involved or getting too close to patients she was caring for. This was a timely conversation for me as I attempted to grapple with the complexity of ethical relationships in HPC. In discussing this further with her, she believed that her colleagues were implicitly implying that the ideal in HPC relationships was that she needed to move more towards the far end of the continuum and, of course, maintain professional boundaries. When I asked her about her relationships with her patients, and why she felt it was so important to maintain this close relationship, even in the face of condemnation from her colleagues, she responded that – “well this is the last time”. I asked her to elaborate on this statement and what she explained to me was that these encounters (with her) were going to be some of the last that her patient would have and so it was ethically significant for her to make them special, intimate and loving. She believed it was essential for her to present “the face of love” for these final days. This one example is coupled with a hundred more and point to the great need to further reflect, converse and develop frameworks of understanding which address relational proximity and ontological intimacy in HPC relationships.

To conclude this chapter, the understandings, articulations and insights that have been provided lay the groundwork for a distinctive ethical framework for HPC practice. This unique framework, as constructed in this chapter, is entitled: A Relational Ethic of Accompanying (REA). This REA framework has layers of ethical considerations, including

**Principles:** Consider and reflect on the bioethical principles:

- The need to understand the differing constructs of the principle of non-maleficence in the context of end of life care, particularly when it comes to considerations of futility;

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48 Verbal consent was gained from this particular nurse to include her statements in this thesis.
A reconceptualisation of autonomy is needed, to be appropriately understood for
the context of HPC, as autonomy-in-relation, thereby acknowledging the
complex interconnections of human beings and privileging relationship;

**Values:** A values-based framework which prioritises:

- An understanding, stance and valuing of dying as natural and normal (acceptance
  of human mortality);
- Care be underpinned by the philosophy of (total) care, also known as whole
  person care, or healing;
- Dialogue (communication) must be open and honest

**Virtues:** The prioritising of developing a virtue basis to the care:

- Further focus and education on virtues such as compassion
- How to develop trustworthiness in the HPC caring relationship

**Relationships:** An understanding of ethics that takes into account the
centrality of the relational:

- To retain and sustain the alterity or otherness of the living-dying person
- To seek closeness and ontological intimacy
- Of power sharing,
- Of facilitating open dialogue which starts from a position of not-knowing
- Of maintaining a proximity stance of in-between;

This REA framework calls for a need to understand and prioritise an accompanying
relationship as playing a pivotal role in ethical caring practices of HPC. HPC
professionals need to consider these many layers of the ethics of their practice, both in
the ethical frameworks that are implicit in their work, and what ethically guides them.
The REA framework has the layers of principles, values, virtues and relationships. This
layered understanding of ethics is explained by Gadow (1999) when she likens the ethics
of practice metaphorically as the “biodiversity of a coral reef” (p. 66). Gadow (1999)
writes that

At the level of immediacy (pre-modern ethics, such as the golden rule or familial
ethic), we are immersed in ethical currents that carry us safely through situations
where reflection would be impossible. When cross currents require us to reflect
and to hold a position, an edifice of ethical principles (modern ethics, such as the
principle of non-maleficence) offers a structure for steadying ourselves. Finally,
there are situations where no edifice can alleviate our vulnerability, and in those
cases we can only turn to each other (a relational ethic) and together compose a
fragile new form of the good (p. 66).
I would suggest that by the very nature of the tumultuous experience that is inherent in the living-dying process that most often it is the last, relational ethic that most comes to the fore. Schotsmans (2002) would most likely agree with this in that he writes that “fundamentally one is dealing with an inter-human event, involving both the attendant and the dying person. This relationship, furthermore, is entirely ethical in nature” (p. 134). This inter-human process, even when the dying person is unconscious, or cannot express themselves, or even deceased, is still relational because “the relational structure of the dying process remains strongly present in the caring responsibility of those being made responsible by the dying patient” (Schotsmans, 2002, p. 138). This relational structure, for Schotsmans, is so fundamental that he believes that

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Being with a dying person, therefore, really means actually participating in the process of dying; the companion comes to deal with their own death, the fate that every human being has to face. Human accompaniment of the dying person is not possible, therefore, unless the relationship between the dying person and the companions is taken with utmost seriousness. This is the revolutionary insight of palliative care, when fully established as relational care (p. 132).
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Hence, arguably, there is a need to continue to clarify HPC as a form of relational care, to understand and acknowledge the centrality of the relationship in this form of care, and finally, to prioritise a relational ethical framework to offer optimal, compassionate, and ethical end of life caring practices.

### 6.18 Chapter summary

This chapter included the important considerations concerning the place of a principles-based approach to HPC ethics and discovered that it did not figure heavily in the professionals’ narratives, but rather a values-base and relational ethic were dominant. This demonstrated an incongruency between the hospice palliative care literature and the articulated practice frameworks of this caring profession. Similarly, the principle of respect for autonomy was viewed in a dubious way by the professionals, seeming not to be suited to, or realistic for, this particular approach to caring at the end of life. Autonomy sat in tension with the relational and social facet of people, the family-centered focus, a team approach to care, and the lived reality of dependency and vulnerability inherent in the living-dying process. This thesis argues that a PBE approach to HPC ethics was inadequate and that there was need for a distinctive ethical
framework. However, there was a notable inclusion of the principle of non-maleficence and it was suggested that further examination of its meanings and implications in the HPC context was required. It was also suggested that autonomy, as a principle and concept, not simply be discarded but rather be reconstituted as autonomy-in-relation for the practice of HPC.

With the quantitative investigation of the values that were understood as central to and underpinning the practice of HPC, it is argued that the original hospice values have not withered in time. Acceptance of human mortality, a total approach to care and open and honest communication were still prioritised as the most important values underpinning the practice. Critically, it was the most mentioned value – that of the acceptance of human mortality, or the understanding that death is a normal part of life – that is a critical insight in understanding the ethical dimension of hospice palliative care practice. Having this value as the number one priority for this practice translates into a unique ethical culture for the profession of HPC. Dying-as-natural needs to be understood as an ultimate good which needs to be sustained and protected. Finally, in relation to values, there is a need for Palliative Care Australia to adjust the stated core values to include these three, not merely as descriptions of the practice, but rather as central goods. Virtues, too, played a role in the articulations of the ethics of HPC. This meant that HPC professionals believed that ethics was ‘who we are’. With this understanding, coupled with the insights of Olthuis’ (2007) study, it was thought that HPC practice is linked with notions of moral development. Compassion, therefore, was viewed as a central motivating force when it came to caring for people at the end of life, and thus a central virtue that needed further reflection and education.

Overwhelmingly, it was the relational sphere that was most mentioned in the ethical frameworks for HPC professionals. This means that a relational ethic was dominant in their understandings of HPC ethics. These relational articulations were foremost in the form of ‘ethics is how I treat another person’ and then elaborated upon through the golden rule and a familial ethic. A thorough rumination upon the ethical relationships in HPC practice then followed, including the considerations of how near or far one stands
in relation to the living-dying person (the proximity stance), of acknowledging both a self-sufficient ‘I’ and an interconnected relationship through the philosophies of Levinas, and of the ethical imperative of maintaining alterity (the uniqueness or strangeness of the other). In this ethical relationship dialogue, seeking understanding through a position of not-knowing and power sharing were all viewed as essential ingredients in the accompanying relationship.

Finally, I have created a Relational Ethic of Accompanying, a new ethical framework I consider, based on analysis of the results of my research, is most appropriate for this social practice. This REA framework included the considerations, understandings and reflections of certain principles (non-maleficence and autonomy-in-relation), remembering and upholding a significant values-base, cultivating certain virtues such as compassion and honesty, and, finally, the central ethical considerations of the accompanying relationship between the living-dying person and professional caregiver. This REA framework incorporates the diversity of understandings of what ethics is according to the people who practice HPC. Overall, however, it was overwhelmingly discovered that any ethic for HPC practice must have at the heart the relationship. Our relationships in this social practice, between each other, accompanying one another, are our ethical compass.
CHAPTER SEVEN
Conclusion: Continuing conversations

The human problem of dying has always been a set of social and moral choices about care, and about how those choices are negotiated between dying persons and their community – whatever form that community has taken in the past. In this precise way, the study of dying is like gazing into a reflecting pool. The waters there reflect back to us the kinds of people we have become. More than ever before then, it is timely to ask the question: what kinds of people have we become? (Kellehear, 2007, p. 250, original italics).

7. Introduction

Caring for the dying is a set of social and moral choices about care, and indeed about what sort of human beings we are, as Kellehear explains. This thesis has gazed into the water and sought to grapple with the meanings, understandings, and indeed choices, which are ethical and moral in nature, about how to care for living-dying people. This care at the end of life is provided by hospice palliative care professionals every day. I sought, and gained rich conversations concerning the many layers of the ethical dimension of hospice palliative care. The final product, this thesis, provides a thorough, textual conversation into this realm of ethical caregiving at the end of life. In other words, this thesis was co-constructed with the narrative accounts of thirty interdisciplinary hospice palliative care professionals. Incorporated into this thesis with these narratives were the ethics research inquiry from the European context (the Pallium project) and the ethics and hospice palliative care literature. In addition, my voice has been included in the articulations and understandings of the ethics of this social practice.

This critical exploration of the ethical dimension of hospice palliative care is a research based inquiry which did not simply focus on one particular ethical issue, but rather took a broad sweep across the underlying ethics of practice. It contributes to the continuing conversations about the ethics of how we care for the dying and the overall development of the practice. This concluding chapter provides a summary of the thesis including the key insights gleaned from the inquiry. Secondly, it includes considerations and suggestions for the future. Finally, this thesis concludes with expressions of hopes for the future by the hospice palliative care professionals.
7.1 Summary of chapters and key insights

A home metaphor was evoked to structure this thesis. The section entitled the floorboards set out the foundational aspects of the thesis, namely the introductory statements and the foundations of thought and processes of research. The reader would have learnt from the introductory chapter the standard definitions of hospice palliative care and been alerted to some of the tensions in the naming, demarcation and politics of this profession.

The standpoint of ethics was briefly outlined in this introductory chapter as well. This was intentional so as to make the understanding of ethics, according to this author, transparent. The stance of ethics taken in this thesis was an engaged ethics approach. This account of ethics is understood as being a humanistic approach to the doing and seeing of ethics. Engaged ethics is practically-oriented with the aim of understanding and transforming human relationships, actions and practices and, overall, to enhance the ethical form of life. Not only does this viewpoint of ethics encompass what it is good to do, but also who it is good to be, or in other words, ontological considerations were included for consideration. This understanding of ethics translated into a research inquiry that was broad and rich. It did not simply focus on a singular ethical issue or an ethical decision; rather, ethics was viewed as occurring on a moment to moment, daily basis. Thus, the distinction was made between the ethics in HPC, and the ethics of HPC. The ethics of HPC was understood as the “crucial examination of the meaning of palliative care, its nature, concepts, purposes and value … this assumes that palliative care [is] a practical human activity” (ten Have & Clark, 2002, p. 236). Furthermore, this approach to ethics starts from the position that we need to examine the ethical as internal to the practice, not external from a moral philosophical tradition. In other words, ethics starts in the practice and so the meanings and understandings of ethics from the hospice palliative care professionals were privileged. It was important that this understanding of ethics was made transparent from the start so that it was not assumed that there is only one way of understanding the ethical agenda.
The second ethical foundation utilised in this thesis was that of a social practice framework. This framework was developed by Isaacs (1998) for the practice of medicine, but was easily utilised in hospice palliative care practice. Not all features of this social practice framework were included; however, the central features of practices as constituted by a past (tradition), by people (ontology), and a telos (purpose) were the main elements focused on in this study. Finally, narrative inquiry was thought to be the most appropriate methodological approach for this type of study as stories provided an excellent medium for locating understandings and meanings, as well as facilitating articulation.

Certainly there were important reasons justifying such a research inquiry as this. Firstly, in building from the Pallium study, the intention of “providing direction towards an articulation of the moral specificity of palliative care” was an important rationale (Janssens et al., 2002, p. 73). This study continued the European scholars’ intent of focusing on this broad, and often missing, dimension of the ethics of hospice palliative care. Secondly, this profession is making significant developments in Australia. It is growing as a specialised field. This rapid growth provides both opportunity and crisis. At this crucial stage of development it was thought pertinent to provide such an ethical conversation, through research, as this thesis has done, so as to influence the development of the profession. Thirdly, I was very curious as to whether the original hospice values-based platform was still intact. I was interested in McNamara’s (1998b; 2001; 2004) research which argued that some of the traditional values had been lost. Fourthly, I thought it was interesting that the profession, as shown in the literature, was adopting a biomedical ethical approach and wondered whether principlism was an appropriate ethical framework for this specialised care of the dying. The applied ethics discipline was taking a turn away from principlism more generally, yet the HPC literature was largely adopting a principles-based ethics. I was interested in learning from the professionals whether this was a helpful ethical framework for their practice. A fifth reason was that so much of the ethics research in this area of practice focused on euthanasia and a few other specific ethical issues. I perceived an inadequate attention being paid to a broader ethical inquiry and was not alone in thinking this. Jennings
(1997), too, thought it strange that “systematic reflection on ethics in the hospice field is curiously underdeveloped” (p. 2).

Overall, it was surmised that there was generally insufficient research into this area. Not much has been known about the specific moral notions of hospice palliative care, wrote ten Have and Clark (2002). Hence, armed with all of these questions and curiosities I have presented in this thesis an exploration, articulation, interpretation, and appraisal of the ethical dimension of hospice palliative care practice. This is the first of its kind in Australia. This has provided a fuller and richer articulation of the ethical specificity of hospice palliative care as understood by its professional members. As with any such significant conversation, key insights were located, new articulations were spoken, and considerable understandings and meanings have been generated. In other words, our horizons have been broadened by this inquiry. Overall, new insights have produced an enlargement of our understandings of the ethical dimension of hospice palliative care practice.

The second section of this thesis, entitled the walls, covered the three main features of a social practice. The ethics of hospice palliative care, when understood through the lens of a social practice framework, requires a greater understanding of the past of this practice. All social practices are embedded in a particular time and thereby shaped by a tradition. Hospice palliative care is no exception. This meant that the ethics of this practice are historicised. Isaacs (1998) pointed out that the tradition holds sets of beliefs and sets of actions laid down by the past which translates into a collective consciousness of understandings. These understandings have come out of, and been shaped by, a past. Hospice palliative care has a rich tradition stemming from medieval times, but for the purposes of this thesis, from the 1960s and the development of the modern hospice movement. Modern care of the dying in the hospital system was critiqued and a new way of caring was developed, by and large, by Dame Cicely Saunders. A separate facility was designed, called a hospice, solely for people to come and live out their dying time and be cared for in total or whole ways. This hospice tradition had a strong values base, not only from its Christian foundations, but also the
values of an acceptance of human mortality (dying-as-natural), an awareness of dying, and open and honest communication. Furthermore, care was directed towards the whole person who was understood as having the facets of the physical, the psychological, the social and the spiritual; with each facet interacting and affecting each other. Care was to address all of these elements of the person by an interdisciplinary team of professionals.

As mentioned above, I was curious as to whether Saunders’s original philosophy of care was understood in similar ways. This curiosity was prompted both by a statement at a conference: “Isn’t it great to see the palliative care philosophy being practiced in so many different places” and by McNamara’s (1998b; 2001; 2004) study into the changes to the notion of a good death. Did the profession have a common and shared understanding of the so-called philosophy which underpinned their practice? The hospice palliative care professionals’ expressed an array of responses to their understandings of this philosophy. This diversity of responses can be interpreted to mean that there was not a common and shared understanding of the philosophy of care. Yet, it was noticed that most of the professionals believed fervently that the concept of total care or whole person care, or what is sometimes referred to as holism, must be central to this philosophy, hence, the term philosophy of (total) care.

This philosophy of (total) care included a whole person understanding of human beings which included the four domains mentioned above, a team approach to caregiving, an acknowledgement of a dying time and choice of a place to die, an acceptance of death as a normal and natural part of life, and the concept of total pain which moved beyond the physical body, and attempted to deconstruct mind-body dualism. This concept of total pain incorporated the sense that each facet of the person would be affected by pain and suffering, not just the physical. This philosophy encompassed a new, positive approach to caring for the dying, with a distinctive set of values, beliefs and goals. The total care aspect of the philosophy, this study suggests, continues to be a central concept sustained over time into contemporary hospice palliative care practice.
However, it was found that total care is being eroded and contested. There was a disagreement in the philosophy. Furthermore, interdisciplinary teams are being undermined with often only doctors and nurses now making up palliative care teams. Randall and Downie (2006) are suggesting that the social and the spiritual domains be disregarded as being too difficult to attend to. A hierarchy of care now puts the physical domain largely at the top (McNamara, 2004). As one professional expressed it, “they’ve just taken out hospice and left philosophy. I don’t think anybody knows what that is in palliative care these days … I think something’s slipped out. I don’t think there is a philosophy of palliative care at all anymore”. Something has definitely slipped out, where the hospice palliative care professionals state that the concept and practice of total care must be central, but that this is being slowly contested and eroded. There is a great need to reinstate the understandings and practice of this philosophy of (total) care. Total care must be central to the philosophy underpinning practice, but this concept is being contested and eroded. Even though the majority of professionals believed that total care must be central in the philosophy of care, it is not a commonly shared concept, and if not reinvigorated it will be eroded by powerful internal and external forces.

Corresponding with the philosophy of (total) care were the implicit understandings of personhood. The next feature of a social practice is people, for social practices exist only in, and through, persons (Isaacs, 1998). Thus, an exploration of the ontological was needed. This was especially important in light of the prioritising of whole person care. In addition, it was suggested that in applied ethics a rich account of personhood is largely missing and so an engaged ethics approach calls for the re-examination of the implicit and explicit understandings and articulations of personhood. Mapping these existing understandings of personhood, including the assumptions and limitations of these, was an important aim in this study. An engaged ethics approach acknowledges the richness and complexity of personhood, thereby attaining an enrichment and enlargement of our appreciation of who others are. It was noted that these understandings of personhood directly influenced end of life caring practices, for these practices are ultimately constructed and constituted by people.
Firstly, the point was made that our understandings of what constitutes human beings have been, and continue to be, shaped over time and according to particular cultures. With this in mind, it is vitally important to make transparent our assumptions of personhood in any research inquiry. This study located a predominantly modernist account of personhood, or what it means to be a human being, both in the hospice palliative care literature and as articulated by the professionals. The subtle and implied versions of personhood mainly included a focus on person-as-individual and person-as-mind. Holding these central modernist assumptions of personhood, it was argued, involved several limitations. This modernist account of self de-centered or silences a person’s significant ties to others and his or her embeddedness in a web of social and cultural ties. Furthermore, privileging mind as the central locus of being meant that these understandings decentralised or omitted something else. The limitation of the viewpoint of person-as-mind is that usually this is unquestioned, centralised and viewed as the only significant basis for personhood, and one that directly influences how a dying person is cared for. It was argued that this modernist account of personhood is not sufficient for the caring practices to correlate with the philosophy of (total) care or whole person care. The profession was expressing that the concept and practice of total care was crucial to the philosophy of care, yet their understandings of personhood did not correlate with a rich version of what it means to be a human being. Thus, an acknowledgement and understanding of human beings as multifaceted beings was required.

These insights paved the way for an exploration of an alternative account of personhood which drew on several key scholars. This account of personhood suggested that the human condition is irreducibly a condition of embeddedness; a person is always situated within a larger context. In other words, a person is understood as being an integral part of a surrounding whole. This whole is understood as being the world and the society we live in, our culture, a particular time, our language, important social relationships, a moral terrain and a spiritual horizon. In addition, human beings are embodied beings; that is I do not simply have a body, I AM body. We are storied beings as well, writing and rewriting, constructing and reconstructing, our versions of self and life through
stories. This account of being contained a greater inclusion of the various facets of our being and, arguably, provided a richer account of ontology, and one that fits with the concept of total care. Hospice palliative care, as a practice and a profession, needs to take into account the whole that a person is immersed in, influenced by, and connected to. Each human being has an inescapable connectivity with the world. We are shaped by the world, yet as we are interpretive beings, we uniquely construct our world. It was suggested that uniqueness was a preferable term for living-dying people, rather than individuals.

The last section of this chapter offered the possible implications for the living-dying person, including the disruptions to these varying facets of self. Our sense of self can become altered, lost, threatened, disturbed, disrupted, damaged or assaulted. The overall ontological implications were bracketed as either suffering (woundings) or opportunity (healing and transformation). To attend to both suffering and opportunity at the end of life requires both attention to richer ontological understandings and a centrality of stories. Overall, the key insight of this chapter was that a predominantly modernist account of personhood was located in the HPC professionals’ narratives and that to maintain the philosophy of (total) care this modernist account was insufficient and needed to be reconceptualised. An embedded account of personhood provided for a much richer account of personhood and one that would assist with understanding suffering and providing total or whole person care.

With an embedded ontological understanding of personhood, this study suggests, hospice palliative care professionals could work thoroughly towards the purpose of their practice. This was the focus on the next central feature of a social practice. The teleological features included the purposes, goals, ends, goods, or objectives of the practice of hospice palliative care. All social practices have this feature of being directed towards an end or good. The teleological features are central to the ethical dimension of this practice. The telos bestows an identity on the practice and makes it known to others. I was curious to understand more about the current understandings and articulations of the purpose of hospice palliative care practice and how these may have
changed over time; were there many differing understandings or was there a hint of a shared understanding of the goal of practice? I had suspected that the purpose of the practice, like the philosophy, may have become somewhat confused, blurred, weakened or fragmented.

The European Pallium project identified four overarching goals for hospice palliative care practice. These were the achievement of best quality of life, the relief of suffering, the promotion of the good death and the prevention of euthanasia. Three of these goals were examined, noting the problems and limitations in each. I acknowledged firstly, however, that the original goal for Saunders was that of attaining comfort. This goal does not hold a central place in the stated purpose of the practice anymore. Similarly, an original goal of the good death did not figure in the professionals’ narratives either. Ten Have and Clark (2002) believed that the goal of the good death has been increasingly abandoned. McNamara (2004) also found that the current valuing of individualism, choice and autonomy had changed the goal of the achievement of the good death.

It seemed, according to the European scholars, that the relief of suffering and attaining quality of life were usually the preferred goals now. Ten Have and Clark (2002) noted a preference for the relief of suffering as the goal of hospice palliative care practice. However, there is a need to understand more about what constitutes suffering if this is going to be the main goal of care. Yet, this goal still comes with its share of problems in that it is generally not well understood, not specific enough, is usually linked with the medical good or viewed in a medical way, and is often understood as a negative goal or as a problem. Finally, there was also the recognition of the limitations of being able to relieve someone’s suffering and that if people chose to suffer this was their right. In addition to these concerns, there is also a general failure to recognise the positive and creative elements in suffering. Overall, the relief of suffering was not overtly mentioned as a goal by the professionals in this study.
Rather, it was the achievement of quality of life, both in the hospice palliative care literature and in the professionals’ narratives, that was mentioned as the purpose of the practice. Quality of life had become widely accepted by the profession as the goal of end of life caring practices. This might be because of the commonly utilised World Health Organization definition of palliative care. The European project found that there was nearly universal agreement that quality of life is the most important moral notion and overall goal in palliative care (ten Have & Clark, 2002). Yet again, however, this goal comes with its share of difficulties and limitations, most notably the difficulty in understanding it and of knowing whether it had been achieved or not. Randall and Downie (2006) assert that there is not a shared conception of quality of life, that it is impossible to define, and any further attempt to define and measure it should be abandoned. I suggest that the goal of quality of life has been adopted by the profession and is now used in an unreflective and unarticulated way. It is largely rhetoric. Ten Have and Clark (2002) believe that it is an unrealistic goal and Randall and Downie (2006) argued that it is an entirely unhelpful goal. In addition, the dominant story of dying in our culture is negative, so locating quality during this time is extremely difficult for many.

Generally, with each of these overarching goals the influence of valuing individualism and choice has led to a diversity of meanings, tensions and confusions about what these goals mean. Thus, they become unhelpful to guide the professionals in their practice or as an identity for the practice. Nowadays, it seems, hospice palliative care professionals adopt the goals of aiming for pain management and symptom control, both because of the influence of biomedicine, but also because these are goals largely within their sphere of achievability. Individualism has largely affected each of the goals and now translates into the goal of helping people to ‘die my own way’. Yet, an individualistic or choice telos does not take into account that it is the professionals who are called upon to facilitate and present the viable choices for living-dying people. Individualism could result in lack of direction for people or may translate into providing every person simply with what he or she wants; for example, euthanasia. McNamara (2004) believes that individual responsibility created an emotional and moral weight of uncertainty for the
living-dying person. Individualism certainly upholds diversity and pluralism, but de-emphasises any common and shared understandings about how to die. Choice is simply what is on offer in any particular culture, at any specific time.

Living-dying people are choosing from an array of choices that are socially constructed and sanctioned. What is needed is the recognition of the unique ways that people will respond and travel the path of dying and a shared view of the good in caring for the dying. In addition, cultural stories such as the ‘fighting’ or ‘battling’ scripts need to be deconstructed and people given permission not to choose this way of dying if they do not wish to. What was initially understood by the examination of these stated overarching goals of hospice palliative care is that each of these goals has been largely influenced by either a plurality of meanings, a lack of meanings, or the external influences of biomedicine or individual choice. It seemed, at this point, as if the ideal of a shared, commonly understood purpose for the practice was missing. Indeed, as one professional expressed it, “we are wandering in the wilderness at the moment”.

Yet, this was not to be the case because a shared goal, which was expressed as a hope of their practice by the professionals, was located. In other words, significantly, this ethical conversation illuminated a shared and common purpose to the practice. Overwhelmingly, the hospice palliative care professionals in this study stated as the purpose of their practice the creation and maintenance of a particular type of relationship whereby they could assist the person on their path towards death. These expressions of relationship as purpose were outlined, including the unique features of this relationship. This provided for my new articulation of the telos of HPC practice

The purpose of hospice palliative care is to create and maintain unique relationships based on honesty, trust, professional skill, and ontological intimacy with which to facilitate a person’s journey towards death. This relationship between professional caregiver and living-dying person (and family) can focus upon considerations of the quality of living and dying, the meanings of suffering, assistance with comfort needs, and provision of information and skills as required. This responsive relationship is based on the fundamental beliefs and values of the philosophy of (total) care and an acknowledgement of the interdependent, vulnerable and fragile nature of the human condition.
In short, I offered a possible new purpose for hospice palliative care practice. This new articulation incorporates the ideas of coming home from Dekkers’ (2001) reflections and the relational focus which the HPC professionals spoke of. A condensed version of this purpose was stated as: the purpose of this practice is to create and maintain a unique relationship between professional caregiver and living-dying person (and family) with the aim of accompanying them home. The three central ingredients of this new purpose are: coming home (understood metaphorically); the creation and maintenance of a unique relationship; and the concept of accompanying (travelling with the living-dying person). Thus, the key insight located in this chapter was that the professionals did have a shared and common purpose to their practice and it was overwhelmingly relational. This insight led to the proposal of a new telos for hospice palliative care practice centered on the creation and maintenance of unique relationships which will assist with the clarity, identity and direction of the profession.

Each of these three features of a social practice provided new insights into understanding the ethical dimension of hospice palliative care practice. There was still, however, one last important area to cover - ethical frameworks. An examination of the ethical frameworks which hospice palliative care professionals bring to their practice provided for the last, and crucial, element explored in this inquiry. Ethical frameworks were understood as having two components – the expressions about what constitutes hospice palliative care ethics and statements about what ethically guides them in their practice. It was assumed that there would be a plurality of meanings when it comes to understanding ethics. Ethical frameworks, according to Taylor (1989), provide a set of beliefs which shape and direct people, informing them of how to live, what it is good to do or who it is good to be, and what is thought as valuable or worthy. In particular in these ethical frameworks, I was curious to learn about how central or helpful was principles-based ethics (PBE), and, in particular, the principle of respect for autonomy. This chapter also examined the important values which underpinned the practice and discovered whether these had changed or not over time. Overall, ethical frameworks were a critical component of the ethical dimension of hospice palliative care practice as they influence every action or non action, how professionals relate, and what was
viewed as important in caring for the living-dying person. These frameworks, asserts Taylor (cited in Abbey, 2000), orientate us in a moral space. Hence, I have adopted the notion of ethical frameworks as a compass for practice.

It was noted, initially, that PBE played a large role in the HPC literature having been adopted by the dominant hospice palliative care ethics authors (Randall and Downie, 1996, 1999, 2006; Webb, 2001, 2005). A biomedical ethical approach had been transferred over to the hospice palliative care ethics literature, in effect then ignoring the distinctive features of this type of care and bracketing it with all health care practices. Certainly, however, there was noted dissent from several authors about the application of principles to the practice of hospice palliative care. The European scholars were among the voices in the disagreement of the use of PBE. Importantly, it was found that a principles-based approach to ethics did not figure heavily in the professionals’ narratives. This approach to ethics was minimally mentioned by the professionals and if it was mentioned at all it was thought that the experiences in hospice palliative care practice were unique from other health care settings and, therefore, required a distinctive ethical framework other than PBE. Principlism was thought to be inadequate. The exception was that there was a notable inclusion of the principle of doing no harm (non-maleficence). This principle was considered important and it was suggested that there is a need to further examine the meanings and implications of this principle for the context of hospice palliative care.

Similarly, the principle of respect for autonomy was mentioned infrequently and there was a sense of dubiousness about the place of autonomy in hospice palliative care practice. It was thought inappropriate for the context of end of life care for the reasons that it was seen to be the opposite of relationships, it was incongruent with the family-centered approach advocated by this practice, and it did not fit with the lived reality of dying which was an experience of dependency. There was a paradox noticed, however, in that several professionals still voiced as crucial the concepts of individualism, rights, and freedom of choice so it must be surmised that autonomy does have a place in an ethical framework for hospice palliative care practice. It was proposed that autonomy
needed to be reconceptualised for this specific context and a suggestion was put forth of autonomy-in-relation, thereby acknowledging both autonomy and relationships.

The next dominant articulation of ethical frameworks pertained to values. Central values were understood as both a meaning of the ethics and as central guiding notions. Several authors pointed out that hospice palliative care practice always had a strong values-base and that these values needed reflecting upon and sustaining. There was a concern that the original values may have been lost. The stated values from several areas were combined for this research inquiry (original values, Palliative Care Australia values, and European Pallium values) and a quantitative inquiry noted which of these were viewed as central to underpinning the practice. A table of these findings was presented showing that the original hospice values are still considered of highest worth and have not withered over time. These top values included the acceptance of human mortality (dying-as-natural), total care, and open and honest communication. It was suggested that Palliative Care Australia needed to alter its stated core values to include and acknowledge these three values.

I also proposed that because acceptance of human mortality is ranked as the foremost good in hospice palliative care practice this then translates into a unique ethical context. Clearly, it is the central ethical underpinning in end of life caring practices, whether it is spoken of in terms of an intention or a purpose, as part of the practice, as something which is highly valued, as the ultimate ‘good’ of the practice, or simply a concept to be discussed. It was highly reflected upon by the majority of the professionals in this study. Unfortunately, this value too, like total care, is being eroded by powerful internal and external forces, especially as hospice palliative care becomes more mainstreamed in health care settings and life prolongation is increasingly valued. There is a need to sustain this value through death education and continuing to understand and appreciate this dying time as valuable and precious.
The next element of ethical frameworks articulated by the HPC professionals was that of identity, that is, ethical practice is closely interwoven with who a person is. This is especially important given that the values of honesty and compassion were so highly regarded, and some of the crucial elements of the type of relationship hoped for were things such as trustworthiness. Thus, any ethical framework for hospice palliative care practice needs to include the cultivation of attitudes, dispositions and moral virtues for consideration. Olthuis’ (2007) research into the moral attitude of professionals in hospice palliative care practice provided important inclusions into this understanding of identity and a virtue based approach to ethics was further explored. Virtue ethics relates good behaviour to the kind of person someone is, and offers insights into how such qualities can be further developed. The professionals spoke eloquently about the ethics of practice being about authentically who they are, thereby reinforcing the importance of being ‘real’ and human in these caring practices. Furthermore, the concept, value and practice of compassion was explored, including the varying interpretations of what it means. It was suggested that further education processes were needed to assist hospice palliative care workers with the development of this virtue.

The final and dominant part of the ethical frameworks for hospice palliative care practice was the relational. The relationship between professional caregiver and living-dying person played the central role in the understandings of what is ethics and what guides the professionals. Simply, hospice palliative care ethics was about how the professionals treated others, namely the living-dying person. When explaining how to treat others, most often the statements included an emphasis on treating others as I would wish to have myself treated (the golden rule ethic) and treating others as if they were family (a familial ethic). These two ethics, however helpful they seemed from the outset, held several limitations.
In seeking to understand more about the ethical relationships in hospice palliative care practice a proximity stance was developed to elaborate on how ontologically near or far the professionals were to the living-dying person. The golden rule or familial ethic was thought helpful in bringing the professionals nearer or closer to the living-dying person; something which was important for the type of relationship hoped for. The far stance on the continuum is the oft heard expression in health care relationships of maintaining distance, keeping your boundaries, of being neutral or objective. This far stance was not thought to be appropriate for end of life caring practices. A delicate balance is needed in these ethical relationships where a professional would be not too close, nor merging with the living-dying person, as Frank (2005c) calls it, nor too far or distant. Ideally, a proximity stance of in-between is required for ethical relationships in hospice palliative care practice.

The writings of several philosophical authors were incorporated to outline an account of an ethical relationship for hospice palliative care practice. The writings of Levinas were helpful in understanding that trying to become closer to the living-dying person may equate to reducing the person’s otherness or uniqueness. We must retain alterity, the uniqueness of the other, asserts Levinas (cited in Davis, 1996). Alterity means not pronouncing final words about another and genuinely entering into a relationship from the stance of not-knowing, and then seeking to understand the living-dying person; for the other must always remain wholly other. For this to occur open dialogue is critical – we must speak with each other. A shared power approach was also recommended for this ethical relationship in hospice palliative care practice. Power needs to be employed in a way that best maximises the ethical engagement between the hospice palliative care professional and the living-dying person. Power sharing is the ultimate aim in an ethical framework for this practice. It was suggested that there is a great need, in hospice palliative care practice, to critically reflect, converse and develop understandings which address relational proximity and ontological intimacy in these end of life relationships.
These ruminations about the ethical relationship in hospice palliative care practice, and
the other insights located in this chapter, translated into a distinctive ethical framework:
A Relational Ethic of Accompanying (REA). The layers of ethical considerations in
this framework included principles, values, virtues and relationships. Hospice palliative
care professionals need to consider these many layers of the ethical dimension of their
practice, both in the ethical frameworks that are implicit in their work, and what
ethically guides them. Overwhelming, there is a need to continue to clarify hospice
palliative care as a form of relational care, and to prioritise a relational ethical
framework, to offer optimal and ethical end of life caring practices.

This thesis concludes that hospice palliative care, as a social practice, has a rich ethical
dimension as understood and articulated by the hospice palliative care professionals in
this inquiry. The key insights illuminated, and thorough articulations offered, are
testimony to this richness. I have utilised an engaged ethics approach in examining the
ethics of this profession, which has privileged an internal exploration, rather than
assume that the ethics would be the same as any other health care modality or to simply
adopt and apply a dominant, principles-based approach. This has resulted in the
construction of a new ethical framework reflecting, formalising and adapting the ethical
dimension as understood by its professional members. That it is not possible to squeeze
the ethical dimension this profession has developed into a modern, moral philosophical
paradigm or a biomedical ethical approach is a reflection of the uniqueness of the
hospice palliative care profession. What I have named ‘A Relational Ethic of
Accompanying’ is needed to help maintain, sustain and protect the unique identity of
this profession. This framework adds to the “moral vocabulary” (Jennings, 1997) or
“moral specificity” (ten Have & Clark, 2002) of hospice palliative care practice. In
addition, it would provide significant guidance to palliateurs reflecting on how best to
provide quality, compassionate and ethical care at the end of life.
7.2 A distinctive ethical framework

Before concluding this thesis, and in keeping with the honouring of a plurality of meanings when it comes to ethics, I would like to acknowledge that there is a growing conversation pertaining to this distinctive ethical context of hospice palliative care practice. In the diagram on the next page I wish to reiterate the core components of the REA framework, whilst at the same time deliberately entwining other ethical conversations from the European context. This figure, therefore, represents the growing moral vocabulary for this practice, one that clearly looks different to a biomedical, principles-based approach.

Looking across these three accounts for the ethics of hospice palliative care practice, three ethical imperatives begin to emerge:

- To endeavour to develop the moral attitude and identity of the professional caregiver (i.e. phronesis, virtues, moral attitude, authentic human being, continued enhancing of the self, awareness of the vulnerability of life);
- To appreciate the living-dying person as a human being of ‘wholeness’, of unique interpretations and experiences, biographies and embedded in a context and listening to who they are and the changes they are facing in the living-dying process (i.e. enhancing of the other, maintaining alterity, starting with the moral experience of the living-dying person);
- To create, maintain and reflect upon the unique type of relationship required in this caring-ethical endeavour (covenant, caring conversations, accompanying, bond, and ontological intimacy).

With these three ethical imperatives in mind, ten Have and Clark (2002) suggest that “ethics itself may benefit from the peculiarities of the palliative care as a movement and philosophy of care, including new moral notions of wider relevance in the healthcare context” (p. 233). By reflecting on ourselves as professional caregivers, on the unique lived experience of the living-dying person, and the flourishing of both, and the type of relationship that will enhance the living-dying time, the ethics of hospice palliative care practice will grow.
A Relational Ethic of Accompanying
(Wilson, 2008)

Principles
Non-maleficence (do no harm and futility)
Autonomy-in-relation

Values
Acceptance of human mortality
(dying-as-natural)
Total or whole person care (healing)
Open and honest communication

Virtues
Compassion
Trustworthiness

Relationships
Retaining alterity
Closeness and ontological intimacy
A proximity stance of in-between
Power sharing
Dialogue

An Embedded Ontology

Who Cares?
(Olthuis, 2007)

Phronesis
Practical wisdom is required to enable a person to deliberate about what is good or bad and then to act appropriately. This requires the development of self awareness

Caring Conversations
People need others to give meaning to their existence.
The moral elements of care include attentiveness, responsibility, competence and responsiveness.
Caring conversations are a mode of connecting to a living-dying person and as a way of exploring suffering.

Covenant
Two moral conditions:
The commitment of the caregiver to the total good of the living-dying person and the living-dying person’s trust in that commitment.

Interpretive Ethics
(ten Have & Clark, 2002)

Experience
Start with the moral experience of the living-dying person; this requires interpretation

Attitudes and Emotions
The affective dimension
A change of focus from the ‘what to do’ to the ‘how to live’
Reorientation from activity to passivity, from acts to attitudes and emotions, from speaking to silence

Community
Our understandings are always a community phenomenon; our interpretations are orientated by cultural assumptions
Discover the particularities of our own prior understandings
Attain a more general level of understanding

Ambiguity
Ethics primarily aims at interpreting and understanding moral experience; this experience is complex, uncertain and tentative.

Figure One: Moral vocabulary
7.3 The transformative dimension

‘Growing’ this ethical practice means taking what has been learnt and illuminated in this study and adapting these towards practical change. Isaacs and Massey (1994) call this “an imperative for action – theory spills over into practice, the appraising ushers in the transformative” (p. 21-22). The transformative domain of the engaged ethics approach addresses “the means whereby the ideal might be achieved or pursued” (p. 22). This next section of the concluding chapter outlines suggestions for change in the areas of research, education and practice.

7.3.1 Research

In the area of research, it is hoped that further ethical inquiries continue where this research has left off. This is especially important as the growing field of hospice palliative care develops its evidence base. However, I would call for rigorous qualitative research such as this to counterbalance the quantitative and clinical studies currently being undertaken. Evidence, it needs to be appreciated, comes in different shapes and sizes. Narrative studies such as this, which tap into the lived realities of living-dying people and palliateurs, pave the way for considerable development of knowledge for hospice palliative care practice. Specifically, in ethics research I would call for a study that investigates the meanings of the principle of non-maleficence in the context of hospice palliative care, and its companion concept: futility. Another ethical topic ripe for research would focus on total care and its changing understandings. These two topics are possible suggestions for future research. What is called for, ultimately, is that ethics research is understood more broadly, rather than narrowly. Ethics inquiries need to go beyond single ethical issues such as euthanasia.

7.3.2 Education

It is with education that practical change can occur. I have made several suggestions throughout this thesis where processes of education are required. Education could assist with understanding an embedded ontological account or in examining attitudes and understandings of dying and death. These are two areas where I would strongly advocate for further education. If hospice palliative care professions are committed to
whole person or total care, there must be parallel educational opportunities to learn and reflect on: what does it mean to be a human being? There is a need to appreciate the multi-faceted and embedded account of personhood which goes beyond the dominant and largely ingrained view of personhood. Here the work of embodiment theory can assist, as it has done in the educational processes carried out by the ethics scholars at the Queensland University of Technology49.

A further topic recommended for education concerns the concept and practice of compassion. As a central and highly valued virtue it, too, needs further examination and reflection. In other words, professional development opportunities need to go beyond ‘updates in pharmacology’! Finally, something that I have already endeavoured to put into place is educational processes concerning how we spiritually support each other at the end of life. The spiritual aspect of personhood, I would suggest, is the least understood aspect of care in hospice palliative care practice, yet it is central to the living-dying process. If this profession is to remain committed to total care then the spiritual needs to be learnt about; not through the processes of assessment, but rather through the concept of connection and listening. Finally, when it comes to education, I would like to see an alternative ethics text than the dominant, moral philosophical type one on offer.

7.3.3 Practice
There are two practices which I strongly recommend, as a consequence of this study, be put in place in hospice palliative care services.

7.3.3.1 Articulation of the ethical
From the outset of this inquiry the facilitation of articulation was of primary importance. I take seriously the task of developing an ‘ethical space’ and facilitating ‘tellings’ to enhance our understandings and awareness of ethical practice. Articulation, according to Taylor (1989), is the process whereby the tacit background or what is unsaid about the

49 An embedded ontological account is taught in subjects such as Researching Applied Ethics, Reshaping Life and Death and Ethics, Law and Health Care (Dr. Peter Isaacs, Humanities Program, QUT).

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ethical domain is expressed and acknowledged. This is because, as is often the case, our values, attitudes and philosophies go unnoticed and unarticulated. In addition, our meanings change about these things. Thus, I would recommend that any hospice palliative care service sets aside time for discussing the ethics of their practice.

There are multiple benefits in doing so. Firstly, it brings the ethical into the light of awareness. This translates into a greater understanding and awareness of what professional caregivers are doing (and being) or not doing (and being). Secondly, values change, and their meanings change, so discussing these with each other is crucially important, especially considering that hospice palliative care has such a fundamental values-base. Articulation will strengthen an ethical framework, including a person’s commitment to it. It is a process that acts as a critique, challenging some of the ideas and attitudes held; for example, the ethical guidance of the golden rule and what might be problematic about this. On a broader scale, ethical articulation can strengthen a profession and sustain its unique identity. Palliative Care Australia sets out in its standards guidelines that staff reflect on their practice, yet I would question how much time and priority this is given. It was obvious from the comments of the professionals in this study how helpful and interesting this process had been (p. 27). Articulation of the ethical is greatly required.

What needs to be incorporated with this articulation of the ethical is an overt focus on relationships. As relationships are so central in the hopes and ethics of hospice palliative care professionals, this would warrant enhanced practices. Open and honest discussions about the types of relationships that are being created and maintained in hospice palliative care practice are required. The mainly nursing mantra of ‘maintaining boundaries’ does not seem to be a helpful one in this context of end of life care. My vision would be that at handovers or case conferences discussions and questions concerning the relationships professionals were establishing with their living-dying companions would be given equal weight as the changes in physical symptoms. I understand, first hand, how these relationships impact upon hospice palliative care professionals and living-dying people, and so are extremely worthy of reflection. Given
the centrality of relationships in the ethical dimension of hospice palliative care it is somewhat surprising that there is a dearth of research, education and discussions around this crucial aspect of care.

### 7.3.3.2 Adoption of an ethical framework

Unsurprisingly, I would suggest the adoption and usage of a distinctive ethical framework such as the one proposed in this study. It is quite surprising that this practice has developed for so long without a formalised ethical framework for practice. Certainly, the profession has borrowed from health care for its ethical considerations and the specialty of palliative medicine has some useful guidelines. However, for the specific and unique context and practices of hospice palliative care something new is needed. I would hope that an ethical framework is adopted by the profession so as to further enhance the quality of care provided to living-dying people and their families and friends.

### 7.3.4 Recommendations to Palliative Care Australia

A last recommendation is directed to the peak body for this profession in Australia – Palliative Care Australia. The core values in the *Standards for providing quality palliative care for all Australians* (2005) need to include the valuing of dying and death as a natural part of life and the valuing of total care. These two values need to be explicitly mentioned in the list of core values for the profession. Secondly, and similar to Randall and Downie’s (2006) recommendations, I would like to dismantle the adopted World Health Organization’s definition of palliative care, take out the aim of quality of life, and work towards a new telos. I hope that the insights from this study will pave the way towards a new purpose of the practice of hospice palliative care. Finally, I would recommend to Palliative Care Australia that an ethical framework be further formalised and promoted through its media. The REA framework is worthy of consideration for hospice palliative care professionals to reflect on their work. It could also be adapted with reflective questions for each layer of the framework and be of assistance in ethical decisions and education. I fervently call for a distinctive ethical framework for this practice which resonates with the uniquely normal experiences of living-dying people.
7.4 Temporality: Towards a moral horizon

There is always the tension between the philosophy and ideals of caring for someone who is dying and the realities of care because you have to do some things for the person physically, but to me the secret, in the future, is going to be finding that balance. The scales have gone out of balance … the doctors have become so involved and have seen it as a medical challenge, not as an issue about people’s quality of life or about people dying as whole human beings (Vivienne, cited in McNamara, 2001, p. 135).

Any ethical inquiry needs to take into account a moral horizon, that is, what is hoped for into the future. As this quote alludes to, this future, moral horizon is often uppermost in professionals’ minds, as it was for the professionals in this study. The future hopes and thoughts pertain to the embedded nature of any social practice. A practice comes out of a past, but is also working towards a future. Temporality plays a significant role in the identity of this profession. Back in the 1990s Rumbold (1998) believed that the profession was in crisis, “facing both risk and opportunity” (p. 14). The opportunity, he wrote

is that of bringing the insights and practice of hospice care to bear within the new horizons offered by the emerging discipline of palliative care. This risk is that the very process of mainstreaming hospice care will rob it of its essence, leaving palliative care with the forms, but not the substance, of hospice care (p. 14).

Similarly, Zimmerman (1986) wrote at that time that the “the preservation of the name hospice is not the overriding consideration; however, the philosophy and principles that it embodies is” (p. 292). There are several commentators who reflect on the future of this practice, however, I wish to privilege the hospice palliative care professionals, again, with their hopes for the future. For some of the professionals it was vitally important to “remember our roots”

We need to retain those fundamental core care components that are about compassionate care, holistic care, and holding people. Hospice took people and embraced them at the end of life and made them feel safe (Stacy)

We would have to incorporate the fundamentals of hospice care. We need to go back to its grass roots. Go back to its history and revisit the core values of hospice care (Amy)

We need to get back to what that philosophy of care means. Palliative care help put the care back into health care. But we’ve started to lose that ourselves in palliative care now (Jackie)
We have to remember our roots. To stop and reflect on the gentleness that is needed. At the end of the day there is a human being and their family and their life in front of you (Jennifer)

I think the most important thing we do is just be and I think sometimes just that sense of being is the most powerful tool in palliative care. Just the sense that another human being is prepared to take the time to sit and be with them is very powerful. I think we lose that because it is viewed as not enough according to a medical model. But then I stop and think, well why did palliative care become important in the first place? It’s based on that very premise of ‘watch with me’ (Zoe)

I think we need to keep it simple. We need to look at why she (Saunders) decided to do this in the first place and we need to remember the basics. These don’t change. The humanity of caring for somebody who is dying (Fiona)

I think responsiveness is key. The modern hospice movement was a response to something. I think that we need to retain the ability to respond, to change and be flexible (Ken).

The past is very much a reminder for these professionals, in how it was and how it needs to continue on. There is a call to remember why it was established, how it was conceptualised, and not to forget these crucial, core values and underpinnings of this practice.

Another important theme that emerged in these expressions of hopes for the future were ‘cautionary tales’

What many of us fear in palliative care, that we’ve got to be careful not to over-medicalise it. We’ve got to be really careful that we don’t lose sight of those four rooms. We run the risk of becoming victims of the powerful hospital structures that don’t pay credence to the social, psychological and spiritual domains of what we should be about (Jim)

That we don’t take a prescriptive approach. We need to be careful that we don’t pathologise a natural process (Peter)

There is a need for self awareness and wisdom. There’s such a drive to make it so much more medical. The further you go down that track, with that imperative to treat, that’s when the problems start (Elizabeth)

I think that there will be an area of palliative treatment and an area of palliative care. It will go more and more into the hospitals and it’s not going to be palliative care as it should be. This is going to be tricky for us. They’ll call it palliative treatment and they’ll treat them till death. We need to be able to move in there and say ‘you’ve got to stop this’ (Kate)
Importantly, connecting with the people. Technology changes, drugs improve, and change. We should not forget the relationship side of things. And being a real person because you can’t divorce who you are with how you are with another person (Melanie).

These sorts of cautionary tales speak of the concerns of over-medicalisation of the practice, the processes of mainstreaming and the futility of treatments. These expressions promote the very real concerns of the direction of the profession and the words of wisdom and advice pertaining to these fears.

For one hospice palliative care professional there was a real sense of pessimism about the future of her practice

Honestly, unless things change, I think it will be lost. For our model of care (hospice) there is an unknown future (Julie).

It can be acknowledged, though, that all futures are unknown. A sense of loss, however, did emerge for some of the community based hospice services who voiced the concern that they were being made redundant.

I would like to leave the last words about the future of hospice palliative care to Natasha, a highly experienced and eloquent palliative care physician, who coined the ‘accompanying’ term. Her wisdom deserves highlighting, as she speaks of the role of continuing learning and self awareness

I think the most important thing is about self work. You need to constantly face your ego and deal with it. You know, ‘physician heal thyself’ … for all practitioners … because I see now a sort of arrogance developing. If at any point you start to think that you begin to understand, you need to think again. You have to continue to be open, to being changed and learning (Natasha).

Most of all, as Natasha explains, when being face to face with a living-dying person, hospice palliative care professionals need to seek to understand their experiences and interpretations. Palliateurs need to develop their skill and knowledge, whilst at the same time remain humble in the face of the experience of dying. The professionals who specifically care for the living-dying in our society need to continue to look towards this moral horizon and ask the questions about what sort of future we wish for. For, as Kellehear (2007) pointed out at the beginning of this chapter, the dual considerations of
how we are to care for our dying and what type of society or human beings we wish to become, are intertwined.

7.5 Conclusion

Almost four years ago I wrote a quote by Widdershoven (2002) at the front of this thesis. I will repeat it again

The experience of art makes concrete the process of the fusion of horizons. When we understand a work of art, we experience that our horizon is broadened, not by giving up our own viewpoint, nor by overpowering that of others, but by opening ourselves towards the view of others and thereby acquiring a new and richer view (Widdershoven, 2002, p. 45).

The intent of this study was to acquire and share a new and richer view of hospice palliative care ethics. It has sought to reinvigorate the tradition, ontology, telos and ethical frameworks of this practice. What comes of this reinvigoration is unknown. I hope that is contributes to the continuing development of the profession. I hope that it strengthens the unique identity of the profession. Like Schotsmans (2002) and Olthuis and Dekkers (2003a) I believe that it will enhance the ethical culture of this practice. Like MacLeod (2003) I believe that it will protect the moral framework of end of life caring practices. I hope that it guides development into the future and orientates the professional caregivers in moral space. What can be obviously stated is that a clearer, shared sense of the ethical dimension of hospice palliative care practice has been gained. This thesis has enhanced the shared understandings of the ethical in this practice. My intention has always been that, with this ethical conversation, the care that people receive when they are living their dying is the best it can possibly be. May the ethical conversations continue.

I watch my chest slowly rising up and down, ever so faintly. I wonder at the marvel of breath, so taken for granted. Soon mine will stop and my self, my life, as I have known it, will end. In, out, as the oxygen goes, life slowly shutting down. Oh what an extraordinary adventure it has been, these last few months. Did I battle? Yes, maybe a little, but mostly with my thoughts. Now my mind is quiet and I can hear the trees fluid in the wind. Love has surrounded me on these remaining days, hours, minutes. I have
been accompanied by people who have refined their understandings and practices of care, at the end of life. People who have appreciated who I am and how I die in every gesture; holding me, enabling me. One person still accompanies me in a different way though. He cannot go any further with me, yet he still sits beside me. What I see now of him, and what’s outside my window, has acquired a shimmery quality, as my passage to another place begins. A new time, a new adventure, a new book begins! Dying and death are a part of life.
Bibliography


Asia Pacific Hospice Palliative Care Network. URL: www.aphn.org


de Raeve, L. (1994). Ethical issues in palliative care research. Palliative Medicine, 8, 298-305.


*Recognising religion: A study of religion for senior secondary students*
(pp. 300-327). Katoomba, NSW: Social Science Press.

and personal: The teaching and learning of narrative research.*

contestation.* Calgary, Alberta: University of Calgary Press.

personhood in hospice care. *International Journal of Palliative
Nursing*, 9(7), 283-289.

Kaufman, S. (2000). Senescence, decline and the quest for a good
death: Contemporary dilemmas and historical antecedents. *Journal of Aging
Studies*, 14(1), 1-23.

*Palliative Medicine*, 6, 39-46.


*Annual Review of Health Social Sciences*, 7, 28-34.

Switzerland: Harwood Academic.

C. Waddell (Eds.), *Health matters: A sociology of illness, prevention and care*
(pp. 287-299). St. Leonards, NSW: Allen & Unwin.

Kellehear, A. (1999a). *Health promoting palliative care.* South
Melbourne, VIC: Oxford University Press.

Kellehear, A. (1999b). Health promoting palliative care:


Palliative Care Australia (2000). *Australia’s future in palliative care research: A collaborative approach*. Deakin West, ACT: Palliative Care Australia.

Palliative Care Australia (2003). *Palliative care service provision in Australia: A planning guide* (2nd ed.). Deakin West, ACT: Palliative Care Australia.

Palliative Care Australia (2004). *National directory: Palliative care services and hospices in Australia*. Deakin West, ACT: Palliative Care Australia.

Palliative Care Australia (2005). *Standards for providing quality palliative care for all Australians*. Deakin West, ACT: Palliative Care Australia.

Palliative Care Australia (2006). *Palliative Care Definition* [Online].
www.pca.org.au


Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M. & Tulsky, J. A. (2000). In search of a good death: Observations of patients, families and providers. *Annals of Internal Medicine*, 132(10), 825-832.


Thompson, P. K. (2000). *The dark night of the soul: A metaphor for understanding the ethics and spirituality of hospice care* [Unpublished PhD thesis]. McAnulty College and Graduate School of Liberal Arts: Duquesne University. 4-65.


Appendix One

Caring for the Dying Other: Mapping the Ethical Dimension of Hospice Palliative Care Practice.

Monika Wilson
Queensland University of Technology
School of Humanities and Human Services
Centre for Social Change Research
(07) 3864 4780
ma.wilson@qut.edu.au

Statement of Consent

By signing below, you are indicating that you:

• Have read and understood the information sheet about this project;
• Have had any questions answered to your satisfaction;
• Understand that if you have any additional questions or queries you can contact the researcher (Monika Wilson) or her supervisor (David Massey) on the telephone/email contact details provided;
• Understand that you are free to withdraw at anytime, without comment or penalty;
• Understand that you can contact the QUT Research Ethics Officer on 3864 2340 if you have any concerns about the ethical conduct of the project;
• Understand that participation in this project is completely voluntary;
• Understand that any information provided by you will remain confidential – neither your real name, nor any explicit information identifying you, will be used. All information will be stored in a secure, locked place; and
• Agree to participate in this research project, with the understanding that your responses will be included in the final PhD thesis, journal articles and conference papers.

Name: .................................................................
Signature: ............................................................
Date: .................................................................
Contact Details: ....................................................
Appendix Two

An Invitation to Participate in an Applied Ethics Research Inquiry into the Ethics of Hospice Palliative Care

THE RESEARCH INQUIRY

Caring for the dying other: Mapping the ethical dimension of hospice palliative care practice

Professional care of the dying, or palliative care, has developed significantly in the last twenty-five years in Australia. Development of this important form of care is crucial, yet critiques of this growth have been proposed including the ad hoc manner with which it has progressed, the potential medicalisation of this practice and the loss of the original values of the hospice movement.

Ethical inquiry into this professional practice has largely focused on particular issues, problems and dilemmas, such as euthanasia. Although specific ethical issues are important considerations, a broader investigation of the ethics of palliative care practice has not been given sufficient consideration in the growing accumulation of palliative care research literature in Australia. This research inquiry resolves to bridge this gap. More recently European scholars have identified a distinctive set of moral values that palliative care professionals state as important to the practice. These moral values provide for a unique ethical dimension in the practice of palliative care. It is this ethical dimension that this research inquiry intends to articulate, interpret and appraise. Specifically, this study investigates two significant features of this ethical dimension of palliative care – firstly, the teleological features that include the ‘goods’, aims or overall purpose which the practice seeks to achieve and secondly, the ethical frameworks that guide and inform practitioners towards these ends.

RATIONALE FOR THE INQUIRY

Palliative care in Australia has undergone many changes since its humble beginnings and continues to grow as a specialised field. Notably, this growth has accelerated in Australia since the 1980s. The broader ethical dimension of the practice of palliative care was chosen to be of significance for this research endeavour. There are several reasons for this. Firstly, McNamara suggests that the contemporary practice of palliative has lost the original values of the hospice movement. Secondly, contemporary palliative care in Australia, it seems, can be viewed as being, more than ever before, embedded into mainstream healthcare. Possibly because of this integration, the profession of palliative care may have adopted an ethical framework for practice stemming from biomedical ethics - a principle-based approach. Thirdly, there are few studies that discuss these particular features of the ethical dimension of palliative care, except in terms of issues, dilemmas or problems. In other words, there is inadequate attention being paid to a broader ethical inquiry of palliative care as it has developed since its origins. Jennings surmises that “systematic reflection on ethics in the hospice field is curiously underdeveloped”.

This inquiry will focus on the current changes taking place in palliative care practice, and the role and influence of external values. Research into this area will provide direction towards an articulation of the ethical specificity of palliative care. This articulation could provide for a coherent ethical culture and agreed upon understandings of the purpose of palliative care.
YOUR PARTICIPATION
Your involvement would require a face to face conversational-interview for approximately 1 hour (possibly longer). The types of questions I may ask to orient our conversation would include:

When I say ‘the ethics of palliative care’, what does this mean to you?
What do you draw upon to ethically guide your practice?
What do you believe the overall purpose (or purposes) of palliative care practice to be?
What do you understand of the concept of autonomy?

These interviews will be audio-taped and transcribed (word for word) and then sent to you for final verification and inclusion in the findings of the study. This interview can take place in a location of your choice. Interviews will be carried out between the months of June to December 2005.

BENEFITS AND RISKS
Overall, it is anticipated that the outcomes of this research will be a contribution to the ongoing development of the profession and the enhancement of end of life care. Specifically, the end result of this inquiry will provide us with clear articulations of what palliative care seeks to achieve and some possible templates about how to do so. For you, the individual participant, it will be a chance to add your voice to the ongoing conversation about what palliative care seeks to achieve, thereby shaping the future identity of the practice of palliative care. There are no expected risks in relation to your participation in this project, as you are familiar with the practices of palliative care on a daily basis. Certainly, I would assume that you would access de-briefing services in your organisation if the need arises.

CONSENT, CONFIDENTIALITY AND VOLUNTARY PARTICIPATION
If you wish to be involved in this research project, then I would first need your permission. This can be done by reading this invitation, asking any further questions and then reading and signing the consent form attached. By signing this consent form you will be agreeing to the points on it. Additionally, before commencing the interview I will again ask for your verbal consent. You are consenting to the details of this interview being integrated into the final PhD thesis and other documentation (conference papers and journal articles). Confidentiality will be assured by not requesting your personal details or place of work. The only identifying details I will use in this inquiry are your role e.g. palliative care nurse and the type of palliative care context you work in e.g. community based service. No other personal details are required. Your real name will not be used in any way. All transcribed interviews will be kept secure and not be made available to others. Finally, participation in this research inquiry is entirely voluntary. Any subsequent decision to withdraw from the project will not involve any loss of benefits; and you may choose to discontinue participation at any time without comment or penalty.

QUESTIONS OR FURTHER INFORMATION
If you have any questions regarding this research inquiry, I invite you to contact me personally:
email: ma.wilson@qut.edu.au; phone: 3864 4780 / 0428 777809. Alternatively, you can contact my supervisor David Massey: email: d.massey@qut.edu.au; phone: 3864 4744. If you have any concerns or complaints about the ethical conduct of this project, please contact the QUT Research Ethics Officer at ethicscontact@qut.edu.au or 3864 2340. You can also write to the QUT Research Ethics Officer at: Office of Research, O Block Podium, QUT GP Campus, GPO Box 2434, Brisbane QLD 4001. I ask you to please retain this letter for future reference.

This research project has received Level One Ethical Clearance (QUT Ref No 4071H) through the University Human Research Ethics Committee (UHREC).


8 McNamara, B. (2001).
