A CONCEPTUAL ANALYSIS OF
CANADIAN PALLIATIVE CARE ETHICS

by

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Abstract

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Introduction: In the palliative care literature there has been debate over the occurrence and the desirability of the rationalization of palliative care. The discussion is based mostly on opinion, anecdote and argument. Little discussion is based on research, or is specific to Canada. Considering this question of rationalization, this thesis asks whether Canadian palliative care ethics has changed, and if so in what regard.

Methods: Discourse analysis was used to evaluate texts and interviews from early and late Canadian palliative care. Based on expression, influence and comprehensiveness, two key texts were identified from each of the early and late periods of palliative care. Ten interviews were conducted with Canadian palliative care pioneers practicing across these periods. These interviews were semi-structured, and were based on the background literature and the textual analysis.

Results: Analysis of the textual data led to the descriptive themes of person, profession and well-being. These themes, when compared across the early and late periods, generated three themes of process. Analysis of the interview data generated three similar themes of process. The themes of process from the textual and interview data were similar enough to generate three overall themes of process – routinization, medicalization, and professionalization.
Conclusion: Canadian palliative care and palliative care ethics were found to have undergone rationalization, understood as the processes of routinization, medicalization and professionalization. For palliative care, this has meant that care has become more routine, more of a career and less of a calling; has meant the increased use of medical interventions and medical understandings in palliative care; and has meant that practitioners identify more with traditional professions than previously and self-identify as palliative care specialists. For palliative care ethics, this rationalization has meant a shift in emphasis in the goals of palliative care. Early palliative care emphasized the goals of palliation, presence and meaning as a response to the sufferings and abandonment of dying persons. During rationalization, palliative care shifted to focus primarily to palliation. This thesis also prescribes a revision of palliative care ethics that retrieves the early goals of presence and meaning as a response to abandonment.
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Preface

Thinking of why I undertook this project, two pithy comments come to mind. Together they nicely capture the much longer, more elaborate, and more prosaic question-and-response of this thesis. Both comments came from palliative care practitioners, one a gadfly and the other a pioneer.

The first came almost a decade ago, as I drove home from a day of shared visits with the first practitioner, the gadfly.

He paused as I parked the car. “So why are you in palliative care,” he asked.

“To help the patients,” I said.

He smiled and stepped from the car, “Help them what?” he said. “There’s your question.” He closed the door, waved, and walked away.

The second comment came during the interview process, as I stood at one hospice’s front door, half in and half out of the cold, saying thanks and goodbye to the other practitioner, the pioneer.

He paused. “One last thing,” he said, now long after the interview had stopped.

“The only thing that’s ever truly set palliative care apart is dying. All the rest is or could be part of medicine – the symptom control, the counseling, and all that – but meeting the dying person…that’s different.”

What should palliative care be doing? In this thesis the question is expanded and made sociological, methods of inquiry are employed, and the eventual response is lengthy. But at the core of it, the key question remains, what are the goals of palliative care and what sets palliative care apart from the rest of medical care?
Chapter 1: Introduction

1.1) Thesis Questions

This thesis explores the nature of Canadian palliative care, especially its ethics. Using qualitative methods, it develops an understanding of some formal and substantive features of Canadian palliative care. Conceptually, the thesis proceeds by developing questions, situating them in the relevant literature, addressing these questions through discourse analysis of texts and interviews, and responding to the questions in the Discussion chapter. The present chapter begins the process by introducing the questions and reviewing related research on similar questions.

Specifically, this thesis considers the following questions:

- Has Canadian palliative care and its ethics changed since palliative care began in Canada?
- If Canadian palliative care and its ethics have changed, how should we understand this change?
- What importance might this understanding of palliative care ethics have for present and future palliative care?

1.2) Responses

1.2.1) Thesis Response

The questions underlying this thesis encourage responses that are conceptual and somewhat general, and consequently they lend themselves to responses based on opinion, on anecdote and on qualitative research. Responses given to such questions are ‘situated’
ones, that is, they carry assumptions, bias, and values more or less openly within them. From my own perspective, my experience as a palliative care physician and my academic background (i.e. philosophy, bioethics, social theory) have influenced my response - motivating the effort, shaping the question, and overall both limiting it and making it possible. But in hopes of providing something that also reaches beyond my own experiences and background, I have used qualitative research methods, and before reviewing the published research regarding the questions of this thesis, I will here briefly introduce these methodological approaches (full description in Chapter 3: Methods).

In this thesis I used literature reviews, discourse analysis of texts, and discourse analysis of interviews:

- Three literature reviews were performed: one searching for research similar in method and topic to this thesis; another searching for research on the history of dying in Western civilization; and another searching for research on the history of palliative care. The results of the first search are reviewed in this Introduction, and the results of the other two are included in the Background and the Discussion sections.

- Using discourse analysis techniques and guided by the background literature, I compared early and late texts important to Canadian palliative care palliative care. The texts were chosen on the basis of expression, influence, and comprehensiveness. Discourse analysis involved analyzing the texts using reiterative coding, comparison, aggregation, and refining. This resulted in the generation of descriptive categories, which, when compared and considered with an aim to understanding changes over time, were collected into themes of process.
I interviewed ten palliative care pioneers who had each practiced from the early into the late periods of palliative care regarding the changes in palliative care. The interviews were conducted using a semi-structured questionnaire as a guide, and transcripts of the interviews were analyzed using the discourse analysis techniques mentioned above.

1.2.2) Previous Responses

There is some published literature that concerns questions similar to those of this thesis. Those papers and studies that are based more on opinion, anecdote, and argument will be reviewed in the Background and Discussion chapters. Those that use qualitative methods are reviewed here.

Literature searches were performed to locate qualitative research concerned with questions similar to those of this thesis. The initial search was restricted to the Canadian context, and the second search was unrestricted by geography (but restricted to the English language). The searches looked for research on palliative care ethics using qualitative methods similar to the discourse analysis used in this thesis. Two searches were conducted in 2009 on Scholar’s Portal, History of Science Technology and Medicine, Ovid Medline, American Humanities Index, Francis Database, Humanities Abstracts, Social Science Abstracts, POEISIS, and Google Scholar. The first search used the terms “palliative”, “ethics”, and “Canada”, and the second search used the terms “palliative”, “ethics” and “qualitative”. These searches were extended in 2012 to capture any new literature appearing in the interim. Selection was based on review of titles, then review of abstracts if warranted, and finally a review of the paper itself if warranted.
Five works were found that are loosely related to this thesis. First, a book chapter was found that reviews the history of Canadian bioethics (Kenny, 2003). Using as sources a variety of literature – from professional associations, medical education associations, Royal Commissions, Commissions of Inquiry, and statutory and common law – the chapter presents a picture of a changing ethical landscape. Themes considered include: the rise of patient autonomy, a focus on end-of-life issues (primarily assisted death), research ethics, and issues of access to care. The discussions of these themes are expressly cursory, and deeper analysis of ethical foundations is not undertaken.

Second, a paper was found that reviews the literature in palliative care journals to discover themes of palliative care ethics (Hermsen and ten Have, 2006). The main themes were found to be: quality of care, end of life considerations, communication, and moral problems in research. The discussion categories and summarizes the topics of palliative care ethics, but it does not undertake analysis or conjecture into the foundations of those issues.

Third, a paper was found that reviewed the ‘official statements’ of thirty-four ‘main health organizations’ to find which dimensions of palliative care are expressed (Barrazzetti, Borreani, Miccinesi, and Toscani, 2010). The dimensions (in the words of the paper) include: symptoms, relational and social area, preparation [for death], and existential condition. As with the preceding works, the effort aimed to categorize the themes, and it did not attempt an examination of deeper ethical foundations.

Fourth, a book was found examining the foundations of palliative care ethics (Randall and Downie, 2006). The authors begin with the World Health Organization definition of palliative care as expressing the ethics of palliative care, and then go on to
critique this ethics and propose a new ethics. While the methods of this book only loosely resemble those of this thesis, its considerations of palliative care ethics come closer, and are therefore worth reviewing in more detail here.

In *The Philosophy of Palliative Care* Fiona Randall and Robyn Downie (Randall and Downie, 2006) examine the founding philosophy of palliative care, show where they believe palliative care has gone astray since, and propose a path to restoring it closer to its original form. They suggest that two currents have always run through all of medicine to some degree. The ‘Asklepian’ current is said to embody a holistic, healing practice, which is accepting of mortality, and attentive and adaptive to the individual patient; the ‘Hippocratic’ current is said to seek causes and cures for disease, to generalize to abstract rules and principles, and to embody an interventional approach to care. The idea seems to be that palliative care’s foundational concepts – one group of concepts derived from the care of the dying by religious orders centuries that includes ‘meaning’, ‘fulfilment’ and ‘authenticity’; and a second group of concepts derived from a reaction against modern medicine that includes ‘dignity’ and ‘quality of life’ – were originally interpreted in an Asklepiian way and later became interpreted in a Hippocratic way. This reinterpretation of the foundation concepts of a palliative care constituted the ‘colonization’ of palliative care by the Hippocratic approach.

The restoration that Randall and Downie offer attempts to remove some of the rationalizing influences of the Hippocratic approach. Ultimately, their hope is that the ‘Asklepian’ version of palliative care that they envision might promote “the concentrated attention, the quietness, [flowing] more authentically from the professional’s own humanity than from externally imposed guidelines, protocols, scales, and assessments”
(Randall and Downie, 2006, p.21), and in this way facilitate the achieving of goals such as pain and symptom palliation, promotion of physical function and appropriate provision of information.

Fifth, a paper was found that is more closely related in method to this thesis than those discussed so far (O’Connor, 2005). Using discourse analysis, the paper reviews the mission statements of forty palliative care services in Australia. The results and discussion are focused in several areas: the intended uses of the statements, the intended audience, the language used, and service information. The statements are diverse but share an apparent intent to define palliative care against a more uniform, standardized medical culture. The identity of the intended audience remains unclear, including perhaps both the’ public’ and ‘other services’. The language used suggests that palliative care is ‘special’, ‘comprehensive’, given in an ‘environment of choice’, with goals of ‘living as actively as possible’ for those with advanced disease. Dying actually figures little in these mission statements (on care of the dying).

Taken together, this research is relatively cursory and disparate, and to my mind no clear themes arise across it. Three of the works provide categorizations of topics of palliative care ethics; one work suggests that palliative care has become less holistic and humanistic and has become more clinical and structured; and one work suggests that palliative care identifies itself in its relation to standard medical culture.
1.3) Potential Thesis Contribution

There is some literature that considers the changes in palliative care ethics using opinion, anecdote and argument (see Background), but there is little relevant research based on data. The five works of research that I found that use qualitative methods to consider questions similar to that of this thesis provide only a vague sense of possible changes in palliative care ethics. A sense of the Canadian context is to be mostly extrapolated to the Canadian situation from other contexts. While there is other literature available on specific ethical issues in palliative care, such as assisted suicide and euthanasia, the questions of this thesis are broader than those specific issues, and this leaves a gap in the literature in which this thesis may find a place.

This thesis aims to contribute to the research on palliative care ethics by using qualitative methods. It seeks to provide a novel understanding of Canadian palliative care ethics, and it will propose a revised palliative care ethics based on that understanding. It is my hope that this understanding and this revision – as a dissertation, in presentations, and in publication – might stimulate reflection upon the nature of palliative care ethics, and in the end, that it might influence the practice of palliative care.
Chapter 2: Background

This thesis considers how Canadian palliative care and its ethics may have changed since its beginnings. The research question and relevant literature have been reviewed in the Introduction. This Background section reviews other literature that is helpful in interpreting the results and in framing the discussion.

There are three parts to this background review. The first section will review the literature on dying through the history of Western Society. It will give an indication of the background within which palliative care first appeared. The second section will review the literature on the beginnings of palliative care, showing in particular the manner in which palliative care differed from the medical culture of that time. The third section will review the literature on the subsequent development of palliative care, especially its supposed rationalization. The sections are organized under the following headings:

2.1) The History of Dying;
2.2) The Beginnings of Palliative Care;
2.3) The Development Palliative Care.
2.1) The History of Dying

“We are yet to recognize that the dying behaviours we know today have been built up over thousands of years. Where dying is seen to begin and end, who controls dying, where it takes place, what happens during that time, and what personal sense is made of it, have evolved from the material and cultural pressures of history” (Kellehear, 2007, p.16).

Over the past few decades historians have begun to describe how dying has changed across the history of Western society. This section will give an overview of these changes as discussed in the literature, providing a description but not reviewing the various explanations as to why the West has changed in the way that it has. Though there are some difficulties with such broad historical description – considering Western society as homogeneous, a lack of sources, parts of society over- or under-represented in the sources, or the elusiveness of attitudes to dying – which to some extent are inescapable, nonetheless the resulting description is sufficient to provide an idea of the background within which palliative care appeared. This section will present first in broad strokes the distant history. The finer detail about the appearance of the palliative care movement itself will follow in other sections (Sections 2.2 and 2.3).

My review of the literature identified three writers who have undertaken a long-range review of dying in the West, and all use similar historical frameworks to separate out periods of stability. Kellehear suggests that the history of the West be distinguished into pre-historic, pastoral, urban, and cosmopolitan periods (Kellehear, 2007), and Walter similarly suggests distinguishing the West into its traditional, modern, and post-modern periods (Walter, 1994). The third writer, Philippe Aries, considers the history of dying from the middle ages forward, using designations that also fit loosely with the first
two Aries, 1994). Other sources I reviewed are more specific in their focus, extending across much narrower periods that fit within the designations of the three mentioned authors.

Thus, I will use the ideas of Kellehear, Walter, and Aries to establish a temporal structure within which to arrange the other sources, using specifically the terms of Kellehear to designate these periods. As a loose guide, the pre-historic period can be considered to run up to the start of agriculture, the pastoral period to extend from there forward to the end of the medieval period (with the exemplary period understood to be the early medieval period of 5th-11th C), the urban period from there to the late nineteenth century, and the cosmopolitan continuing from there through to the present. The periods are temporally and geographically vague. For instance, some early periods, such as the Greco-Roman period, are better seen as urban in their dying and death, and some later periods, such as agricultural nineteenth century Russia (or arguably even some contemporary societies), are better seen as pastoral. But the periods are clear enough to be helpful in capturing general agreements running through the literature, combining the complimentary ideas of many sources.

2.1.1) The Pre-historic Period

Research on the pre-historic period provides the barest starting point. For early humans, malnutrition, trauma and disease would have meant little recognized time between dying and death, and little opportunity to influence the process (Kellehear, 2007). And so whatever stance these people took to dying, most of it would need to unfold long before dying and after death. The lives of present hunter-gatherer societies
and archaeological evidence suggest that pre-historic societies believed that some essence of the deceased persisted after death. Likely, preparation for dying would have been woven into the rituals and practices of daily life. For example, aid might have been offered the recently deceased in the form of food, weapons placed in the grave, and prayers for what was believed to be a perilous ‘afterworldly’ journey (Kellehear, 2007).

2.1.2) The Pastoral Period

From the traces left by the prehistoric period there can be inferred a belief in death as a transformation, and the accompanying ideas that death should be prepared for. The pastoral period continues this idea of transformation and preparation, giving it (for the most, in the West) a Christian understanding. Dying and death remain common and woven through the community, but what the pastoral period notably adds is the idea that the time of dying is a time of action. There appears therefore in the pastoral period the ideal of the ‘good death’.

This pastoral period – beginning about twelve thousand years ago, as humans assumed a more sedentary, agricultural existence – is exemplified for the West by Christian, medieval Europe before the eleventh century (Holmes, 2001). Such societies were traditional in the Durkheimian sense that the range of beliefs in these societies was narrow, the intensity or commitment to these beliefs was high, and form of these beliefs was religious (Durkheim, 1972 [originally 1893]). The world was understood as imbued with meaning, both natural and supernatural, and life was lived with shared expectations of social behaviour.
Dying and death were part of everyday life. Aries writes, “death was both familiar and near, evoking no great fear or awe” (Aries, 1994, p.13). In Aries’ words, here was “tamed death”, meaning by this not to suggest dying was comfortable or death desired, but that death was familiar. In the way the dead were buried near the living, for example, sometimes with their bones conspicuously displayed, they engaged the living in a way not seen prominently since (Aries, 1994). With death so immanent, the living could hardly help but consider the goals, obligations and expectations that a life bound by death implied. Aries writes, “They were as familiar with the dead as they were familiarized with the idea of their own death” (Aries, 1994, p.25).

Dying, and the sufferings attending it, was understood as part of the expected transition from the temporal to the eternal upon physical death, “salvation and eternity, not longevity, were the goals of life” (Lewis, 2007, p.64). Divine transcendence was assumed to follow simply by dying within a lived allegiance to the Church. To die baptized, without grave sins, was enough for one to expect salvation at Judgment, and for the sinful, public penitence and ritual reconciliation allowed a similar expectation for salvation (Paxton, 1990).

There may have been, in the pastoral period, more time to act between dying and death than there had been in the pre-historic period. Trauma and malnutrition were somewhat more predictable (as consequences of war or civil discord), and diseases became a more frequent cause of death than previously (spreading perhaps with the domestication of animals (Diamond, 1997; Kellehear, 2007)). This extended dying meant that preparations for death could be more easily located in the period of dying than they could have been in the more precipitous deaths of the pre-historic period. Some efforts
could be made to heal, but mostly the effort would have been spent on preparing for death, “the Middle Ages were pervaded by the expectation that death should be prepared for” (Hadley, 2001, p.56). Such preparation might include arrangements for inheritance (including by later in the medieval period both upper and lower classes, including peasants), emotional reparations, and funerary and mourning rituals. The meaningful and often simple rituals around death were not chosen so much as understood as part of tradition. These were occasions in which persons of a variety of ages and stations were expected to participate in the transformation of the dying person from the living world into the next world (Aries, 1994).

The final preparations that should be undertaken during dying became part of what comprised a good death. A good death was a death that followed a life that had been ‘long enough’, that occurred at home with family and friends nearby, that occurred with necessary preparations completed. But when the tasks of dying were undertaken somehow unsatisfactorily, by chance or oversight, the resulting ‘bad death’ might send personal, social and political ripples of disorder through the community (Kellehear, 2007).

2.1.3) The Urban Period

In the pastoral period dying was a familiar part of life; it was part of an expected spiritual transformation; and it drew the community together to provide what was needed for a good death. In the urban period dying underwent several changes. Dying lost its familiar feel. Dying became an uncertain, individual spiritual trial. And dying became a process to be managed.
In the urban period death remained a common occurrence across the lifespan, but it nonetheless lost some of its familiarity. As the pastoral period could conceive of a wild/tamed distinction unavailable in the prehistoric period (before the domestication of animals), so the urban period could conceive of a civilized/natural distinction unintuitive to the pastoral. The body, with its cycles and eventual dissolution, acquired in the urban period some sense of unpredictability and strangeness. Historians have noted evidence of increasing unease toward dying and death during the Italian Renaissance (Strocchia, 1992), the Romantic period of eighteenth century Europe (Aries, 1994), and nineteenth century Victorian England (Jalland, 1996). Dying became intensified with fears of obliteration and hopes for salvation (Aries, 1994).

The pastoral period understood dying as a herald of the necessary spiritual transformation that came with death, but the urban period understood dying as an uncertain, individual, spiritual trial. Somewhere early in the modern period there emerged a new ‘individualism’ not seen clearly before – an emphasis on the self relative to the whole (i.e. the larger natural, social, and spiritual world) (Gittings, 1997; Elias, 1985). In the art, burial practices, and rituals of dying, the individual assumed a more important place (Gittings, 1984; Aries, 1994). Around the same time, the presence of Church dogma in the rituals of dying and death of the common person increased with the slow spread of organized and learned Christianity beyond the cloisters (Paxton, 1990). However, in the process, some of the ideas surrounding Judgment Day – such as the certainties of purgatory and rebirth – lost their universal and unchallenged status (Boase, 1972; Daniel, 1997).
This combination of individualism, ritualistic formality, and spiritual uncertainty led to the appearance of the ‘salvationary’ death. Now, though family, friends, priest or doctor still served to aid, to remind of God, and to undertake the practical aspects of dying, they did not direct the newly personalized spiritual transition from life to afterlife. The last days and hours of one’s physical life were increasingly seen as the final opportunity to amend for spiritual mistakes (Tait, 2002), and dying became a time wherein “each man is to be judged according to the balance sheet of his life” (Aries, 1994, p.32). In effect, Divine judgment moved from Judgment Day alone to twin judgments, with one at death and another at Judgment Day (Mormando, 1999). Texts of the Ars Moriendi (i.e. ‘the art of dying’) of the period exemplify this crucible, with its list of temptations and corresponding inspirations to instruct the dying, showing for instance that to feel the pride of vainglory, to despair, or to remain tied to persons, pleasures and things, was to fail (Worcester, 1999; Duclow, 1999; Mormando, 1999).

The length of the dying, which had become longer in the pastoral period, became longer again in the urban period (Harding, 2002; McManners, 1981; Kellehear, 2007). But whereas in the pastoral period this extension had meant more time to prepare for death, in the urban period it meant more intervention into the process of dying – marking the appearance of “the well-managed death” (a change that would continue to unfold in the cosmopolitan period) (Kellehear, 2007). The fairly public dying of the pastoral age was gradually replaced in the urban period by a dying that included mostly ‘family’ and a handful of professionals. Initially, the idea of family was broad enough to include many relatives, servants, and other dependents, but later this might mean only close relatives (McManners, 1981; Jalland, 1996).
The professionals attending the dying might include a priest, nurse, doctor and a lawyer. The role of the priest diminished over the period (Lewis, 2007; Jalland, 1996). And with decline of the doctrine of purgatory, the spiritual duties of family (i.e. masses, prayers and other rituals meant to shorten purgatory suffering) also diminished (Gittings, 1984). The role of the doctor increased. Long before they could affect the course of disease, when opium and its derivatives were still most of what was offered to the dying, doctors became overseers of dying, fairly usurping the clergy by the eighteenth century (Jalland, 1996).

Dying as a spiritual trial was beginning to be replaced by dying as a physical trial, “by allaying these anxieties [i.e. of spiritual trial], doctors were implicitly reducing the moral significance attached by Christianity to the hour of death itself” (Jalland, 1996, pp.81-82). The medical emphasis also meant an increase in institutional dying, such that persons died more often in the hospitals that were then becoming more numerous (Harding, 2002). The work of lawyers also increased, as more of society began to make wills (Hadley, 2001). These wills were initially wide and overtly religious, so that besides financial and material arrangements the wills might also mention bequeath of the author’s soul to God, might direct funereal arrangements, might encourage remembrance, or might even avenge insults and redress other social misunderstandings (Tait, 2002). But by the end of the period, wills focused more narrowly on disposing financial and practical affairs.
2.1.4) The Cosmopolitan Period

The cosmopolitan period, which has early roots in the eighteenth century but comes fully to fruition in the twentieth century, has a dying marked by societal uncertainties associated with the accelerated rate and scope of social change (Giddens, 1991; Kellehear, 2007; Walter, 1994). The qualities of dying that appeared through the urban period are extended and altered in the cosmopolitan period. The urban period’s growing unease with death becomes the cosmopolitan period’s denial or sequestration of death. The sort of managed dying that appeared in the urban period continues, and is deepened, most noticeably within the medical realm. The urban period’s understanding of dying as a salvationary trial changes into the cosmopolitan period’s understanding of dying as a trial of self-dissolution. This cosmopolitan attitude to dying and death (i.e. unease, denial, management, trial of self) is complicated in the mid twentieth century by the appearance of palliative care, and though I will touch on palliative care here, for the most I will consider it in other sections below (Sections 2.2 and 2.3).

The unease toward dying and death that appeared in the urban period deepened in the cosmopolitan period, and a number of ideas have sprung up as to how to understand this unease. The causes of this unease are contested, but most commentators agree that increasing life expectancies played a role. Beginning in the second half of the nineteenth century, with the exception of periods of war, infant and child mortality dropped and life expectancies began to climb (Clark and Seymour, 1999; Lewis, 2007; Haines, 2008). Somewhere in that time, European industrialized countries passed through a turning point in which the half century prior saw life expectancies rise just a few years, while the half century afterward saw them rise nearly twenty years (Easterling, 2000). Life expectancies
of just over forty years in Europe around the early nineteenth century have today risen to about eighty in most developed countries (CIA, 2009). At a minimum it could be said that the cosmopolitan period sees dying and death as an “external event” (i.e. unconquerable, ineluctable, always partly uncontrollable) that always threatens to introduce the “disorder of chaos” into the world. Where previously religious beliefs gave meaning against this chaos, the more secular cosmopolitan period struggles to find a place for dying and death (Mellor, 1993).

This growing unease with dying and death has been described alternately as a denial or as a sequestration. The idea that society is death denying, and therefore also dying denying, is the more common of the two (Gorer, 1965; Dumont and Foss, 1972; Kubler-Ross, 1969; Elias, 1985; Aries, 1994; Howarth, 2007; Lewis, 2007). Evidence of denial is said to be visible for example in public and medical avoidance of dying and death, in funereal practices (e.g. hidden cremation, embalming), and in the privatizing and pathologizing of mourning. Even so-called ‘strategies for immortality’ – such as nationalism, creative and biological progeny, monuments and so forth – are taken by some to constitute a form of death denial (Bauman, 1992). But conceiving recent society as unusually death-denying is contentious in a society where dying and death have become topics of academic study, factor clearly in public policy and medical care, and appear ubiquitously in contemporary entertainment (Seale, 1998; Howarth, 2007). It has also been suggested that conceiving of a whole society as death denying misplaces a psychological explanation where we should seek a sociological one (Seale, 1998; Howarth, 2007; Zimmermann, 2004).
One response to this ambiguity toward dying and death has been to conceive society as not so much denying as sequestering these realities. Death can be sequestered in the straightforward sense that the dying and dead are physically isolated – for example in hospitals and hospices – but also in the sense that awareness of dying and death enter into the public sphere only in certain ways. Studies from the 1960s showed that the diagnosis of terminal disease rarely entered medical conversations between patients and professionals, but by the 1980s that physicians overwhelmingly favoured the disclosing of such diagnoses (Glaser and Strauss, 1965; Seale, 1998). The move toward open communication about dying and death meant that the physical sequestration of institutionalization no longer necessarily meant emotional and psychological sequestration of death for the individual. In such a situation sequestration of dying has been taken by some to mean instead a shift in the dominant ‘voice’ that speaks of dying and death. In this notion, the rise of the voice of medicine and bureaucracy of the nineteenth century sequestered the voice of the patient, family and community (Armstrong, 1987). Contemporary voices of policy and entertainment are then also pictured as rising to the fore, while private and subjective experiences of death remain hidden. In such a situation, an individual may feel comfortable adopting the dominant (and public) voices, while at the same time suppressing their own experience (see for example, Dumont and Foss, 1972; Elias, 1985).

But these notions of sequestration have been challenged as well. It has been proposed that private understandings of dying and death only seem sequestered because of the multitude of understandings available (Mellor, 1993), or that understandings seen as private and public may each be ascendant at various instances (Walter, 1994). The
private discourse of dying is seen in these senses to appear in both individual expression
and in rationalized understandings of individual experience,

the human encounter with death has been split – on the one hand into expert medical
discourse and associated bureaucratic procedures, and on the other hand into an intensely
personal sense of loss (Walter, 1994, p9; and see Walter 1996).

Another urban trend that continues into the cosmopolitan period is the
management – especially medical management – of dying and death. Initially this
management was dominated in understanding and practice by the medical model. This
medical discourse gave the cosmopolitan period a version of natural death as one that
“occurs as a result of technically irreversible disease processes” (Seale, 1998). As the
ability to cure increased (e.g. with surgery, radiation, antibiotics and other medications),
medicine focused more on cure and less on care (Lewis, 2007; Jalland, 1996; Shorter,
1985). As curing was institutionalized, so too was dying further institutionalized – from
the nineteenth century upper classes and spreading through to the poor – so that by the
twentieth century most Western deaths occurred in hospitals (Lewis, 2007). But around
that point it became apparent that institutionalizing medical care, with a focus on cure,
meant that when patients reached the limit of treatment, they were set aside, overlooked
and avoided.

This marked the beginning, not so much of a less managed dying, but a dying
managed by the patient and family, and coincided with the beginning of palliative care.
In the rise of the palliative care movement in the 1960s (discussed further below) a
challenge appeared in the form of what Walter calls “the authority of the self” (Walter,
1996). In the cosmopolitan period, this directing and overseeing self becomes the
manager: medical regimes are decided upon; symptoms are expressed, quantified, and
treated; financial and social arrangements are made; and plans are made for the time when the dying person cannot speak for herself or himself.

The dying patient and his or her family help to choose not only from the medical care available, but also (more or less consciously) from the discourses available – whether dying is to be understood as medical, natural or spiritual, for example. A study of palliative care suggests that people often talk about death using just such idealized types of ‘good’ dying and death (Bradbury, 1996). And even in cases where, on the surface, aspects of cosmopolitan dying might appear traditional (e.g. similar to that of the pastoral period), they are distinctly not so by being chosen, rather than being accepted unquestioningly as ‘the way things are’ (Walter, 1996).

This shift in agency to the patient, along with the individualism arising in the urban period, and the growing secularity of society, all helped transform the urban trial of salvationary dying into the cosmopolitan trial of self-dissolution. In the cosmopolitan period dying forms part of the more pervasive continual struggles of the individual to give life meaning against a paucity of shared understandings, leaving a sort of chronic reflexivity (Mellor, 1993). And yet, when meanings and rituals must be made and chosen, the very search for self-identity may become itself a source of meaning. Dying may become herein part of a heroic challenge,

involving the facing of inner danger, engagement in an arduous search, defiant displays of courage, and the demonstration of the (once ‘manly’) virtues of compassion (Seale, 1998).

Even palliative care, which originally seems to have carried a loosely shared discourse of the good death, seems likewise to have given way in this vein to more pluralistic notions (McNamara, 2004, Stienhauser and Tulsky, 2010). And in this situation, those who
cannot choose the story of their death, either by incapacity, by the chronicity of their
disease, or an unwillingness to consider death, face an ambiguous dying and death in the
cosmopolitan period (Kellehear, 2007; Seale, 1998).

2.1.5) Summary of Changes in Dying

I have proposed a history of dying and death in the West based on the relevant
literature, one that is similar to the picture presented in the (little) literature specific to
Canada (Northcott and Wilson, 2008). In the periods designated, several aspects of dying
stand out.

Pre-historic dying would likely have been brief, such that the understanding of
death played out in the rituals and practices of the community. The pastoral period saw
the appearance of the good death and the accompanying potential for failing that ideal.
The slightly lengthened dying of the period meant mostly that traditional, communal,
religious preparations for death could be undertaken. This was a death that was ‘tamed’
in the sense of being woven into life. The urban period saw dying lengthened again, but
now this lengthening meant the beginning of managed dying. Professionals and family
became the main actors in a dying that was no longer as public as in the pastoral period.
Dying and death were seen with increasing unease, and were often seen as comprising a
spiritual trial. The cosmopolitan period saw the transformation of urban unease,
management and spiritual trial into still other forms. The unease of the urban period
became the denial or sequestration of dying and death in the cosmopolitan period. The
management of the urban period increased and was also taken up by the patient and
family themselves. The spiritual trial became a trial to find meaning against the threat of self-dissolution.

Two of the key qualities of the modern Western world can be seen in the changes of dying and death – a growing individualization and a growing rationalization. The concept of rationalization is especially relevant to this thesis, and I will consider the concept at several points later in the thesis, but for now a few points are pertinent. Before the beginnings of palliative care, especially during the urban and cosmopolitan periods, dying underwent rationalization, most notably in the growing involvement of professionals. The religious understandings and importance of religious figures decreased, while the importance of medical figures increased. And while the loss of meaning that accompanied the decreasing involvement of community and religion in dying was partly filled with medical understandings of dying, a new uncertainty remained. In this uncertainty palliative care appeared, offering an alternative to the narrow medical understanding, and aspiring to return a sense of community, spirituality, and meaning to dying.

2.2) The Beginnings of Palliative Care

“The past century has witnessed the development of innovative techniques to diagnose and treat disease. But with attention increasingly focused on life-saving machinery, it has become more and more difficult to view a patient as a human being and part of a family unit... What people need most when they are dying is relief from the distressing symptoms of their disease, the security of a caring environment, sustained expert care, and the assurance they and their families won’t be abandoned” (Craven and Wald, 1975, p1816).
The phrase ‘palliative care’ became prevalent only in the 1980’s, but I will follow Clark and Seymour to understand it to refer to the loosely coherent practice running through the 1950s to present (i.e. including ‘terminal care’, ‘hospice’, ‘palliative care’, ‘supportive care’ and ‘end of life care’) (Clark and Seymour, 1999). This practice of palliative care has been seen as beginning and thriving most in the English-speaking world (Seale, 1998), and I will consider it likewise within these bounds. The phrase may refer to the approach to care, or the way of understanding care, or to the medical specialty of palliative medicine (Doyle, Hanks, Cherny, Claman, 2004). In these senses, upon considering various definitions of palliative care, a reasonable definition for this thesis would include at least the ideas that in palliative care: 1) practitioners undertake attitudes and actions or ‘interventions’, 2) toward ‘persons dealing with life-threatening disease’, 3) in the hopes of promoting ‘patient well-being’, 4) as part of a ‘team’, 5) while self-conscious of themselves as ‘practicing palliative care’ (see for example, CHPCA, 2002; Doyle, Hanks, Cherny, Claman, 2004; WHO, 2004; AAHPM, 2011; TLCPC, 2011; EAPC, 2011). The quotation marks indicate some ambiguity or variation of these phrases as they appear in many definitions of palliative care.

The previous section discussed the history of dying and death in the West, but did not discuss palliative care in depth. This section will consider palliative care in light of that discussion. It will review the literature that describes the beginnings of palliative care, giving special attention to the way that palliative care initially defined itself relative to the medical model of the time.
2.2.1) The Palliative Care Tradition

Palliative care appeared in the second half of the twentieth century, following two important, broad changes across the whole of medicine – the ability to diagnose and the ability to treat (Shorter, 1985). And as discussed above, although the care of the dying in the cosmopolitan period fell under the scope and idea of medicine, the dying nonetheless fit poorly into this medical system. The system focused on cure and saw death as a failure. It seems fairly agreed upon that palliative care appeared in response to the plight of the dying, but whether it should be understood as reviving an overlooked tradition, or as reacting against modernist medicine, or as some combination of these trends is more contentious.

When seen as continuing a tradition, precedent is sometimes located in the medieval way stations for sick and weary travellers (i.e. ‘hospices’) (Saunders, 1980), sometimes in the nineteenth century ‘homes for the dying’ in France, Australia or the United Kingdom (Clark and Seymour, 1999; Paradis and Cummings, 1986; Thompson, 1981), or sometimes in the medical interest in caring for the dying that appears in influential nineteenth century works of doctors such as William Osler and William Munk (Hughes and Clark, 2004; MacLeod, 2001). In all cases, the story goes, the worth and prominence of these forms of care for the dying diminished during the surge of curative medicine in the first half of the twentieth century. Following this diminishment – a time when a physician could write that care for the dying could “almost be written in one word, morphine” (Leak, as quoted in Clark, 1999a, p232) – the rise of palliative care seemed to indicate the revival of a lost tradition.
But there are alternatives to conceiving of palliative care this way. Some have suggested that the traditionalist interpretations are too neat. For example, Armstrong’s suggestion has been that there has been no hidden and recovered tradition but a sequence of novel discourses supplanting one another (Armstrong, 1987). He contends that the modern palliative care movement has its unique ways of understanding and acting. Others have noted that the proffered precursors to palliative care seem to lead just as clearly to the rest of medicine as to palliative care. Instead, they suggest that an important feature that distinguishes the palliative care movement is its rejection of modernist medicine (Seale, 1998). This ‘modernist medicine’ supposedly reacted against is medical care focused first or almost entirely on cure, on finding the lesion or derangement and correcting it, and on using detached objective observation to manage – all under the hopes of emulating the perceived successes of the scientific method. Anti-modernism only became possible at the turn of the twentieth century, when diagnosis and cure became possible. Even then the dying were generally lumped together with the other ‘incurables’ who were no longer welcome in the hospitals (i.e. travellers, orphans, the indigent, the chronically sick, the aged), and thus the care of this bereft lot did not present a distinct notion of care directed specifically towards the dying (Clark and Seymour, 1999). So, on this interpretation the supposed revival was in fact something new, with a lineage that was both shorter than suggested and based less on a tradition of care than on a position of anti-modernism.
2.2.2) The ‘Problem’ of Dying

Despite their disagreements, these understandings agree that Britain should be seen as the birthplace of modern palliative care. It was there, in the middle of the twentieth century, that dying and death entered medical and public discourse in a new way. Demographically speaking, the trend in Britain through the middle of the twentieth century (as in the Western world generally) was away from an infectious death toward an institutional death, usually in old age and typically after a period of chronic illness and disability spent mostly at home (James and Field, 1999). Prominent reports solicited by health institutions, foundations, and the fledgling National Health Service began to appear in the late 50’s. They described this new dying as a needlessly lonely, frightening and suffering-laden. The reports documented not only the great suffering afflicting the dying, but also other trends: the population was aging; the length of debility and suffering preceding death was being prolonged by advances in medicine; and most patients preferred to die at home but many families had not the resources to facilitate this outcome (Clark, 1999a). These reports drew attention to the plight of the dying, moving it from a private experience to a public understanding, and in so doing they opened the way for palliative care (Clark, 1999a), “the vision, or mission, of the early hospices resonated with the public concern about the care of the dying” (James and Field, 1992, p1367).

The rise of palliative care can also be seen in the medical literature, visible in such compilations as the ‘Medline’ database. The ‘philosophy’ of palliative care is absent from early writings on palliation, which appear under much more pragmatic, unassuming titles. This research, concerning palliative treatment of cancer, appears in a handful of
papers published in the late 1940s that are primarily technical, clinical papers without a palliative care worldview. Through the 1950s, in a similar fashion, just under a hundred clinical papers appear discussing the merits of palliative surgery, radiation and chemotherapy. Through the 1960s however a change begins, with nearly seven hundred ‘palliative care’ papers published. These papers frequently focus on the care of the dying as a distinct philosophy of medical care, either in regards to symptom control, or into the very nature of dying as a social event.

Something similar happens in the sociological literature. In the 1960s the idea that the dying had been overlooked by medicine and society began to be supported by early sociological research. Glaser and Strauss described the extent, negotiation, and management of patients’ death awareness in medical care (Glaser and Strauss, 1966). Often, it seemed, death was not discussed at all, neither by professionals nor by patients. Gorer described the experience of dying, the disposition of the dead, and grief and mourning (Gorer, 1965). Hinton reviewed the attitudes, experience, care and mourning related to dying (Hinton, 1967). Hinton and Gorer both called for greater openness and attention toward dying and death. While the results of this work showed that in practice the patient’s experience was marginalized, the very questions and focus of the work brought the patient’s experience to the fore.

2.2.3) Beginnings

This rise of palliative care – led by administrative reports, public awareness, medical care, and sociological research – indicated the broad recognition of a ‘new problem’ of dying. The ground was laid to support the efforts of pioneers such as Dame
Cicely Saunders to establish palliative care as a practice, which in its emphasis implicitly made clear the failings of medicine and society (James and Field, 1992). In 1967 Dame Saunders opened St. Christopher’s Hospice, and although in the decade prior some less conspicuous hospice services were already in place in Britain (James and Field, 1992; Clark, 1998), most commentators set palliative care’s ‘official’ beginning at this opening (see for example, Gentile and Fello, 1990; James and Field, 1992; Ford, 1998; Vachon, 1999; Kaur 2000; Clark, 2007).

To see palliative care as beginning in the midst of ‘modernist medicine’ means to see it as beginning in the midst of a scientific, bureaucratic biomedicine focused on hospital care. In palliative care’s birthplace, the National Health Service (NHS) embodied the bureaucratic side of this modernist medicine, aspiring from the outset to somehow standardize the profuse patchwork of smaller, often charitable, medical organizations that had been the norm up until its beginning (Clark 1999a). The upshot for palliative care, however, was that those practitioners caring for patients that could expect neither cure nor rehabilitation were left to continue under episodic support, often charitable and rarely substantial (Clark, 1999a). In this period just preceding the beginning of palliative care, the dying patient was more a recipient than a participant in his or her care: the doctor diagnosed, attempted curative therapy, administered morphine, pronounced death; nurses provided most of the day-to-day care in aid of the doctor’s plans; and the clergy provided spiritual support in background and as coda.

Against all this palliative care was “unashamedly reformist” (James and Field, 1992, p.1363) and flush with a feeling of purpose (Vachon, 1999). Palliative care rejected many of the features of modernist medicine – the focus on cure, the sequestration to
hospitals, the hierarchy, the secularism, the paternalism – and aspired to be looser and more egalitarian in its organization, more spiritual, more focused on the dying individual and on relationships between persons. This was less just a way of treatment and more a broad, sometimes zealous, espousal of a way of care and a philosophy of life and death.

2.2.4) The Subjective Turn

A prominent example of this reformation lies in the novel approach palliative care took toward pain. Modernist medicine sought above all to become an objective enterprise, one in which neither the vagaries of practitioner nor patient would obscure an accurate grasp of disease and its successful treatment. But pain remained irremediably subjective. In Saunders’ innovative concept of ‘total pain’, pain was understood to derive from many sources beyond the physical (Clark, 1999b). Previously, a mechanistic medical understanding conceived of pain as electrical signals carried straightforwardly along nerves to the brain. But the concept of total pain understood pain to be highly subjective and plastic. Now pain was what the patient said it was; pain was influenced by the patient’s cultural and psychological history; and pain was to be addressed regardless of the underlying pathology. Instead of relying on surgical and anaesthetic interventions to disrupt the pathway of pain, morphine gradually became accepted for pain treatment, as did non-pharmacological social and psychological approaches. The rapid development of pain as a clinical and academic speciality underscores the shift of palliative care (and later, medicine overall) away from strictly biomedical, modernist approaches (Seymour, Clark and Winslow, 2005).
In this way, the shift in views toward pain and pain control indicate a turn toward the subjective, the subjective experience especially of the patient. In the literature on palliative care, three areas figure most prominently in this turn: an emphasis on spirituality; a new model of profession and organization; and a focus on the ‘self’ of the patient.

**Spirituality.** In the increasingly secular field of medicine, palliative care appeared as a distinctly religious movement, carrying religious and spiritual influences beyond that typical of medicine at the time (Clark, 2001a; James and Field, 1992; Ford, 1998; Saunders, 1996; Bradshaw, 1996). Cicely Saunders herself was openly religious, as was much of the support she received from institutions, professionals and volunteers (Saunders, 1996). Though as Clark makes clear, the intent of Saunders in developing St. Christopher’s was to found a medical unit with spiritual emphasis, and not a religious community with medical abilities (Clark, 2001a). The model of care exemplified by Saunders was nonetheless grounded not simply in compassion, but specifically in a Christian understanding of compassion – medicine provided the means and Christian teachings provided the goals (Bradshaw, 1996).

**Organization.** Palliative care differed from the medical world around it not only in its focus but also in the form of its care. The hierarchy within palliative practice tended to be ambiguous and fluid, each person adding their skills with respect for their colleagues, so that “the early hospices deliberately blurred or altered traditional patterns of hierarchy” and “there were no rules to follow, no established authorities or organizations to set standards” (James and Field, 1992, p1369). In this regard, palliative care was an early instance of an ongoing revaluation of the position of the physician in
medicine and society. Physicians were no longer held in the same esteem as they had been; there was a public sense of alienation from the impersonal feel of medicine; and there appeared the beginnings of a slow revolt against medical authority (Shorter, 1985).

Instead of the typical hierarchy, palliative care honoured nursing, spirituality and medical (i.e. doctors’) management equally, striving for multidisciplinary teams in which skills and knowledge were equally respected (Field and Johnson, 1993). The founder of modern palliative care, Dr. Saunders, was herself first a nurse, then a social worker, then a doctor (Saunders, 1996). Some early hospices were led by nurses, some by chaplains, some by social workers, and some by doctors (James and Field, 1992). Furthermore, palliative care differed from the rest of medicine also in the contribution of volunteers, which included both those within and without the health care fields (Vachon, 1999). Professional or volunteer, the providers of early palliative care worked with a deep sense of calling and sacrifice (Tehan, 1985).

The Person. Palliative care focused on the ‘person’ of the patient. It emphasized the patient’s felt experience, and it was in this way unlike much of medicine at the time except perhaps psychiatry. And even compared with psychiatry, palliative care was unusual, seeking initially less to classify and remodel experience and more to simply affirm it. Listening was seen as deeply supporting the origination of palliative care, and one of its ‘essentials’ (Saunders, 1998; Thompson, 1991). This emphasis on subjective experience is one of the various instances in palliative care in which can be seen a valuing of the individual. It appears early in the seminal works of Kubler-Ross (Kubler-Ross, 1972), and also in Saunders’ emphasis on ‘total pain’, discussed above, and her sense of ‘dignity as self-direction’ (Saunders 1996, 1998, 1999; 2001a; 2001b). It appears
later in the notion of informed consent – the conceptual and procedural requirements and rights of patients in directing their lives – that grew in large part around issues during terminal disease (Nelson-Marten and Rich, 1999). In a typical recent example, a review of the concept of a good death found that a good death was one that continued the person’s project of personal growth, which the paper endorses by proposing a patient-directed approach to care (Steinhauser and Tulsky, 2010).

In all of these examples we can see a valourization of the choosing, determining self, where, in palliative care “a new craft of dying is being developed – and the new craftsmen and women are none other than the dying themselves” (Walter, 1994, p198).

As mentioned in the history of dying and death, this was one of the key characteristics of the cosmopolitan period – that the patient, newly empowered through patient rights and a societal mistrust in authority, should direct care rather than being directed by practitioners (Shorter, 1985). Here was the move from modern to postmodern medicine – a move from a focus on the doctor to a focus on the self (Walter, 1994).

2.3) The Development of Palliative Care

“Now in its second decade in the U.S., hospice has moved from a fringe alternative led by an idealistic group of volunteers and professionals to a mainstream, industry-like approach to the care of the terminally ill” (Tehan, 1985);

“the hospice movement appears similar to other reform-oriented movements which eventually became much like the institutions they sought to change” (Paradis and Cummings, 1986).

In the years since the opening of St. Christopher’s hospice, palliative care has spread geographically, clinically and academically through the rest of medicine,
supported among other things by the formation of associations for palliative practitioners, the launching of palliative care journals, and in some jurisdictions the creation of the medical specialty of palliative care (Clark, 2007). According to some, during this time palliative care has also lost its more radical roots. This section will consider these changes accompanying the development of palliative care.

2.3.1) The Question of Rationalization

In the 1990’s discussions developed concerning the supposed rationalization of palliative care. These discussions have been proposed as falling into two inter-related categories, those concerning the way the practice of palliative care itself was to be understood (e.g. medicalization), and those concerning the overall organization and delivery of palliative care (e.g. routinization) (Clark and Seymour, 1999). In this section I will consider these processes of change together under the more general process of rationalization, which figures prominently in this thesis. The concept itself is discussed in greater detail in this thesis in the Discussion, but here it will be employed in the manner that it appears in discussions of palliative care – as a somewhat imprecise collection of ideas related to certain changes in the practice, organization and ethics of palliative care (here ‘ethics’ understood in a very broad sense).

In 1994, David Clark published an editorial in Palliative Medicine titled, “At the Crossroads: Which Direction for the Hospices?” (Clark, 1994). He suggested therein that a ‘first wave’ of palliative care expansion had come to an end, and he speculated on what might best animate the second wave. He also identified challenges, such as the ongoing financial constraints and changing models of care provision, and also concerns about
trends concerning the foundational understandings of palliative care. In hindsight, the appearance of several articles posing similar questions, in the years just before and after his editorial, suggest that palliative care was indeed moving from one stage to another. The underlying questions Clark asked concerned whether palliative care could maintain its ideals under what he saw as its ongoing routinization and medicalization, that is, under its rationalization.

2.3.2) Areas of Change

Questions about whether palliative care has become rationalized, and if so how to evaluate such a rationalization, have been asked for many years. In the history of palliative care presented above, palliative care was seen as being more spiritual, less hierarchical and more focused on the person of the patient than was conventional medicine of the time. It was also mostly defined by its focus on dying. The question of rationalization has in the literature typically been framed in regards to whether palliative care has in these areas become like the medicine from which it initially strived to distinguish itself.

Spirituality. As mentioned above, palliative care has been seen as becoming more secular, even if still preoccupied by a non-specific ‘spirituality’ in which “spirituality [becomes] the existential search for human integrity” (Bradshaw, 1996, p.416). This secularization is seen as influenced not only by larger changes in society but also by the early direction of its originators. It has been suggested that Cicely Saunders, the religious founder of palliative care, took a ‘pragmatic turn’ in which she both became more
inclusive of other denominations and religions, and became convinced a therapeutic emphasis should supplant the earlier religious emphasis (Clark, 2001a).

Organization. In its acclimation to mainstream medicine and society, it has been claimed that palliative care’s creative and unorthodox origins gave way to codification and routinization, that palliative care became structured in the more hierarchical and specialized way typical of medicine (James and Field, 1992). The result being that once again doctors led nurses and social workers and others, and no longer were workers encouraged to ‘blur’ their professional distinctions to suit whatever a situation demanded of them (James and Field, 1992; Bradshaw, 1996). In the past, the ability of the practitioner to connect and care was paramount, and in this light the distinction of doctor, nurse, chaplain, counsellor, volunteer, or other, was less important. But in time the specialist began to replace the general hospice worker, and by the 1990s specialization in ‘palliative care’ or ‘palliative medicine’ had become, in some jurisdictions, possible and expected. As disciplines developed requirements for diploma or certification, and as sacrifice and pro bono work were no longer expected as they once were, palliative care became according to some less of a calling and more of a career (James and Field, 1992). In early meetings, for example, practitioners might “hug and burst into tears, carrying considerable unresolved grief for all the people they had cared for who had died”, while later “there was some tension as meetings became more ‘scientific and professional’” (Vachon, 1999, pp.235-237).

The move from calling to career coincided with a growing bureaucratic structure that included standards and formalized expectations, in which palliative care became “caught up in the complex policy environment that surrounds it” (Clark and Seymour,
Volunteerism could not overcome a need for funding, and fiscal constraints greatly affected early palliative care in the United States, leading among other things to the creation of standards of care (Beresford and Connor, 1999). Such standards were eventually introduced across palliative care, initially in the face of resistance from many of the original palliative care workers who saw such standards as threatening the ‘humanistic’ belief that care should simply meet need (Tehan, 1985). Standards appeared from professional organizations, health care institutions, and from political bodies, including various levels of government and national advocacy bodies such as the Canadian Hospice Palliative Care Association. These bureaucratic demands dampened the creative zeal of palliative care, drawing criticisms that, for example, “increasingly, the visionary is being replaced by a professional health care manager with administrative, fiscal management, and fundraising skills” (Tehan, 1985, p.13).

The introduction of standards and the need to justify palliative care contributed to a focus on quantifiable outcomes. The introduction of clinical and financial auditing privileged measurable goals, such as those concerning bed use, expenses, medications prescribed, and symptoms and expectations that can be captured in quantifying evaluations (James and Field, 1992). In such an environment, even suffering could become quantified (see for example, Cherney, 2004), and the more ephemeral and vague goals of relationship and authenticity tended to fall by the wayside, captured only tangentially and poorly in various ‘satisfaction’ surveys.

Focus. With such a focus on more concrete goals, along with a gradual acclimation toward the ideas and practice of conventional medicine, palliative care moved toward a greater focus on treating symptoms (Bradshaw, 1996; Meghani, 2003).
In the decades following the opening of St. Christopher’s the scientific literature on symptom control expanded enormously, especially regarding pain control (Ford 1998; Saunders, 2001a). Pain as a medical and research interest began in the 1950s and developed into an established independent field within two decades (James and Field, 1992; Clark 1999a). In this more interventionalist, symptom-focused approach, it has been suggested that there lies a historical and present tension between the (overlapping) discourses of care and cure (Clark and Seymour, 1999). Care focuses on understanding and supporting the whole person, while cure, in the sense applicable to palliative care, focuses on minimizing suffering, especially as related to physical symptoms. An early emphasis on care over cure has given way to an emphasis on this revised form of curing. The worry of some palliative care pioneers (Kearney, 1992; Doyle, 2003), the fact of present practice (Meghani, 2004), and the prescription of some contemporary doctors (Zimmermann, 2004), is that symptom care comprises or should comprise the bulk of practice for palliative care doctors.

The emphasis on symptom control has accompanied an increasingly technical focus. Palliative medicine initially avoided and discouraged the use of technical medicine so that the respirators, intravenous fluids and medications, cardiac monitoring, cardiopulmonary resuscitation, and such, were to be left behind, allowing the dying to spend their remaining days in peace, ‘unmedicalized’ (Clark, 2002). But over time more and more interventions became possible and used. This technical emphasis underscored the change to a more hierarchical structure. In early palliative medicine there were few specific treatments that were the exclusive purview of the doctor, the strands of spiritual, nursing and medical (i.e. doctor’s) care blended together. But then, as many palliative
pharmacological, surgical, and radiological treatments were developed that could only be
prescribed or administered by doctors, the position of doctors acquired more importance,
encouraging once again the typical medical hierarchy.

The emphasis on symptom control has also facilitated a broadening of the focus of palliative care, for virtually every disease carries some burdensome symptoms, whether the patient is considered in ‘terminal’ condition or not. This is especially so when included are the many psychological and counselling approaches used to mitigate or conceptualize the stresses of disease, dying and death – by the 1960s, papers on such topics as truth-telling, anxiety, depression and anticipatory grief began to appear alongside Saunders’ considerations on meaning and emotion in pain (Clark, 1999b; Clark, 2007). The broadening focus can be seen in palliative care’s move toward treating patients further ‘upstream’ from their death, and in its treatment of more patients suffering from non-cancer conditions (Clark, 2002). For example, palliative care has been understood in Canadian national guidelines as

appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care (CHPCA, 2002). And even in cases where the patient’s condition should be considered terminal, the focus of care has, according to some, shifted from death to the process of dying (Bradshaw, 1996).

The Person. Early in palliative care, the practitioner was encouraged to engage in careful and empathetic listening to affirm the patient’s experience. Over time this listening changed from simple affirmation to something more interventionalist. Across many areas of medicine it seemed that, “if medicine was to penetrate further into the
workings of the patient, it had to penetrate the patient’s mind and social relationships as well as his or her body” (Walter, 1994). Mining the depths of the person made possible the recognition, re-creation and direction of the self. In hindsight, it would seem that Kubler-Ross’ theory of the stages of dying intimates just such a ‘journey’ that others would develop further afterwards (Kubler-Ross, 1972). As was written in the section on the history of dying, the drama of facing self-dissolution became for some a self-defining effort (Seale, 1998). The emphasis on listening has proceeded to the point of founding the ‘new’ expertise of psychosocial oncology, which also extends into palliative care (Dolbeault, 1999). The charge has been made that the interpersonal communication of palliative care has moved from an intuitive act of care to a professional act of technique (Bradshaw, 1996). Where once the goal was to meet ‘person-to-person’, the goal has often become to achieve a ‘healthy’ and ‘therapeutic’ meeting between therapist and patient.

2.3.3) A Concern

Taken altogether, these changes suggest Clark was right, that somewhere along the line palliative care began a second wave. Some were optimistic, but others less so. It has been said that as a result of these changes, “some...wondered if hospice was losing its heart”, and perhaps that in its expansion palliative care risked becoming the “‘Kentucky Fried Hospice Movement’, the idea of a hospice on every block” (Vachon, 1999, pp.235-237). The focus on alleviating suffering over other less distinct goals, such as achieving the ‘good death’, or establishing deep relationships between practitioner and patient, worries some. There is a concern that palliative care may now be creating experts with a set of skills that risk becoming “meaningless unless it comes genuinely from the heart”
(Bradshaw, 1996, p.414). The idea of suffering as total pain begun by Cicely Saunders may have led not only to “a key to unlock other clinical possibilities” but also to “an elaboration of the clinical gaze, a new mode of surveillance and an extension of medical dominion” (Clark, 1999b, p.734).
Chapter 3: Methods

The questions of this thesis ask whether and in what way Canadian palliative care has changed since its beginnings. Several lines of investigation are used to form a qualitative response. The preceding literature reviews considered the change in dying when seen over the history of Western society, and as seen over the origins and development of the palliative care movement. I used ideas arising from these reviews to direct the analysis of several texts from both the early and late periods of Canadian palliative care. The two literature reviews and the results of the textual analysis then provided ideas that helped guide the interview of palliative care practitioners. The development of themes was loosely sequential as I have described it, but I also moved back and forth between the literature, the texts and the interviews in developing these themes.

This chapter has two sections divided into six parts:

3.1) Methodology considers concepts used to structure the investigation
   3.1.1) Ethics
   3.1.2) Structuralism
   3.1.3) Discourse Analysis

3.2) Methods explains the methods used in the three lines of investigation.
   3.2.1) Literature Reviews
   3.2.2) Textual Analysis
   3.3.3) Interview Analysis
3.1) Methodology

3.1.1) Ethics

In this thesis I attempt to describe, to analyze, and to critique an ‘ethics’, a term that can be used in various ways, all having something to do with norms of attitude and action and being. I have employed initially a broad conception of ethics to direct the identification and collection of normative instances in the text and interviews. In the Discussion section, in reflecting on the results, I develop a narrower conception of the term to consider palliative care ethics specifically.

A fairly standard philosophical distinction separates ethics as either descriptive or prescriptive – either to collect and consider the ethics of a person or group or period, or to propose which actions are good or right, how to live, and so forth. Some efforts are simultaneously descriptive and prescriptive. In this thesis I use both senses. In the investigation of texts and interviews early in the Discussion, I consider ethics from a descriptive stance to describe a particular set of norms as expressed in the movement and profession of palliative care (a description that includes also analysis of assumptions and arguments). Later in the Discussion I also present more prescriptive considerations.

An initial issue is to determine what should be taken to constitute the ‘data’, ‘evidence’ or ‘expression’ of palliative care ethics. The notion of ethics I have used to collect data is somewhat loose, but intended to be precise enough to distinguish which parts of the texts and interviews are relevant for analysis. A broad conception of ethics can include a great variety of manifestations, including as Gilbert Ryle suggests “tempers, habits, dispositions, moods, inclination, impulses, sentiments, feelings, affections, thoughts, reflections, opinions, principles, prejudices, imaginations, and
fancies” (as quoted in Blackburn, 1998). This thesis looks for these manifestations in the ‘social activity-institution-understanding’ that I have considered as ‘palliative care’, described in the Background section.

The ethical instances appearing in the texts and interviews are diverse, rarely theoretical, and only occasionally do they have an argumentative structure, and, being a practical endeavour, palliative care also includes some normative elements that are only partly ethical, such as the methods of palliation. All of this means that a degree of judgment is needed to choose what is relevant to the thesis. In this thesis I have bracketed out ‘practical’ normative elements that appear mostly or entirely instrumental to another ethical end, and yet not all practical norms have been excluded. For instance, it may be that a certain medication or intervention is promoted, and while rarely will this sort of prescription carry ethical importance, at times it will – for example, perhaps the whole idea of intervention could be ethically significant. It is difficult to provide a precise algorithm for these sorts of selections. I have relied on my clinical (palliative care physician) and academic (philosophical, bioethical, and social theory) experience to make these judgments.

3.1.2) Structuralism

This thesis proposes that it is possible to infer a reasonably coherent picture of palliative care ethics by analyzing ethical instances collected from a handful of texts and interviews. To draw conclusions about palliative care in this way requires some particular notions of social structure. That is, in this thesis I have taken a ‘structuralist’ view of society, which in theoretical terms means a conviction to the priority of social structure
over agency, or persons. In the structuralist view, traces of social structure are to be found throughout the social group, or period, or institution under consideration, and as a consequence each part has something to say about the whole. The qualitative method used in this thesis to analyze the texts and interviews is discourse analysis (discussed below), which is a method supported theoretically by the structuralist position. And while this thesis does not capture all the ethical meanings available in either early or late palliative care, it does capture some important meanings for each period, and it will understand these to be relevant across the periods under question. This section will outline the idea of structuralism in social theory as it relates to this thesis.

Structuralist theories focus on structure, understood as the shared cognitive, normative, and experiential understanding of groups of individuals, an understanding that can be considered in abstraction from particular individuals. This differs from theories of agency, which focus on the experience, action, interaction, intention and being of the individual as lived by that individual (King, 2005). Structuralist theories see structure as in some way conditional to or determining of agency, or as heuristically required for an understanding of persons and society, or as explanatory or predictive of the shape of persons and society, or as otherwise of first importance for social theory.

Structure, such as the ethical structure of palliative care that this thesis considers, is conceived of similarly in various structural theories. Structuralist and post-structuralist theories accept the priority of structure, and see it as both enabling and constraining thought and action. The notions of ‘institution’ in the work of Emile Durkheim, and ‘discourse’ in the work of Michel Foucault are examples this idea of structure. Durkheim writes of institutions as the “collective ways of acting or thinking [that] have a reality
outside the individuals who, at any moment of time, conform to it” (Durkheim, 1972, p.71), and Foucault describes discourses as the “reflexive categories, principles of classification, normative rules, and institutionalized types” (Foucault, 1972, p.22) that organize our way of being in the world. Both thinkers treat the events, rules and understandings of social life as things, at least minimally in the sense that discourses and institutions can be discovered in the traces that they leave.

While both thinkers investigate social structures as investigating a thing, they differ in ontological commitments, method, and purpose. This thesis draws a bit from the position of each in these regards. In their ontological conception of structure, both are nominalists, though Durkheim’s views lie closer to realism. Durkheim believed that underlying the manifestations of structure there existed something which should be treated conceptually as if it were an independent existing thing (though not a physical thing); Foucault believed that the something which was under investigation should be treated as a conceptual whole, but for heuristic effect, and not in actuality. Durkheim believed that the objective and quantitative method of science should be emulated; Foucault believed that knowledge appears always from a particular situated (i.e. non-objective) understanding, and that a hermeneutic, flexible approach should be used. Durkheim believed that describing structures, particularly ethical structures, could lead to a justified prescription of an ethical position; Foucault eschewed prescription.

This thesis is Foucauldian on the points of ontology and method, and Durkheimian on the point of prescription. Like Foucault, this thesis will accept that, while there are ways of seeing the world that are more or less supported with observations, and that one way may be understood to be better than or preferred to the next (even though the criteria
judging may also be contended), that nonetheless the justification for preferring one view does not involve a question of correspondence to an independent reality. Like Foucault, this thesis seeks to find structure through its ‘traces’ in the texts and opinions related to practices and institutions – a Foucauldian creative searching for coherence among the details. Like Durkheim, this thesis believes that a description of the way ethics appears in society can serve as a fair foundation to propose an ethics – in this way accepting Durkheim’s Aristotelian notion that discovering the nature of a thing is also to discover its teleology.

3.1.3) Discourse Analysis

A discourse, simply put,

is conceived as an ever developing collection of statements about what it is possible to know, to do and to be (Seale, 1998, p12);
consists of a set of common assumptions that sometimes, indeed often, may be so taken for granted as to be invisible or assumed (Cheek, 2004, p.1142).

These statements or assumptions may pertain to a larger or smaller part of society that is of interest to the investigator. Theoretically, discourse analysis is compatible with the structuralist view in that sense that discourse analysis searches for discourses, and these discourses are understood to constitute coherent wholes in part because they comprise aspects of a social ‘reality’. For this thesis, my idea has been to treat palliative care ethics loosely as a ‘thing’, which leaves traces in the beliefs, practices, events and objects of the social world. It is helpful to consider the traditional conception of material things as having an essence, qualities, and to appear in experience. Similarly, in considering palliative care, the structures discussed above can be considered as the essence (understood as a nominal placeholder), and the discourses can be considered as the
qualities of the thing (understood as an aspect, or interpretation), and the actual data can be considered as the experience or traces of the thing.

Discourse analysis as a method is described in various ways. Adherents of discourse analysis often ground the method in the work of Foucault, but given that Foucault’s method is complex and at times obscure, it is not surprising that there exists great diversity in method as inferred from his work. Any formulaic interpretation would contend against the hermeneutic essence of discourse analysis, but general features are shared by descriptions of the method. Using this general sense of discourse analysis, I have adopted in this thesis something along these lines,

Discourse analysis involves a close scrutiny of language to examine the ways in which certain themes and topics are discussed, allowing some ways of thinking, and undermining and excluding others (Burck, 2005, p.249).

The analysis is aimed toward developing ‘themes’, which can be gathered together and considered in relation to one another, and result in a discourse, or way of understanding. One of the strengths of discourse analysis is that by making the assumption of an underlying structure, and using the methods of analysis to consider the traces of this structure, it is possible to bring a profusion of details toward a coherent understanding. It need not be the case that all details agree, and where they seem to conflict, one must either posit the existence of several structures or fewer, sometimes self-conflicting structures. Using this version of discourse analysis, I have sought to discover the ways in which the ethics of palliative care has been understood, looking especially toward the changes in understanding between early and later periods.
3.2) Methods

3.2.1) Literature reviews

I performed three literature reviews. The first review is described in the introduction, and concerned research similar in method and topic to this thesis. The two other reviews concerned research on the history of dying in Western civilization, and research on the history and development of palliative care. The results of the first search are reviewed in this Introduction, and the results of the other two are included in the Background and Discussion sections. The literature reviews were performed using similar approaches, although the specifics of the searches and selection were adjusted to reflect the topics. The literature review regarding the history of dying, for example, found predominantly books as sources, and journal papers less often. This reflected the lack of journal papers on the topic, aspects of which often had to be found by sifting through larger works focused on the history of medicine, religion, and culture in general. Conversely, the sources for the review of palliative care consisted more of journal papers.

In both cases, an initial search was conducted on the University of Toronto Libraries catalogue, Scholar’s Portal, Wilson’s, History of Science Technology and Medicine, Ovid Medline, American Humanities Index, Francis Database, Humanities Abstracts, Social Science Abstracts, POEISIS (recent review shows that the databases available through the University of Toronto have changed since these searches). The search terms included “history”, “dying”, “death”, “palliative care”, and “hospice” in several combinations.
Abstracts were reviewed and either rejected or the papers and books retrieved. Retrieved papers and books were further reviewed and those that appeared appropriate were read through for content. The reference lists of these sources were themselves reviewed for further sources.

In neither literature review did I intend the searches and selection to be systematic or exhaustive. The aim of the review was to generate a reasonable picture of the social history relevant to the palliative care movement, both in a long-range sense and specifically during the existence of the movement. These reviews produced interesting results in their own right, but they were undertaken primarily to give context to, and to help structure, the analysis of texts and interviews.

3.2.2) Textual analysis

Selection. The texts chosen for analysis were selected to represent early and late palliative care in Canada. They were chosen on the basis of expression, influence, and comprehensiveness, as judged by me with the advice of four palliative care pioneers.

The literature review on palliative care indicated that palliative care underwent a watershed decade in the 1990’s (see Background section). In that period, a number of articles questioned the definition, role and direction of palliative care. There were changes afoot in palliative care that suggested a rationalization was occurring. Using this observation as a starting point, this thesis separates the palliative care movement into two periods, loosely understood as an early period from the origins to the 1990’s and a late period from the 1990’s onward. Some programs or practitioners will embody aspects of
one period even though their work or existence lies in another period, but as a general
division the distinction seems appropriate.

I began practicing palliative care in 2002, and this provided me a sense of the
many sources available in the early and late periods of palliative care. This experience
gave me at least a notion of which sources might be appropriate for analysis. I discussed
the idea of the thesis informally with three palliative care pioneers, and another early
practitioner (whose career started a bit late for inclusion in the interviews). These
discussions directed me to two sources that appeared most appropriate to represent the
early period of palliative care. The number of possible sources identified that met the
criteria for consideration were very few. A similar procedure of reflection, consultation
with palliative care pioneers, and review of possibilities, led to the identification of two
sources in late palliative care that I judged appropriate for comparison. As in the
literature review, the aim was not to identify all sources, but a handful of reasonable ones
with which to extend the picture beginning to form from the literature reviews.

In particular, the sources were chosen for expression, influence and
comprehensiveness. By expression, I mean that the sources were judged likely to express
the discourses of palliative care at the time, especially in the Canadian context. By
influence, I mean that most palliative care practitioners of the time would have read and
consulted the sources. By comprehensiveness, I mean that sources would be ones that
spoke on several levels about much of palliative care (e.g. philosophical, clinical,
administrative). The two early sources were related in their production and represented
the only sources identified as expressive and influential across Canada. They covered a
great array of topics by many authors, and were thus comprehensive as well. With the
great proliferation of sources available in the later period, choosing appropriate sources was challenging. Taken together, the two sources chosen for the later period met the criteria of expression, influence and comprehensiveness, and seemed to form a reasonable comparison in form and content to the early sources. Three of the four sources used for comparison of the early and later periods were created in Canada. For one source (i.e. the *Oxford Textbook of Palliative Medicine*), I decided that the qualities of influence and comprehensiveness were more important than a Canadian origin (though the source nonetheless could still be argued as being expressive of Canadian palliative care for that period). This was a source that most practitioners at the time would have found important to their work. Overall, the approach to selection is reasonable up to and including the decade following 2000, but would have been be more challenging thereafter because of the proliferation, and availability to practitioners, of many sources.

Using this method, the following sources were chosen:

*Early*  1976, Palliative Care Service Report, Royal Victoria Hospital, McGill University
*Late*  2002, A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice, CHPCA
2004, Oxford Textbook of Palliative Medicine, 3rd Ed. Oxford University Press (Sections 1 to 3, 11, and 12: *Introduction, The challenge of palliative medicine, Ethical issues, Cultural and spiritual aspects of palliative medicine, and Emotional issues in palliative medicine*, pp.1-84 and 949-992)
2010, Oxford Textbook of Palliative Medicine, 4th Ed. Oxford University Press (because it became available partway through the work on this thesis, I reviewed those sections corresponding to
Analysis. The texts were analyzed using coding, comparison, aggregation (based on similarities of form, content, presuppositions, style, etc.), and refining. Coding began with an initial reading of the texts. This coding was ‘open’ in the sense that the contribution and importance of the segments to the eventual developed themes was still fairly undetermined. The segments that seemed relevant to palliative care ethics (i.e. ‘ethics’ broadly understood) were recorded, either as quotes or in paraphrase. At a point estimated to be approximately one third of the way through each text, this open coding was paused, and the collected segments were compared with one another and with other ongoing or completed analysis (the textual analysis proceeded for the most part before the interview analysis, but not entirely). Comparison revealed similarities, which allowed for aggregation of the segments into groups. Once groups were established, these groups were reconsidered and aggregated into larger categories based again on similarities. After this point, the analysis returned to the remaining two thirds of the text, one third at a time, using the same approach. The rationale for breaking the analysis into thirds was to attempt to preserve a degree of openness in the initial coding, so as not to fix the groups, categories and themes too early in the analysis.

After the data had been coded into segments, groups, and categories, all the categories were compared and refined, where refining refers to rearranging and renaming categories based on their similarities to one another. For the early period this generated the twelve categories of: uniqueness, meaning and growth, depersonalization, care, relationship, relations with medicine, relations between practitioners, boundaries, legitimacy, spirituality, acceptance, and suffering. For the late period this generated the
nine categories of: person, care, relationship, expertise, scope, relationship to medicine, quality of life, normalcy and societal welfare.

These categories were refined and aggregated into descriptive themes for each period. For the early period, the categories of uniqueness, meaning and growth, depersonalization, care, relationship were aggregated into the theme of person; the categories of relations with medicine, relations between practitioners, boundaries, and legitimacy were aggregated into the theme of profession; and the categories of relationship and care, spirituality, acceptance, and suffering were aggregated into the theme of well-being (relationship and care appeared here as well as in the theme of person). For the late period, the categories of person, care, and relationship were aggregated into the theme of person; the categories of expertise, scope, and relationship to medicine were aggregated into the theme of profession; and the categories of quality of life, normalcy and societal welfare aggregated into the theme of well-being.

Further comparison between each theme of person, profession and well-being in its early and late incarnations, combined with comparison with the themes arising from the ongoing interview analysis, generated three themes of process: routinization, medicalization and professionalization.

3.2.3) Interview analysis

Interviewees and interviews. The interviewees were chosen for their position in the development of Canadian palliative care. The criteria for selection of these palliative care ‘pioneers’ were: that the person had a therapeutic role in palliative care (the majority also had administrative roles as well); that the person had been an early practitioner of
palliative care (i.e. practiced before 1985); and that the person had continued to practice into the late period (i.e. practiced after 1995). This spanning of practice across early and late palliative care allowed for reflection on the changes over that time.

From my clinical work I identified nine potential candidates, six of whom met the criteria for inclusion and agreed to be interviewed. These interviewees in turn identified six further potential candidates, four of whom were interviewed. Two other pioneers were mentioned, but were recently deceased. Three other potential candidates were identified through discussion with current palliative care practitioners, and though they were seen as potential interviewees, practical impediments stalled their recruitment and in the end, after consideration of the data collected, they were not interviewed.

The self-identified professions of the interviewees included: five physicians, two nurses, two social workers and one psychotherapist. Five of the interviewees were men and five were women. Nine of the interviewees were still active in palliative care, though two of them had retired from clinical practice and participated through administrative and political work. One interviewee had retired from palliative care. The interviewees had practiced in five Canadian cities (Montreal, Hamilton, Winnipeg, Toronto, and Victoria).

The interview process was given ethical approval by the Research Ethics Board at the University of Toronto. Each person was interviewed face-to-face for roughly an hour, though in one instance this was shortened to approximately forty minutes for reasons of scheduling. The interviews were conducted using a semi-structured questionnaire as a guide (see appendix 1), and the interview was recorded. A professional transcriber was employed to produce written transcripts of the interviews. All interviewees gave verbal
consent for the interview, nine interviewees signed a consent form, and one waived this procedure (see appendix 2).

Analysis. Like the textual analysis, these interviews respond overall to the question of whether and how palliative care has changed since its beginnings in Canada. The interview transcripts underwent an analysis similar to that performed on the texts. First, the sources were coded preliminarily, resulting in a collection of descriptive phrases, sometimes verbatim of key passages and sometimes a loose paraphrase. The phrases were compared for similarities and affiliation with one another, resulting in aggregating of segments into groups. Descriptions of these groups were recorded, and these descriptions again compared and aggregated into categories. This categorization was attempted in an unstructured but closely-considered way, and also in a table cross-listing the descriptive phrases. These attempts at categorization were combined, and upon further review generated nine categories: interprofessionalism, spirituality, motivation, credibility, practice style, goals, bureaucracy, medicalization, and professionalism. After further review, these were condensed into three themes: motivation and practice style and some aspects of spirituality fit under routinization; credibility and professionalism and other aspects of spirituality fit under the theme of professionalization; and bureaucratization and medicalization fit under the theme of medicalization. Two of the categories – interprofessionalism and goals of palliative care – did not ultimately describe changes in palliative care as I had expected from the textual analysis, but instead concerned ongoing features of palliative care.
Chapter 4: Results of Textual Analysis

The analysis of these sources is discussed fully in the *Methods* section. Briefly reviewed here, these sources were chosen as representative of Canadian palliative care, and chosen to allow comparison between the early and late periods. Normative instances were collected through initial open coding of the texts, and instances were aggregated into descriptive phrases (groups), then aggregated in categories and lastly into themes. The themes of the early and late periods were revised by ongoing comparison between each other and with the emerging themes of the interview analysis to derive a narrowed focus on three descriptive themes: *person, profession* and *well-being*. These descriptive themes, when the early and late periods were compared, translated into three themes of process: *routinization, medicalization*, and *professionalization*. This chapter is organized into:

4.1) Early Themes  
4.2) Late Themes  
4.3) Comparison of Early and Late Periods
4.1) Early Themes:

4.1.1) Person.

The theme of ‘person’ is an important focus of early palliative care, constituting ideas of self, personhood, and humanness. In the works reviewed, this is reflected for example in the many instances of life stories, descriptions of patients, and case histories. The theme of person also refers to the agency and worth of those involved in palliative care – the patient, the family members, the professionals, and volunteers. I have used the theme of person to collect the categories of: uniqueness, meaning and growth, depersonalization, care, and relationship.

Uniqueness. In the early writings, persons are understood to be unique, shaped through personal history, institutions, relationships, biology, and contingencies. As written in an early work,

> Each person...has a unique understanding of life and its meaning. This has been moulded by ethnic origins, social class and family expectations, as well as previous exposure to religion and philosophy (The Royal Victoria Hospital Manual on Palliative/Hospice Care, 1980 (hereafter RVH), p47).

All this is seen as especially important in persons’ confrontation with their own mortality. Such confrontation was written often in the words of both hope and acceptance,

> Let us see life and death in perspective: the true meaning of any one of these flowers can be fully appreciated only in the context of the other flowers (Palliative Care Service Report, Royal Victoria Hospital (hereafter PP), p33).

Despite such aspirations, a person’s uniqueness is understood sometimes to preclude some aspects of the palliative care perspective, “Not all persons need or desire palliative care” (RVH, p76).
Meaning and growth. In the early writings it is understood that uniqueness is found partly in the creation of a meaningful existence and growth of self. This is a sense of self that, while it resonates with ideas from theoretical or practical psychology and philosophy and social theory, has its own character. Practitioners are expected to engage palliative patients in the process of creating and maintaining such a meaningful existence, proposing that palliative care,

affirms each person’s search for ultimate meaning by respecting and responding to each individual’s personal truth (RVH, p69).

The fairly undefined term ‘growth’, in the sense of personal development, also refers to this process,

The arena of terminal illness is recognized as being a setting of great potential for personal growth (RVH, p270).

And in these efforts, it is thought that the practitioners and patients will influence one another, seen for instance in a description of care,

the privilege of seeing [the patient] grow as an individual during her final weeks of life, provided ample reinforcement for the P.C.U. [palliative care unit] team (PP, p16).

Depersonalization. Against these notions of person as unique, as meaning-making and as having the potential for growth, lies the threat of depersonalization. Such compromising of growth is seen as a significant obstacle to good palliative care, “We have limited the potential growth-producing participation by institutionalizing dying” (RVH, p242). In this way personhood is often understood as a contrastive notion in the early writings. That which is human and personal is seen as so by virtue of being not technological, or not institutional, or not bureaucratic, or not clinical and so forth. Thus proper care “maintains the personal identity and role that is often lost in a large
institution” (PP, p11). The early writings warn against allowing the non-human to subsume those parts of life that should remain human,

hospitalization was found to involve a series of dehumanizing events...so that eventually all sense of autonomy, identity and status as an individual was eliminated (RVH, p41);
the suffering of the terminally ill is greatly intensified by the isolation and de-personalization of a general hospital ward (PP, p34).

Notwithstanding, there exists in the early writings also an understanding that some sort of institutions needed to support and structure palliative care – as put in an early work,

Institutional depersonalization is ever present. It is watched for and minimized while recognizing that ‘efficiency is very comforting’ (RVH, p270).

Care. In these ideas of person appear some aspects of the sense of ‘care’ that is mentioned often and variously in the early writings. This care may be a quality of being, may concern the motivations causing one to act, or the intentions one has in acting, and may underlie the very understanding of the action itself. It is an important focus of early palliative care. Several examples,

In the palliative care unit the emphasis is on total care (PP, p14);
the secret of the care of the patient is in caring for the patient (RVH, p42);
to care for another person is to help that person grow towards self-realization (RVH, p43);
caring, then, involves a profound respect for the ‘otherness’ of other people, grounded in a sense of the individual’s unique worth (RVH, p42).

The scope of care is thus wide, from the broad sense of having a concern for someone to the more articulated sense of wanting things to go well for a person and striving to make that so, and it is seen as valuable. For example, it is written that for the palliative patient,

the presence of individuals whose caring reaffirms your personhood and worth…is a priceless boon (PP, p20).
Relationship. The expression and result of such care is relationship. The notion of relationship figures prominently in early discussions of palliative care. The person that is the patient is understood to exist in relation to the others around her or him – family especially, but friends and acquaintances too, including professional acquaintances. We saw above the way that practitioners were encouraged to bring that person to a renewed sense of self,

through sharing, the patient becomes able to differentiate himself or herself as a unique person with a unique set of experiences in life (RVH, p235).

But the writings also express something less instrumental in the idea of relationship. Relationship is seen as worthy in its own right, independent of its therapeutic usefulness. Over and over the importance of forming worthy relationships with the dying is stressed, the idea that practitioners should aim to

meet the patient where they are...[which]...requires sufficient meaningful contact to learn the nature of their interests, fears and hopes, plus the time and interest to respond to those needs (PP, p18).

The ideals of warmth and sensitivity, the willingness to give time, these are seen as informing worthy relationships between the professional and the patient, “understanding the needs of the total person requires time and attention” (PP, p15). Nonetheless, as with other ideals, the early writings considered as well the limits of care and relationship,

The global goals of ‘total care’ all too frequently lack clarity of definition in measurable terms. They produce anxiety, a sense of impotence, uncertainty regarding priorities and inevitability of at least partial failure (RVH, p464).
4.1.2) *Profession.*

The early writings spend much time considering the profession of palliative care. Palliative care is often portrayed as a young discipline or movement, “hospice care is ‘something new’” (RVH, p475); it is described as “the fledgling field of palliative/hospice care” (RVH, preface). It is explicitly presented as worthy of clinical attention, but thereby also implicitly revealing fears of unworthiness,

the challenges and rewards of Palliative Care Service work are sufficient to sustain the physician, nursing and support staff involved in such work (PP, p35). This novelty seems to encourage reflection on the question of what palliative care is or should be, leading to the categories of: palliative care’s relations with medicine, the relations between practitioners, its boundaries, and its seeking after legitimacy.

*Relations with medicine.* Early palliative care aspires toward changing the way the dying are treated, positing that this influence should include the field of medicine, and occasionally suggesting that it should extend to society generally. From palliative care as a force that “exerts its humanizing influence on the rest of the hospital” (RVH, p39), to palliative care encouraging us to see that “as a society, we must re-examine our attitudes towards death as part of the life cycle” (PP, p33). The idea seems to be that through “significant departures from the traditional medical model” (RVH, p269) and with an emphasis on “whole person care” where “the patient is seen as a person and family member rather than as a disease process” (PP, p14), the depersonalizing influence of past and (then) standard or traditional medical care could be opposed. Standard medical care is portrayed as focusing on persons as diseases, or persons as parts, resulting in the “traditional mediocrity of terminal care” (RVH, 243), care which contributes to suffering. We find for instance the suggestion that,
the skills of the institution and the needs of these patients [the dying] are mismatched, resulting in isolation and compounded suffering (PP, p9);

the medical, emotional and spiritual needs of the terminally ill and their families are, in general, neglected in the delivery of health care (PP, p34).

Generally, early palliative care feels that the routine and the standardized are to be suspected or rejected, seen among other places in the idea that,

the relaxation of institutional regulations concerning visitors, food, pets, and other details of daily life promotes a relaxed atmosphere (RVH, p270).

**Relations between practitioners.** As we saw in the section on person, the goal of this change was to ‘humanize’ care for the dying. Given this tension with conventional medical care for the dying, there is frequent discussion of the existing and hoped-for shape of collegial relationships. The traditional hierarchy of medicine is to be rejected,

The traditional hierarchical, physician dominated, health care team is inadequate for this task [i.e. of caring for the dying] (RVH, p236).

Instead, volunteers, nurses, doctors and others are seen as having equal contributions to make. An early presentation of standards for palliative care includes the statement that “Hospice care consists of a blending of professional and nonprofessional services” (RVH, p76), such that volunteers are considered integral to the delivery of palliative care,

No professional team will ever have the time to do this adequately [i.e. give comprehensive care], and success will come only as professionals and volunteers work together (RVH, p273).

The result of such egalitarian relations should include at times the ‘blurring’ of professional boundaries. This translates into the understanding that

all members of the team have a common commitment to meet the patient and family’s needs, and this commitment supersedes the boundaries of their own disciplines (RVH, p83).

And not only that this role blurring occurs, but that it is good that it should occur,
A blurring of traditional professional roles is accepted – necessitating patience, skilled listening and a minimum of professional insecurity (RVH, p270). Practitioners are to take responsibility for as much as seems appropriate, neither delegating difficult or menial tasks nor avoiding tasks as outside one’s scope – at least so far as this was safe and in the patient’s interest, such that,

each member of the team may thus be involved in delivering aspects of the care plan, resulting in what is often referred to as ‘role blurring’ (RVH, p83).

**Boundaries.** There is an understanding in the early writings that these intimations of change require some limits, appearing most clearly in the discussions of boundaries. There are concrete and pragmatic geographic boundaries, for instance in the area from which patients were drawn. But there are also more abstract and contested boundaries based on disease,

first priority be given to…oncology patients, but that others in the ‘patient pool’ be considered eligible (PP, p39);
although the current interest in hospice care in the United States is especially concerned with the dying cancer patient and his family…hospices should consider in their concerns those with other long term progressive illnesses, chronic pain, and…frailty and old age (RVH, p24);
Hospice practice is very different from geriatric medicine or the care of the chronically sick – the specialties to which it has been compared (RVH, p37).

These boundaries based on prognosis do in the early writings seem almost unanimously to include specifically those with a terminal diagnosis.

**Legitimacy.** Despite aspiring to distinguish itself from and to reform traditional medicine, early palliative care seeks at the same time to acquire clinical legitimacy,

The suggestion that this [i.e. palliative care] may prove to be a field with demands appropriate for those physicians reaching retirement has given way to a clearer picture of a challenging, ever-fascinating pursuit (RVH, p37).
However, the ascendancy of palliative care is thought to pose also a possible liability in “the risk of too rapid development and resultant mediocrity” (RVH, preface). There is an emphasis on those areas where palliative care sees itself as having ability or potency. We are told that “with care and attention to detail, important advances in the standards of medical care have been achieved” (PP, p16), and this passage is followed by a description of the advances in pain control as a prime examples of such advances. There appears a strong sense that palliative care has begun, and should continue, to build a repertory of skills, backed by evidence. Interventions, whether psychological, physical or spiritual, are to be founded in research and outcomes. There is then an aspiration toward balance,

the hospital provides the quality controls [to the hospice/palliative program] which help to ensure that the hospice will not become simply a ‘soft option’ and a haven for mediocrity in medical care (RVH, p39);
The goal was not to compete, but to complement and extend the care given by other services within the hospital (RVH, p368).

4.1.3) Well-being

Much of the early writings concern the ends of palliative care, what it is that patients, families, professionals and others do, and should, strive for – what it is that is the goal. Broadly, the goal can be called ‘well-being’, a word used in the writings that seems to carry the senses of what could be considered the aims of life such as flourishing, happiness, pleasure, achievement, virtuous action, knowledge and so forth. The theme of well-being includes the categories of: relationship and care, spirituality, acceptance, and suffering.
Relationship and care. Care and relationship have already been discussed above, understood in the early writings to be important instrumentally to achieving other ends and also as being intrinsically worthwhile. In the instrumental sense, care and relationship are seen as supporting meaning and personal growth.

Spirituality. A particular form of growth important to palliative care is spiritual meaning and growth. The early writings contain among them the writings of religious professionals, such as chaplains. Indeed, the ‘clergy’ are considered part of the ‘core team’ (RVH, p77). As one author put it,

religious and philosophical questions [are] of supreme importance to patients facing the ultimate crisis of impending death (RVH, p255).

Spirituality is understood to concern the relation of persons to the “metaphysical or spiritual”, as written in one passage,

the fundamental precept on which both the European and the American hospices are based emanates from an understanding of the nature, purpose, and process of religion (RVH, p68).

The religion of spirituality that one finds is non-denominational, and is in fact fairly non-committal to any doctrine, supporting widely variant, individualized and subjective senses of spirituality. For example, in a section on the role of the chaplain, ‘religion’ was used in the broad sense of ultimate concern about the meaning of life and existence; its use is not the narrow meaning of a particular form of belief and practice (RVH, p244).

In this sense at least, we were told, “dying is a highly religious process” (RVH, p244). In these ways spirituality was frequently cited as a goal of palliative care.

Acceptance. Early palliative care aspired to normalize dying and death,

One of the tenets of Hospice is the belief and recognition that dying is a normal process whether or not resulting from disease (RVH, p70);
Hospice recognizes that anxiety, fear, depression, and grief are normal in families dealing with dying and death (RVH, p80).
Normalcy as the hope for returning to the normal is also valued in the early writings, but always with the background acceptance of death, so that palliative care might produce a state of physical and mental relief so the patient can live and relate to others as normally as possible (RVH, p75).

There is in this hope for relative normalcy shades of the idea of quality of life, such as when we read,

the hard won expertise of the general hospital (to investigate, diagnose, cure and prolong life) is no longer relevant...the only appropriate goal is symptom control aimed at providing the optimum quality of life (PP, p8);

The focus [in palliative care] is not on dying but on the quality of remaining life (RVH, p270).

Yet even a ‘normalized’ death may be difficult, the writings assert,

The dying must adapt to and accept a succession of losses – job, physical strength, mobility, interests, home, family ties and finally life itself (PP, p20).

Dying and death are thus unstable notions regarding well-being in the writings of early palliative care. There is, on the one hand, the obvious way in which they are disvalued, being as they are tied with suffering, yet the understanding of dying and death, and the incorporation of this understanding into one’s life story – the “coming to terms with the reality of an impending loss” (PP, p21) – this is understood in the early writings to be a good. And dying and death may also produce good in the sense that,

Participation [in the process of dying], although unpleasant and painful at times, can enrich the lives of the dying and those who surround him (RVH, p243).

The idea appears that through,

the promotion of a caring community sensitive to their needs, patients and families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them (RVH, p67).

The need for such supports arises in consequence partially from the problem, confronting Western society as we face death... ‘The conspiracy of silence’, that tendency to avoid discussion of death at all costs (PP, p149);
which too frequently surrounds the terminally ill [and] heightens anxiety, strains relationships, enhances isolation (PP, p22).

*Suffering.* Palliation, the root of term palliative care, is founded on concepts of suffering. Seen through the eyes of early palliative care, suffering is understood to be the primary compromise of well-being. Suffering can be physical, and a great deal of the writing concerns the symptoms accompanying terminal disease. But one of the striking aspects of early palliative care is the attention it gives to suffering that is not exclusively physical. Much is written about the loneliness, isolation, meaninglessness, lack of professional care and attention that visits the dying. Suffering is described in many ways in the early writings and attributed to many sources,

those dying in our hospital suffer unnecessarily – physically, mentally, interpersonally, and spiritually (PP, p1).

And correspondingly, the area over which palliative care should aim to intervene or support is wide, so that palliative care requires a total approach which makes it mandatory to consider psychosocial issues, as well as life’s ultimate metaphysical or spiritual questions (RVH, p37).

Included in these efforts, the early writings stress the need for palliative care to include bereavement services, “Terminal care is viewed as a prelude to bereavement follow-up” (RVH, p270).

Suffering is understood in the early writings as an experience that we usually recognize intuitively, without the need of intellectual parsing. But given the insecurities of early palliative care over its clinical legitimacy, there is also some discussion of how to make the understanding of suffering more quantifiable – talk of scales, or types of suffering, but not much. In the end the overriding sentiment seems to be that suffering’s
impact cannot be measured in milligrams, percent or mean survival times. It is difficult to quantitate and ascribe a statistical significance to a lessening of loneliness or pain, or an easing of anxiety or the pangs of bereavement (PP, p2).

In the early writings we see that suffering, even if accepted, may still be attenuated or accommodated – where some issues such as symptoms oblige attenuation, and others such as the fact of death oblige adjustment. Attenuating, adjusting, and accepting are all understood in the early writings to be important to reducing suffering.

4.2) Late Themes:

4.2.1) Person

The idea of person figures importantly in the later writings of palliative care. In one sense the person is the particular human involved (similar to what appeared in the early writings). In another sense the person is the abstract entity founded partly in ethical discourse. Where the writings expand on the nature of the patient-practitioner relationship in palliative care, it does so employing a somewhat technical and rationalized language. Persons require care and persons enter into relationship with practitioners, but in both cases this is conveyed through ideas of treatment and management as well as concern or empathy. The theme of person is comprised of the categories of: person, care, and relationship.

Person. In the later writings it was frequently written that treatment and care should be provided with the idea that the person receiving it is a unique individual,

All aspects of care are provided in a manner that is sensitive to the patient’s and family’s personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process (A Model to Guide
Hospice Palliative Care: Based on National Principles and Norms of Practice, CHPCA, 2002 (hereafter NPNP), p19

Patients are to receive care spanning a range of areas,

palliative care is holistic care – equally concerned with physical, psychosocial, and spiritual aspects of each patient (Oxford Textbook of Palliative Medicine (hereafter OXF), 2004, p2).

and this care “should be patient-centred rather than pathology-centred” (OXF2004, p2).

Yet despite this acknowledgement of uniqueness, patients are described also in ways that are founded on universalizing concepts, often connected with ethics. This ethics is presented as principle-grounded, rule-governed and procedural, seen for example in such phrases as ‘ethical framework’, ‘standards of practice’, ‘principles and norms of practice’, ‘standards of professional conduct’, “the ethical principles of autonomy, beneficence, nonmaleficence, justice, truth-telling and confidentiality” (OXF2004, p55; NPNP, p18). In this idealized understanding, values are to be located, principles deduced, conflicts identified and decisions made with justification. These notions influence the idea of a person. We are told for example to respect “the intrinsic value of each person as an autonomous and unique individual” (NPNP, p19). And in this way, while the particular autonomous person is unique, the ‘autonomous person’ becomes somewhat of an ethical place-holder. The autonomous person is worthy of respect, bears rights, and should receive a certain standard of care.

Care. The term care is used, for the most, as synonymous with treatment, as in, “care is only provided when the patient and/or family is prepared to accept it” (NPNP, p19), such that in the late writings care most often refers to the attention and service provided to patients and their families rather than to an emotional concern (even though this concern is still understood to be part of palliative care). The emotional side of
relationships is acknowledged in the sense that ‘emotional issues’ are given a clinical, therapeutic and managerial discussion. In the Oxford Textbook, for example, a chapter devoted to emotional issues is written from the perspective of the expert, one who shares her personal experience of illness, with direction given toward treating emotional issues (OXF2004, Ch12).

With an understanding that “caregivers must be able to identify and respond to all the complex/multiple issues that patients and families may face” (NPNP, p14), a variety of conceptual tools are described to aid in this end. For example, the process of communication is broken into such components as,

share a common language…use standard protocol to communicate, and to listen and respond…collect data…educate (NPNP, p21).

Manners of discussing, choosing and planning are sometimes itemized and explicitly detailed, “the process of providing care involves six essential and several basic steps” (NPNP, p26), and so forth. Norms and principles appear for “information-sharing”, “decision-making”, “care planning”, and “care delivery” (NPNP, p30-36). And spiritual aspects of care when addressed directly are taken

in the broadest possible sense and reflects the underlying element of depth that people sense in their relationships and in human life itself…divine love, sanctity or value of life, or of compassion (OXF2004, p951).

This sense of spirituality is almost broad enough to be without any sort of normative import.

Relationship. As these views of care might suggest, the relationship between the palliative care practitioner and the patient (and family) is, in the late writings, elaborated and directed. The result is that the ‘process of providing hospice palliative care’ is at
times conveyed as a procedural and clinical process. Practitioners should aim, for instance, for

the development of a therapeutic relationship between those who provide care (caregivers) and those who receive it (the patient and family as a unit). The relationship evolves with time as familiarity, trust and confidence are established (NPNP, p25).

And in this relationship the manner in which the patient is understood to require help from palliative care practitioners appears in neutral or clinical terms. Patients might seek help to

identify and assess each of their existing and potential issues, and opportunities for growth; share information about their illness and bereavement experience; plan their care; assess the outcomes of the therapeutic interventions (NPNP, p25).

The ‘therapeutic encounter’ is broken down into a series of steps: assessment, information sharing, decision-making, care planning, care delivery, confirmation (NPNP, p18). And where the language of relationship is less technical, the direction given in the late writings is based on or justified by empirical studies. For example, in a chapter devoted to communication, the idea that practitioners should talk with patients in an honest way, remaining flexible to the desires of the patient, is justified by empirical studies (Oxf2004, Ch4.1).

4.2.2) Profession

Palliative care, in the later writings, is self-regarding in several ways. The sense appears that palliative care has acquired an area of expertise – notably an expertise in managing symptoms of illness and dying – that qualifies it for specialty status. From this sense of palliative care as a healthcare discipline come questions concerning the scope of palliative care. On the one hand palliative care begins to seem appropriate for almost any
patient, but on the other hand as a specialty it seems to need a restricted area of focus. The writings also attempt to establish where within the healthcare structures palliative care should fit. The theme of profession contains within it the categories of *expertise*, *scope*, and *relationship to medicine*.

**Expertise.** The later writings of palliative care suggest that palliative care has certain skills and knowledge that both mark it as a medical endeavour and set it apart from other medical disciplines. Palliative care sees itself as a specialty, where caregivers are understood to be restricted to the scope of their ‘discipline of practice’, such that “providers are accountable to standards of professional conduct” (NPNP, p18). There is an emphasis on efficacy, seen for example in the assertion that there is more to palliative medicine than ‘tender loving care’, a high level of sympathy, and time and inclination to sit by the bedside holding a patient’s hand (OXF2004, p4). This sense of proficiency appears at the level of individual practitioners, who are to be “knowledgeable and skilled in all aspects of the caring process related to their discipline of practice” (NPNP, p18) and to “have the support they need to fulfill their roles” (NPNP, p1). It also appears at the organizational level, where the organization should be sure that it “manages its activities, resources and functions in a manner consistent with its approach to care delivery” (NPNP, p1).

This sense of palliative care as a distinct field is presented at times in a historical or narrative fashion,

For many years, the approach used in hospice palliative care has helped patients and their families address these issues while they were dying. Now, all the skills and strengths developed in hospice palliative care can be applied throughout the experience of illness and bereavement (NPNP, p1);
Individual grass roots initiatives...have gradually evolved into a cohesive movement that aims to relieve suffering and improve quality of life for those who are living with or dying from an illness (NPNP, p1).

We see it also implied here that palliative care should unify and standardize, “Canada needs a more standardized approach to hospice palliative care” (NPNP, pv), “a clear vision for hospice-palliative care that everyone could use” (NPNP, pv). In the end, with this kind of approach [i.e. a more standardized approach], individual caregivers and organizations will be more consistent and effective at identifying patient and family issues, the care required to manage each issue, and the resources and functions needed to develop and manage hospice palliative care organizations (NPNP, p1).

It is stated that a standardized national approach will “increase the credibility and facilitate maturation of this relatively young specialty” (NPNP, p3), and “serve as a model for the development of similar strategies to change other aspects of mainstream healthcare” (NPNP, p3) and “help integrate hospice palliative care into mainstream healthcare” (NPNP, p3).

Scope. As is visible in the many quotes above, the later writings understand palliative care as to have a broad applicability, almost to the extent of being appropriate for, “any patient and/or family at risk of developing a life-threatening illness due to any diagnosis, with any prognosis” (NPNP, p17). There is even the suggestion that discriminating based on diagnosis would be akin to discriminating on the basis of colour, religion or for any other unjustifiable reasons (OXF2004, p3). But this expansiveness should be seen as contending with a feeling that boundaries should limit the scope of palliative care, such as the concern that palliative care should not become “care of the chronically ill” (OXF2004, p3).

The introduction to the Oxford textbook in fact concentrates on these contentions about boundaries – what palliative care is, when it should be offered, who should receive
it, who should provide it, and whether it can be taught. And while for the most part, the answers lie on the more expansive and inclusive side – suggesting that palliative care can do more within the medical fields than it is traditionally conceived of doing – limits do appear. Sometimes the term ‘palliative care’ is used to refer to the pursuit of the least suffering and the best quality of life for patients with any disease and at any time in their illness, while ‘palliative medicine’ is used to refer to care given to those with “with active, progressive, far-advanced disease, for whom prognosis is limited and the focus is on quality of life” (OXF2004, p1). In this scheme the traditional emphasis on care for the dying becomes only a part of palliative care. For example, in the promotion of national standards, this care of the dying would become but one of eight domains (i.e. along with: physical, psychological, social, spiritual, practical, disease management, loss and grief) (NPNP, p15).

Relationship with Medicine. There appears also the question as to how palliative care, as a healthcare discipline, is to fit with other disciplines. The overall feeling is that “there needs to be collaboration and cooperation among medical colleagues from start to finish of a patient’s care” (OXF2004, p4). The Oxford Textbook gives a good example of this sort of hope. In a chapter on the relation between palliative care and cancer care, rapprochement between the two includes lessons for palliative care, such as suggestions: that “[t]he messianic aspects of palliative care should be complemented by critical review of existing dogma”; that research should become larger and more rigorous; that palliative care needs more resources including faster access to palliative anticancer therapy (OXF2004, p26).
4.2.3) Well-being.

The goal of palliative care, as seen in the later writings can be collected under the term ‘well-being’. This theme well-being accommodates the categories of: *quality of life*, *normalcy*, and *societal welfare* that appear in the later writings.

*Quality of life.* The phrase “quality of life” is common in the later writings on palliative care, such as in the Oxford Textbook of Palliative Medicine in which it is “a concept, a goal that receives much mention in this book” (OXF2004, p1). Quality of life is an important concept in later palliative care. ‘Well-being’ also appears in the later writings, such as “hospice palliative care aims to promote health – physical, psychological, social and spiritual well-being” (NPNP, p13).

Quality of life is taken to mean the worth of the patient’s ongoing experience of their life, usually understood as worth from the patient’s perspective. It has been defined as the capacity for and occurrence of “meaningful and valuable experiences” (NPNP, p12), and notably understood subjectively as a “very personal sense of the quality of life” (NPNP, p12) resulting in “care [that] is guided by quality of life as defined by the individual” (NPNP, p19). With this subjectivity comes a valuation of autonomy as self-direction, “quality of life is closely tied to autonomy, and the capacity and right to determine our own future” (NPNP, p12).

There is also a strong relationship between suffering and quality of life in the late writings. It is suggested that the efforts of palliative care should be to reduce suffering resulting from illness, dying and death, with the aim of improving quality of life. Suffering is typically understood in terms of detriment to quality of life, with an inverse relation between the two. Spiritual suffering is often translated into ‘existential’ suffering
suffering that concerns “hopelessness, futility, meaninglessness, disappointment, remorse, death anxiety, and disruption of personal identity” (OXF2004, p8).

In the later writings, it is suggested that promoting the best quality of life can and should be reached in large part through palliation of symptoms. Thus palliation and improving quality of life are presented as enmeshed, parallel goals, and the aim becomes “relieving suffering and improving quality of life” (NPNP, p13), or “to relieve suffering and improve the quality of living and dying” (NPNP, p17). Although suffering is typically seen as problematic – with one chapter headed “The Problem of Suffering” – it is occasionally remarked that suffering can lead ultimately to an improved quality of life,

The potential for personal development and net positive gain in overcoming situations of adversity and suffering is widely recognized. This potential however, is predicated on the ability to cope with the prevailing problems and challenges (OXF2004, p8).

Such subjectivity in the notions of suffering and quality of life introduce certain barriers to rationalizing the ideas, but nonetheless the late writings on palliative care are often concerned with measuring and quantifying quality of life. A chapter in the Oxford Textbook is devoted specifically to quality of life, noting the difficulty of quantification but also extolling the possibilities in the task (OXF2004, Ch6.3). There is classification based on those affected – patient, family, professionals – and by the nature or cause of suffering – physical, psychological, existential, financial, etc. (OXF2004, Ch2.1). In another case, suffering is understood as made up of several variables (using terms such as: consciousness, intensity, number, severity, diminishing of quality of life, appraisal, perception). The underlying hope seems to be that quantifying experience may facilitate its assessment and management, “Each of these variables [in the definition of suffering] is amenable to therapeutic intervention” (OXF2004, p7). Rarely there does appear a
counterview to the focus on quality of life and to its rationalization, such as the concern that we should

not suppose that ‘quality of life’ is by any means a satisfactory substitute or paraphrase for [sanctity of life] (OXF2004, p952)

and that it is important that some judgments value persons regardless of their abilities, happiness, experience, and so forth. Similarly, in a section on spiritual care we find a rejection of classification and an embracing instead of

the concept of ‘total care’ [which] turns on the insight that the physical, the psychological and the spiritual are but the distinctive perspectives upon what is, in reality, a unity (OXF2004, p952).

These counterviews are rare and in their oppositional stance serve to underscore the more common conception of quality of life.

Normalcy. Also inherent in the understanding of quality of life is the idea that normalcy is desirable. In the later writings, normalcy is an aim of palliative care. For example, in illustrating the aims of palliative care, one diagram depicts the ‘normal path of life’ as a large arrow, from which a smaller downward arrow of illness drops and toward which another small arrow of ‘desired change’ returns (NPNP, p14). We are told that with the right interventions a patient’s and family’s future “may be closer to what they anticipated”, which is understood to be “to live as close to ‘normal’ are possible” (NPNP, p14).

In those situations where illness becomes intractable, and achieving normalcy becomes a difficult objective, and dying begins (however defined), the sense of normal shifts somewhat. In such situations, dying and death are framed as normal in a biological sense, but still as a threat to the normal (as in ‘anticipated’ in the quote above) course of a person’s life. Just as there was ambiguity around the value of suffering, so dying and death are also both portrayed as threats and potential benefits. So, while suffering, and an
unachievable normalcy, and dying and death, are all viewed as threats to quality of life, nonetheless palliative practitioners are encouraged to recognize the value of life, the natural process of death, and the fact that both provide opportunities for personal growth and self-actualization (NPNP, p19).

Societal welfare. The late writings also focus on the societal welfare and equity of welfare. Poorly provided palliative care (or absent palliative care) may ripple outward, so that “a family’s suffering and the quality of their lives is a public health issue” (NPNP, p13). The idea seems to be that those who experience the death of someone close, may not transition safely through their bereavement, such that, surviving family members may themselves become patients in the healthcare system, burdens on society, or ineffective employees (NPNP, p13). The suggestion also appears that palliative care should look beyond its existent geographic boundaries toward serving those communities and countries that have little or no palliative care. This expansive mandate receives some qualification however, in the recognition that the resources of palliative care are insufficient to reach such expansive goals. We find, for example, a chapter on Economics-based palliative medicine, which consists of an approach to the rationing of care based on economic concerns with efficiency, accountability and maximizing of returns on health spending,

With better measurement of the economic attributes of palliative care, existing funding can be better defended and new funding acquired if such investments are demonstrably cost effective. If they are not cost effective and the resources could generate greater health benefits to patients elsewhere in the health care system, it is sensible (i.e. efficient) to deprive palliative care of funding (OXF2004, Ch2.6).
4.3) Comparison of Early and Late themes

In selecting a handful of works from the early and late periods of palliative care, some of what I have found will reflect the idiosyncrasies of those particular pieces. Some of the findings however, especially those that occurred throughout the texts, will speak to larger structural aspects of palliative care at those times. The comparisons and contrasts are presented as findings in themselves, and were also used to guide the interviews that follow in the next section. The descriptive themes (i.e. person, profession and well-being), when compared early to late, show changes that I will collect under the process themes of routinization, medicalization, and professionalization.

4.3.1) Routinization.

In the theme of person in the early and later writings we see early aspirations for human connectedness in contrast to a focus in the later period toward a more clinical relationship – it might be said that ‘care for the patient’ becomes ‘care of the patient’ (a distinction that I will deepen in the Discussion). The theme of routinization collects ideas that pertain to the day-to-day feel of providing palliative care. In this sense, we see the themes of person, profession and well-being differ between the early and late periods.

Early in palliative care, relationship was an especially valued part of care. But gradually care becomes more clinical, moving from a focus on a relationship that is person-to-person toward relationship that is practitioner-to-patient. The idea persists that patients are each unique and that this uniqueness matters, but the goal of understanding this uniqueness as important in itself becomes the goal of understanding this uniqueness
as a means to promote the patient’s well-being, autonomy and rights. The early focus on helping patient to face death, and find meaning, and to continue to grow, becomes later more optional than expected. The emphasis on supporting the person that is the patient initially accompanied a worry about the depersonalizing effects of institutions, but in the late period the threat of depersonalization is mentioned less, and physical and organizational institutionalization seems to be a more common part of palliative care.

Early palliative care focused on dying patients and their sufferings, while later palliative care expanded the focus to suffering from disease at almost any stage. The challenge of accepting mortality that was inherent in early palliative care thus becomes occasional. And while relationships may occur, their role in facing mortality lessens and consequently they are no longer explicitly encouraged with the same intensity. Instead, the practitioner is encouraged to consider the various domains in which issues may arise, of which end-of-life issues may be one. When such issues are identified, a number of conceptual categories are suggested for structuring a response. Each patient as an autonomous person is entitled to respectful, efficient and appropriate care (sometimes elaborated in more neutral and technical language), where care now means something more like management or therapy. The normative justification behind this moves from an intuitive and often unelaborated one to a justification given in terms of a principled, rule and standard-based ethics.

4.3.2) Medicalization.

The process of medicalization is closely related to routinization, and the routinization that develops often involves medical routines. Medicalization includes an
increase in the use of medical interventions over time, an increased focus on quality of life as a goal, and the sense that organization of care should resemble that of medical fields.

There is in late palliative care a greater focus on medical interventions. More interventions are possible, and more interventions are expected. The emphasis on interventions is associated with a move from focusing on the suffering of the dying to suffering in disease overall. There is shift to an understanding of suffering as primarily a problem requiring therapeutic intervention rather than an understanding of suffering as requiring both the therapeutic response and a response that emphasizes finding a meaning and an acceptance for suffering.

The decrease in the focus on relationship, meaning-finding and personal growth described above, accompanies a simultaneous growing focus on quality of life as a goal. Quality of life is understood in a fairly subjective manner, so that it is the patient’s wants that are taken to direct care. The increase in medical interventions used to palliate symptoms fits well with quality of life as a goal – physical suffering is understood to always compromise quality of life and reducing this suffering to promote quality of life. Overall, in an important sense the goal of palliative care drifts from valuing of relationship and palliation together, to valuing the single, more subjective understanding of quality of life.

Where early palliative care was resistant to quantifying suffering, later palliative care more often aspires to quantify. There are measurements and scales and possibilities for intervention and evaluation. And the increasing scope of palliative care toward treating not just dying but disease, and the emphasis on quality of life (especially as
symptom-control), leads to discussions in later palliative care of societal equity (i.e. how to distribute the limited care available).

Early palliative care attempted to reconceive the organizational structure of palliative care. The medical hierarchy of professions was to be avoided, such that nurses, social workers, spiritual workers, volunteers and others were all to be seen as providing important aspects of care. These practitioners were to be equal in importance, in part because what was most important about care was that it involved a close, concerned relationship. As well, the boundaries between the professions were to be purposely blurred, where each practitioner provided as much as he or she could of whatever help was needed. These ideas of reducing hierarchy and blurring boundaries recede over time and are little seen in the later writings. Instead in the late writings the more typical medical organization is promoted and taken as the expected way of organizing care.

4.3.3) Professionalization.

The processes of routinization and medicalization and professionalization overlap. In fact each process can be seen partly as another view of the others, something especially noticeable in the way that the professionalization that does develop involves various medical disciplines. In the early writings we see a palliative care that sets out to re-humanize the care given to the dying. But the writings suggest even early on that the small field of palliative care should grow, partly to provide a light for other medical fields to follow, and partly to provide for more people. The growth that occurs does seem to result in more services, and it does seem to influence other medical fields, but it also adopts an increasing clinical focus and rigour.
Palliative care could be said to become in this way more of a ‘hard’ professional discipline that turns away somewhat from its earlier ‘soft’ humanistic character. This hardness manifests in a growing focus on clinical skills, research, and standards. In this way the later writings aspire more strongly toward medical legitimacy than do the earlier writings. The drive to humanize care falls away to a background understanding, while the drive toward clinical efficacy, research success, and professional recognition come forward. There are hopes for coherence and standardization, and for the rise of a palliative care discipline that might have very broad application, almost to the point of being in some way relevant to any patient. Palliative care should be, these writings seem to say, another of the core specialities of medicine, with its own character but equal respect from the rest of medicine for its abilities.

4.3.4) Summary.

I see the important differences between early and late palliative care as best understood under the inter-related and overlapping processes of routinization, medicalization, and professionalization. Summarized in several points, these changes can be understood specifically in the following way:

- The relationship of care between practitioner and patient becomes more procedural, interventional and medical.

- The goals of relationship (i.e. including finding meaning and personal growth) of early palliative care are subsumed by the larger, more quantitative goal of quality of life.
- The organization, and delivery of care, and interprofessional relationship come to resemble those of medicine.

- The field of palliative care expands in size and in scope of practice and acquires a professional identity.
Chapter 5: Results of Interview Analysis

The selection of interviewees and method of analysis of the interview data is discussed fully the Methods chapter, but I will briefly summarize it here. Like the textual analysis, these interviews respond overall to the question of whether and how palliative care has changed since its beginnings in Canada. In the interview analysis, however, there is less clearly description of early and late palliative individually, instead it is mainly the comparison between the two that comes forward. The interviewees were chosen because of their place in Canadian palliative care – all were pioneers who had begun practicing in the early period and continued to practice or to be closely involved in palliative care through into the later period. The interviews were semi-structured. The interview transcripts were coded preliminarily, resulting in a collection of descriptive phrases. These phrases were then compared in several ways for similarities and affiliation, and were aggregated into groups. These groups were reconsidered and eventually reduced to nine categories: interprofessionalism, spirituality, motivation, credibility, practice style, goals, bureaucracy, medicalization, and professionalism.

After further review, these were condensed into four themes. There were three themes of change and one of stasis:

5.1) Routinization,
5.2) Medicalization,
5.3) Professionalization,
5.4) Stasis – Interprofessionalism and Goals
5.1) Routinization

“And that’s what, I guess, I’m concerned about, is that the relationship is not there”
(palliative care pioneer, interviewee)

The experience of providing palliative care has changed over time, and the interview data gives an impression of the way that this day-to-day feel of providing palliative care has changed. The motivation in early palliative care was more intense than it was later; knowledge and skills grew over time; there occurred a formalization of practice; and the focus on relationship became more clinical.

5.1.1) Intense Beginnings.

In the early days, palliative care practitioners began caring for the dying because of a perceived lack – they noticed either the lack of care medicine provided dying patients, or felt a lack of human interaction in their own medical practice. One interviewee believed that it was the intense experiences of dying patients’ suffering that motivated the early palliative care physicians,

I think for the physicians, they had to feel incredibly passionate about it [i.e. palliative care]. And most of the ones, when I’ve heard them talk about their stories about why they came to palliative care, it was about some patient that they couldn’t control their pain, or…they felt like as a physician they were really failing (110, 52-58), (The references in this section are from the interview transcripts, and have been recorded according to the number assigned to the interviewee and the line number at which the quote appears).

Regardless of profession, the interviewees mentioned being struck by the needs of dying patients, often with the sense that their suffering had escaped the attention and care of the rest of medicine,
there wasn’t adequate symptom control, there wasn’t the family input (I2, 29-30);
we saw there people that were not well cared for (I2, 42-43);
I just had some practice experiences that led me to think that we gotta do something for people who are dying in agony (I6, 33-35);
there was that kind of identified need (I5, 34).

One interviewee described in detail the lack of attention given to the suffering of the
dying before palliative care, adding the reflection that a “great avoidance” was occurring,
in the late ’50s, early ’60s, how we treated the terminally ill, and I can still close my eyes and see those people. First of all, we put them in single rooms. We only gave them 10 mg of morphine – so there was a standard dose for everybody regardless of their threshold of pain – and sometimes they would cry, you know, between dosages, and we would close their doors, sometimes, so that we didn’t have to hear their cries. And we certainly didn’t talk to the families, you know? There was this great avoidance going on (I2, 11-21).

This avoidance transferred also to the way the patients were recognized, whether clinically, pedagogically or bureaucratically,

[before palliative care] in making rounds with the residents we’d say, ‘Oh well, you don’t have to see him, he’s dying’ (I6, 144-145);
[upon reviewing charts] we found 200 patients who were actively dying, and nobody had labelled them like that. And the way to treat the dying was to give them – ‘wink-wink’ – enough morphine that would keep them quiet, and that was standard practice at the time, especially in surgical services (I6, 157-160).

And though there was sometimes a sense of blame in this apparent abandoning of dying patients, the interviewees at times reflected empathetically with the difficult roles of healthcare professionals in the period before palliative care,

in the early days when you worked with surgeons and particularly oncologists, they really, really struggled with their roles around that [i.e. the patient’s suffering], and either they hardened their hearts or they...you know? I saw surgeons who just left the field of oncology surgery because they couldn’t take it anymore, you know? They weren’t curing people, their patients were dying, and so oncologists flame out because they have very little. You know, in ’77/’78 they had very little in the way to offer as far as chemotherapy, you know, there wasn’t a lot to offer (I6, 279-289).
The other ‘lack’ that drew practitioners to palliative care was the lack of person-to-person relationship that conventional medicine at the time provided. One interviewee recalled,

That’s what I went into training for, to look after people…and I remember going home after being on nights [in the intensive care unit] one morning, and I realized I hadn’t talked to any of the patients, I was so busy emptying bottles and putting up IV’s and reading monitors and everything, and I thought, ‘No, this is not for me’ (I1, 107-122).

Together, these two lacks resulted in a great energy and sense of purpose that ran through early palliative care. Early palliative care was made up “in large part [by] the people who had the passion” (I10, 14-15), and who had “a fire in the belly around wanting to make things happen” (I5, 36-37). Said one interviewee, “we were leading with our hearts” (I6, 85). There was a sense of ‘calling’ and there was desire for change, both on the individual level and on the larger level of medicine and society,

most of us [i.e. physicians] and people like the chaplain, social work director, were bitten by the bug of wanting to see things better and different for people (I5, 69-71); I think you had a lot of people from the sixties who wanted to have systems change, who saw that care was not what it could be, and that we wanted to change the system (I9, 18-20). But the calling could be at times imperious, even to the expense of other parts of life,

I remember talking to someone who is still active in the field and she said that she would work as a nurse and come home absolutely exhausted from all the wonderful work she was doing as a hospice palliative care nurse and say to her family, you know, “I’ve given so much, you have to take care of me now,” and they finally said, “Look, if you don’t have anything to give us, why bother coming home?” and so she moved out, because in fact her career and giving to the dying was more “important” than family life. (I9, 83-91). The intensity appearing in this sort of sacrifice that practitioners made was also seen in volunteerism,

volunteerism was the original driver…there were professionals on board, but it was driven by this volunteer approach to care and compassion (I3, 433-444).
One interviewee noted that one of the early Canadian hospices began as an entirely volunteer organization and only after several years did it add positions for a nurse and physician (I3). Another interviewee described a doctor unable to pay his bills because of his volunteer commitment,

one of the physicians that I know from the States said that he didn’t get paid for three years – he was doing this purely as a volunteer – and when his house needed a new roof there was no money, and his wife was furious about this. …And people were sacrificing themselves and their families for the sake of this ideal. (I9, 72-83).

With this passion there sometimes appeared shades of righteousness. As one interviewee recalled “we all thought we were the chosen ones for the story” (I2, 1027-1028). Another interviewee – saying, “[we had] the tendency to think because we’re a palliative care specialist we are the word, the truth and the light” (I9, 38-39) – elaborated this way,

we were leading with our hearts, and that did cause a real backlash, you know, when we first started our team, because we came in like the white knights, you know, ‘We know about dying,’ and all the rest, ‘and all the rest of you are unwashed and illiterate,’ which they were, but saying it that way, instead of working collaboratively. We wanted to take over, and that was one of the first mistakes we made (I6, 85-91).

Alongside the vivid pictures of the early intensity of palliative care, there appeared in the interviews estimations that this original intensity had flagged,

you have new people coming in who weren’t part of the original cause, and don’t have the same passion (I10, 473-475);
there’s much more understanding of your need to do things to take care of yourself. (I9, 94-95)

For some, on reflection, the change in intensity was welcomed for providing some respite from the demands of attending so closely to the dying,

there can be burnout, there can be just enough frustration that some people will move elsewhere. So people I think really continue to volunteer, but it’s a struggle in the
professional field... but there’s been a better balance, I think, to recognizing self-care, not beyond but in alignment with compassionate or altruistic care (I3, 475-501). And in a quote that not only reconsiders the early commitment, but sets it against some of the current focus of research in palliative care,

Now, there hasn’t been that [focus on relationship]... they’ve done more in-depth research and things like that, and tried to get quality of life issues asked of, you know, people that were living with a life-threatening illness and whatever. Yeah, but I think our society...Society has changed...There’s not that same commitment to the patients that we had (I2, 790-791)

In this quote there is also visible a shift in emphasis away from relationship towards quality of life.

On the whole the sense appeared that the extreme suffering typical before palliative care is rarer now. One interviewee reflected on a time as a young student she helped a nun care for a dying mother by taking the children to the park for the day,

this is perfect [said the nun] because we have these five children and their mother is dying today and she’s dying at home of cancer of the cervix and she’s screaming in pain (I9, 31-33).

As that interviewee put it, “I think we don’t have those kinds of experiences in the way that we used to” (I9, 36-37).

5.1.2) Growth in Knowledge and Interventions.

The interviewees described the pioneering period as one in which the techniques and knowledge available were few, and in which there was a feeling of creative freedom. It was a time when there were only small groups of palliative care practitioners, so there were kind of these little pockets around the country, and people really feeling like they needed to...fight to even be recognized as a viable alternative...these little pockets of people trying to find their way to provide different kind of care, and people feeling, well – there’s still an element of it, but people feeling pretty special, you know? I
think as you kind of get with these people with a vision who, you know, “We see the light” and we know how it can be different,” and because they have to fight for every inch that they get, you know, and so I think it gives a different kind of edge to it. (I10, 20-29).

There was a sense of creation,

when we started there was nobody else at all (I7, 96-97); what was happening then was a spirit of adventure (I5, 13-14); there was quite a desire to be a pioneer and make things happen (I5, 73-74).

As one interviewer summarized it, “we were children in the wilderness” (I6, 13-14). In considering this fledging practice, the interviewees reflected on the initial lack of knowledge that was available to the practitioners,

And like the others, I had no particular training in palliative care (I4, 56-57); our knowledge was paper thin…we had the heart but we didn’t sometimes have the mind that went along with it (I6, 16-19); the way the nurses were taught was really entirely by modelling (I4, 516-517); when I applied I didn’t know anything more than the average nurse about death and dying and palliative care, I had to learn everything, the symptom control, the whole thing (I1, 548-549).

Not only was it that these particular practitioners had little knowledge or experience, but there was almost nowhere such knowledge available,

I think what existed was two pieces of material that could be called, you know, teaching materials on palliative care (I3, 245-247); when we started off there were no journals, now there are, what eight, nine major journals in this area, textbooks coming out of our ears (I6, 607-609); we had some pioneering experiences in that we had no protocol because it had never been done (I5, 84-86).

The knowledge that was available was described by some as composed in large part by thanatology and by the often-referenced ‘Red Book’ [i.e. the RVH used in the textual analysis],

At that time the only book we had was either books by thanatologists – like Herman Feifel [and]…Elizabeth Kubler-Ross’s *On Death and Dying*; we walked around with that in our pockets, you know? ‘Boom! Now you’re accepting,’ you know? ‘You’ll be
depressed next week,’ whatever it was – and the Red Book, which was from the Royal Victoria Hospital (I6, 63-69).

One interviewee was pleased with the growth in clinical knowledge, but in reflecting on the move away from the “more heart…than knowledge” stage, added that “maybe it’s swung too much the other way” (I6, 82).

Given the reality of practising in a field with little clinical history or knowledge to turn to, it is not surprising to find that the practice of palliative care was initially less interventionalist than it has become (see also the section on medicalization). The interviewees noted that,

the focus at that time was more the kind of the high-touch, the non-active treatment kinds of stuff (I3, 99-101).

Over time however, practice changed,

now were doing PICC lines and we’re doing IV’s and we’re getting to lab for the test…so I know that that causes great consternation for a lot of the team (I10, 262-265).

Describing a contemporary death that illustrated some of this consternation, one interviewee finished by reflecting, “You know what? We’ve lost thirty years of palliative care knowledge” (I2, 383). This growth in intervention has both extended beyond the physical, “I have to extend this [i.e. the growth in symptom management] to psychosocial management” (I3, 103-104). Notably, when psychosocial management is brought up, it is frequently, almost exclusively, evaluated in terms of improving quality of life,

On the other hand, among the things we’ve learned is the place of psychosocial existential questions in the human economy, and we can’t say that our goal is enhanced quality of life without asking the question, “If that’s your goal, that’s interesting. What promotes quality of life?” And then when the answer keeps coming up, if you ask the question skillfully enough it’s the existential psychosocial issues that are foundational to quality of life, not the physical components. (I7, 132-139)

For some, interventions of all types were seen as a strong step forward for palliative care, “we have better treatments from certainly a medical perspective” (I8, 426-427). Along
the same lines, one interviewee saw the increase in interventions occurring not blindly because they were possible, but because of the palliation they offered,

we then, I think, opened more broadly to interventions that would provide comfort, would provide relief, would be quite appropriate (I3, 107-109).

But at times these interventions were also viewed with some reservation (see also the section on professionalization),

I think that there probably... if you talk to people in our program, the nurses and the physicians, they are quick to say it ain’t what it used to be, and what they mean by that is there are far more IVs, far more epidural catheters, far more Wondermycin used, and on and on, where it wouldn’t have been in the first. I have two comments about that. One is, well, if those things are improving quality of life, hurray, that just is an increasing knowledge base. If they’re doing that at the expense of the core concepts that Cicely [Saunders] had, I think that should be examined quite carefully (I7, 141-149).

In this quote we can see the outlines of a tension, where there appears first the evaluative concept of quality of life, but also a less articulated concern that another, earlier and foundational concept may be threatened by the rise in interventions.

5.1.3) Formalizing Practice.

The interviewees also suggested that some formalization has entered palliative care practice, mentioned at times in: the formalization of ethics, in terms of a ‘checklist’ mentality, and in the form spirituality takes. Ethics was originally much more implicit, in contrast to the express considerations and debates of contemporary bioethicists,

at the time I remember there was only one ethicist in the city…not very clinically oriented. I mean, we thought the only ethical issue was around the issues of euthanasia – or assisted suicide – and everybody was against it because we can cure everybody’s dying and make them really comfortable and all the rest. When you started to see the iffy sort of pieces of that kind of approach... (I6, 257-258);
we just did things right. I think it came down to treating people the way we’d like to be treated (I1, 267-269).
In an interview filled with frequent stories and references to ethics in early palliative care, it was notable that these instances conveyed were as intuitive moral interactions with patients and families, and none were conveyed in the rules, principles, and justifications of more contemporary bioethics. This quote gives another example of this sort of intuitive conception of ethics,

we created an environment, or participated in an environment, in which people could feel free to use their intuition and talk about it, or check with somebody about whether it seemed the right thing to do (I4, 573-582).

One interviewee talked about opening rounds to selected outside observers with the simple request that information not be shared, but without any of the current notions of confidentiality,

we would do a combined ward rounds and death review so that they could see how cases were dealt with while we’re dealing with them…I don’t think you could possibly do that nowadays because of privacy…Considering that climate we now live in, it’s just amazing (I4, 467-478).

In time ethics became more explicit, described in terms of principles and rights,

I think those elements of ethical principles have been clearer now (I3, 380-381); that’s the language we use [now]…‘every Canadian has the right’ (I10, 351-352).

In the closing of one interview, the interviewee offered, unprompted, this reflection,

One young woman, after her mother died, she said to the nurse, “Now what do we do?” And Rachel, the nurse, said, “Well, we’ll fix her up and straighten her and tidy her and we’ll clean her up, and then we’ll put her in a container, a bag, to go to the morgue.” “Can I help?” the young woman said. So Rachel thought, and she said, “Yes.” Now, is that in the policy manual, that you let a family member prepare the body for the morgue? But this woman thanked her afterwards. Ethics (I1, 753-761).

Some reservations about this formalization of practice came forward in terms of the rise of checklists and algorithms,

we just need to be careful, I think, that we keep the personhood of the individual kind of ahead of things and use the checklist as a tool for us (I5, 586-588);
Now, the problem with algorithms, you don’t sometimes consider the individual person, you know?…We’ve gone to doing things like ESAS [i.e. Edmonton Symptom Assessment Scale] and numerical rating scales, and we’ve stopped asking the questions behind it… it’s now used as an instrument that actually tells you what’s going on instead of something that is maybe a help and a guide, but you still have to ask the questions (I6, 668-678).

This kind of formalization of practice could also be read into what some interviewees described as a change in spirituality. The interviewees felt that spirituality in palliative care has become less associated with religious institutions and more personalized, but also seen more as a therapy (see also medicalization). The actual concept of spirituality, though included as important to palliative care practice, was rather expectably ambiguous, ranging from beliefs of a structured, institutionalized religion to more personal, unstructured senses of ‘meaning and values’ underlying a person’s worldview (I9). Across this range, spirituality was regarded as more strongly associated with early palliative care than later palliative care. One interviewee, considering what it was that early palliative care hoped to achieve for patients, reflected on the close relationship between the palliative care and spirituality,

‘Palliative care was my spiritual formation [said a past nurse].’ I didn’t know the term, or if I did it was in the most remote parts of my memory. Well, it really hit me. I said, ‘You know, I could say the same thing.’ (I4, 801-811)

Such spirituality also played a role in the life of the healthcare professionals, for the healthcare professionals, interesting enough, you know, who were watching all this [i.e. suffering] and either you hardened your heart or you kept the grief inside. And we did some amazing work with nurses on the floors, with some of the students, the residents, etc., and even some of the high-powered medical staff who responded very much to the spiritual calling for these people who were dying (I6, 172-177).
Initially in early palliative care, spirituality appeared more often directly in the person of a religious leader fully part of the flow and camaraderie of the team, such as in the person of a nun devoted to the palliative care unit (I1). But spirituality became over time more something akin to a physiological, psychological function, often inquired into in a similar manner,

   a lot of it [i.e. spirituality] became sort of giving people tools and information about, you know, how could they bring spiritual care, how could they attend to spirituality (I10, 503-505);

   people have embraced the idea that you should ask if people have a faith or spiritual centre in their life, but sometimes they ask it like they’re asking, you know, ‘Do your ankles swell?’(I5, 413-416);

   we do see a little bit of a checkmark thing happening [regarding spirituality], which is a change, I think (I5, 431-433).

One interviewee expressed concern (“it got my ire up”) in the view, which the interviewee saw reflected in some recent studies, that spirituality seemed to be beneficial to a patient’s various outcomes (I5). This making of spiritual practice into a therapy seemed to the interviewee a fairly recent trend in palliative care and to her mind trivialized the important of spirituality. Another commented that although the original spiritual advisors “didn’t have the training” (I6, 169), later “the chaplains we had had training as spiritual counsellors, and they made a huge difference very quickly” (I6, 169-171), becoming “one of the components of palliative care” (I6, 187-188). For some, it seemed that along the way spirituality became more ‘task-oriented’,

   it’s kind of like check, “Pain, nausea, vomiting, soul,” you know, so I think we have to just watch and try very hard to keep... so they understand the enormity of what they’re asking, is what do you feel that’s happening to you, and what your thoughts about that are, rather than being quite so task-oriented (I5, 420-425).
The interviewees suggested also that as a whole, over time, an expediency and a distance entered clinical encounters. Practice came to entail less time spent in direct relation between the practitioner and the patient. The interviewees expressed this in many ways, and I have included a number of (truncated) examples to show the great variety of expression:

in the old days, you know, we’d have more time, and we’d be able to sit and be with the families and talk to the patients (I10, 260-262);
I can remember, you know, we had patients who were on our unit for weeks…and you knew each other and it felt like there were more opportunities just for people to stop and talk (I10, 571-576);
we kept people in a lot longer then they do nowadays (I4, 815-816);
we live in a real hectic healthcare system, and rush-rush-rush-rush, and there’s no time to stop and sit down (I8, 529-530);
Far more formal palliative care here [now] is just in the last few days of life (I4, 904-905);
the push for people to leave the facility, the hospital is so heavy that we have compressed a lot or our intervention into a very short time (I5, 109-111);
maybe there’s more volume of people to see now (I5, 280-281);
One of the things…that I think can be happening now, the big hospitals anyway, is expediency (I5, 569-571);
It’s [palliative care] much more acute…in our units there was a longer length of stay…it was slower-paced (I8, 9-13);
the average length of stay in the first go-around was three to four days on our service, because you were seeing people, “Oh,” you know, “they’re in the midst of dying. Please call.” We didn’t have a structured way of looking at dying at that time. And we often got called when there were family issues or communications issues as well (I6, 115-121).
There appeared here, as in the texts, a contrast between the person and the institution,
When you go into a home you see who they are. They’re not made part of an institution, you see their photographs, you see their pets, you see how they’ve decorated, all the different things, you know, that have meant something to them, and you get more into their life at home than you do in the hospital, you know? (I2, 335-341).
And mentioning the introduction of computer-aided note-taking, one interviewee said, they’re already introducing some of that [i.e. computer charting]…I wonder sometimes what we’re teaching in terms of how to talk to people (I1, 464-466).

5.1.4) Relationship and the Patient as a Person.

In the changes mentioned, it seemed to some that something of the ‘patient-centred’ approach had been lost or was threatened in current palliative care. The interviewees expressed it in various ways,

one of the concerns I guess I would have…is the expediency within the healthcare system generally that almost prevents people from encroaching into the world of personhood of the sick person (I5, 220-224);
I don’t see the same patient-centred [approach]… when I’m in the system and I don’t see that happening, I thought that it was all turned around. It isn’t turned around. It has to be constantly reinforced that this is what we’re there for, you know? (I2, 59-68);
our nurses are not happy about the pace of the work and how much less time they have at the bedsides (I10, 633-635).
The sense appeared that the emphasis placed on the person in early palliative care was greater,

the emphasis was so much put on the person and the family that you couldn’t help but have the relationship, because you were going into all of that, you know? And there was time, we had time. And I felt that there was that interest in people. (I2, 304-308);
accompaniment as we knew it in those days…we could know [patients] over time (I5, 111-114).

One interviewee painted a picture of the importance early on of ensuring patients were regarded always as persons by telling the story of an important surgeon being scolded by a palliative care nurse for insensitivity (I1). In this spirit of patient-centred care – “the patient and family were the unit of care - no ifs ands or buts, that was the unit of care” (I1, 228-230). It was important, for example, for the nurse to,
pull a chart, get to know it, keep an eye open, and when the person came in, say ‘Oh you must be Mrs. X. We were expecting you. I’ll show you to your room (I4, 354-356), and for all to make the palliative care unit ‘homey’,
letting the patient and family take ownership of it, letting them do what was important to them, having kids come, having toys for the kids in the family room, you know, that kind of thing (I1, 673-676).

This sort of accommodation of the rules to the needs of the patient and family in early palliative care was conveyed through a number of stories: about a patient’s dog being brought to the palliative care unit (I1, 678-685); about the spiritual practices of a native elder that involved seeds, leaves, and other materials scattered about the ward (I1, 703-714); about candles being used in the hospital (I1, 714-718); about grandchildren leaving materials with the body that might prove problematic to the morgue staff (I1, 728-743).

In the early period relationship was strongly encouraged, but later this was less expressly so. In one description of a contemporary ward with palliative patients, the doctors were rotated every two weeks so that (in the interviewee’s understanding) they didn’t form relationships,

he said, ‘The doctors are rotating every two weeks because they don’t want to get attached.’ And I said, ‘But isn’t that what it’s all about, is the relationship?’ And he said, ‘But it’s not,’ you know? So that is a change. And that’s what, I guess, I’m concerned about, is that the relationship is not there.
(I2, 295-296).

This valuation of the other person extended also to other, fellow practitioners. As one of the interviewees said, speaking of the emphasis she and her team put on respect,

I used to say to [the others on the team], ‘You don’t have to be buddies with each other but we have to treat each other decently and with respect, and help each other and support each other, and then we have the energy to give to the patients and family,’ because there’s so much of the other stuff [i.e. conflict] and “petty feelings”, I find, in hospitals (I1, 14-19).
The worry persists for some of the interviewees that palliative care has, or is at risk of becoming, more ‘mechanized’,

I wouldn’t want my future palliative care colleagues to be mechanized... and yet I find though, if we see a patient who’s been presented to us and then we go and do something – conversations, etc. – and come back out, if you can say something to the nursing staff and trainees and others about the person then they do relate to that, so it isn’t gone by any means, but it is a concern, I think. (I5, 249-255)

And in this quote, the interviewee expresses a concern that attention to relationship and humanity may be threatened by other demands,

we’re working with people at a very intense time in their lives, it evokes a lot of different kind of human responses from us as human beings, so there’s sort of many humans in that equation, so if we don’t pay attention to that we’re in big trouble. And I think, if anything, probably that was probably more of an emphasis earlier on, and I think it’s still an emphasis, and it stills happens, but I think it has competing... it has competition for air time, big-time, you know? (I8, 577-585)

5.2) Medicalization

“from high touch to high tech” (palliative care pioneer, interviewee)

The interviewees suggested that palliative care in Canada has moved away from an “early philosophy that [palliative care] is non-technology, non-medical, it is very much supportive, comfort, volunteer”, and moved somewhat toward a more technological, medical, professional notion (I3, 165-167). These changes in palliative care can be viewed as a medicalization. Sometimes the interviewees stated this plainly,

It’s [i.e. palliative care] become more medicalized, so that the medical emphasis is much higher than it used to be (I4, 889-890).

Other times the suggestion was couched in related terms – for instance, that palliative care has become more ‘upstream’, with practitioners becoming involved much earlier,
what was called upstream and downstream palliative care, and downstream being hospice, close to death, close to dying, and this upstream is taking those principles and moving more into the healthcare system at earlier points in diseases and other things (I3, 82-83).

Similarly, it was suggested that palliative care underwent a process of ‘mainstreaming’, an adaptation to the more conventional, medical way of care, which included adoption of a more bureaucratic structure to accommodate its ongoing expansion. Even the phrase palliative care has changed, with one interviewee noting that some provincial and local groups had switched their description from ‘palliative care’ to ‘palliative medicine’ (I5).

The ideas of medicalization applied the many professions of medical care, “Is [palliative care] more nursing-ized or more social-work-ized? I think so” (I10, 266-267). Overall, this medicalization was seen to include: an increase in interventions, new evidence-based justifications, and bureaucratization. The interviewees also evaluated this medicalization.

5.2.1) Increasing Interventions and a Focus on Symptoms.

In the routinization section above, the interviewees described a day-to-day practice that became more interventionist than it originally had been. This increase in interventions was also understood as a reflection of the medicalization of palliative care. In this way, the idea of medicalization is closely tied to the idea of routinization – the former being more conceptual and the latter more experiential – and many of the quotes here could be included above as well. This increase in interventions was described in many ways,

I think it feels more medicalized because it’s more interventionist and typically the interventions are medically driven (I10, 228-230);
[originally] we didn’t have intravenous going at all (I1, 33);

palliative care is more technical now (I2, 110);

now we’re doing IVs, and we’re getting lab tests, and we’re this, and…you know? (I10, 262-264);

from high touch to high tech…[palliative care] began to move somewhat into some active things (I3, 133-134).

And the increased medical interventions were also pictured by one interviewee as another aspect of distancing of the practitioner from the person that is the patient, a troubling aspect of medicalization,

it’s [i.e. palliative care] more technical. And that’s my concern…You know what? When you have the technology to focus on you don’t look at the demise. See? So there it is again, you know? It’s, “No, don’t get attached, because it's better to make it more professional,” so you hide from that (I2, 808-821).

One interviewee, felt that though in the early days medications were used when needed that even then the administration was somehow less invasive,

Now I know that they have to have access to drugs and so on and so forth, and we used to give a lot of the medication by suppositories, or the patches or sublingually and that’s far less invasive (I1, 35-38).

Another interviewee described the growing tension early on between a less or a more interventionalist approach,

But in the very early days people kind of had to stop chemotherapy and they had to stop treatment, you know, in order to be ‘appropriate’ for a palliative, for a hospice program, they had to stop all of these things, and for many patients back then – and certainly still many patients now – that was a welcome thing, it was kind of like, “Yeah, I’ve had enough of that. I don’t want that.” But there were a number of patients, and in fact a number of professionals, who took issue with that, and felt that ‘what you have to offer is probably good, but I’m still doing some active treatments which I think are still good [as well] but [I] won’t see them then. (I3, 111-123)
This emphasis on medical interventions seemed to the interviewees to reflect a focus on the control of symptoms over other aspects of palliative care, such as addressing spiritual and existential questions. Said one interviewee, “I think the fact that money is going primarily for doctors and nurses says that the goals have changed” (I9, 205-206). And along these lines, several interviewees commented on programs that had over time lost their ‘psycho-social-spiritual’ members while retaining nurses and physicians. To some of the interviewees it seemed that now,

there are teams that are just symptomatologists, ‘Give us pain and symptoms’ and the rest seems to be less important (I6, 128-130);
the consultations are very largely for symptom management (I4, 894-895);
there are significant players in the field who see this as...well, as some have said, we’re symptomatologists (I7, 157-159);
the inpatient services are used much more for symptomatic crises (I4, 891-892).
Many saw these changes in a positive light,

I know that we have developed more expertise in terms of understanding about symptom management (I8, 180-182);
there’s better symptom control (I1, 610);
the field has consolidated into more rigour, more understanding of symptom management (I3, 101-103).
But in the minds of some others, palliative care has in its symptom focus foregone somewhat the more indistinct, holistic goals. Initially the focus was more on the ‘journey’ through dying and to death,

you can take the imagery that was there about hospice being the... I mean, it goes back I guess a thousand or more years, etc., but the one that came forward through Cicely [Saunders] and others at the time was the journey, on the crusades people going on the journey and going up over the Swiss Alps, and there were hospices or places of refuge and rest, and so the concept of people on a journey – which of course the journey is towards death – and a hospice was this place of rest and recuperating and focusing. So
that image was – and I think still is – a very powerful image, and certainly that’s part of... our development here (I3, 56-67).

But over time this focus has fallen by the side to a degree as the focus on symptom-control increased, leaving for some a feeling of ambivalence and caution towards this shift in focus,

I think we may be a little more prescriptive now, sometimes, I think, because I see some of the consults and that kind of thing, but I think that’s when we delve too much into pain and symptoms as our role and not the overall sort of holistic approach to the physical, psychological, social functional and spiritual issues (I6, 537-542);

I think anything that attempts to bring standards and objectivity to examining what we’re doing is good. I mean, this isn’t witchcraft, and I think good old left-brain rational outcome measurement-driven science is not only a good thing, it’s essential, and the issues are profoundly important, so I’m for that, but the perception that reality is more than that, and an understanding of the degree to which, in our society, the balance has been lost (I7, 226-233).

5.2.2) Evidence-based justification

Together with this emphasis on symptom control came a demand for justification of the methods of palliation. As one interviewee said, “now you’re hearing, ‘Well, prove that it works’” (I10, 277-278). The justification provided was often expressed in terms such as scientific and evidence-based, and one result of this search for justification was,

I would say certainly the emphasis on the science of palliative care has increased (I7, 210-211);

there’s an intimation that there’s something soft and touchy-feely in ‘palliative care’ that would not be in ‘end-of-life care science’ (I5, 605-607).

This was in contrast with an earlier time, one seen to be more balanced,

there’s a tremendous emphasis in palliative care these days on the science in palliative care, as I see it. In those days I think we had more of a balance of science and person-centred care. (I5, 103-106)

Occasionally there was speculation on the reasons for such change,
Well, that’s because the docs got involved. You see, when it was just in the soft philosophy kind of thing people could publish, like Herman Feifel wrote a beautiful book, but when you try to actually apply it in the clinical environment it was, ‘What the hell is going on, here?’ you know? So the reality was when the docs started getting involved, because it was doctor-to-doctor, ‘Here, write an order for morphine,’ well, what’s the science behind that?...the docs, and as nursing advanced, really pushed – because we got nursing specialists – it really pushed the science, and so the hard piece. And there was – and there still is – that sort of sense of medicalization of dying. (I6, 622-637)

Interviewees described the change as part of a desire to progress toward better symptom control,

you want to do the best you can and you can’t necessarily sit with complacency that, ‘Okay, what we’re doing now is pretty good so therefore that’s all it ever needs to be,’ so I think that natural drive to do the best possible brought forward various more active interventions. And there’s good research happening in palliative care now as to are they effective or not, when are they effective, when are they not (I3, 124-131); we would see people in our practice who had come through other parts of the healthcare system not being well managed, not being told that they were dying when they were, not having the information that they needed, not having their symptoms addressed, nevermind well managed, just not even addressed. And so being the zealots that we are, I’m sure that egged us on ’til, ‘We’ll go out and, you know, here’s another frontier!’ (I10, 358-365)

This need for justification was closely associated with a growing emphasis on quantification, “initially, the real feeling was [that] palliative care is about handholding and [that] there needed to be quantification” (I9, 310-311). One interviewee described the different emphases this way,

the ‘high road’ is the academic, the rigour, the drive to make better, and the low road...where the bowels are incontinent, where there is sweat and pain and suffering… what we need is people to be there is their hurting, in their time, in their whatever. And it’s always stuck with me, in this beautiful balance (I3, 525-533).
5.2.3) Bureaucratization

There was mention also that palliative care’s immersion in the medical system had resulted in its ongoing bureaucratization. From a beginning in which palliative care “wasn’t organized, it wasn’t institutionalized” (I9, 69) to a situation in which “palliative care has become much more bureaucratized” (I9, 93). Interviewees mentioned the relative ease with which some palliative care programs began,

in those days you could do that, make an appointment with the CEO…the whole of healthcare at the time I think was less bureaucratic than it is now, so we could do that, we could have a chat (I5, 41-46);

in that way that could happen in those days he talked to the university people and other doctors in the hospital and they cobbled together a salary – which was amazing – just over the phone (I5, 56-59);

He just asked if he [i.e. the doctor] could do that [start a hospital palliative care unit], and the hospital said yes. Just as simple as that… I found this very hard to believe, and I actually looked up the administration records three times to read it (I4, 26-31).

Another interviewee, reflecting on a past practice of ‘death review’ (i.e. where all staff together review the deaths occurring on the preceding day or shift), remarked that presently,

you have to justify that experience…all those people around the table – this is costing money, all those people here… whereas that was like a given [then], I’d taken it for granted for years (I8, 531-535).

Interviewees saw this bureaucratization resulting in part from financial, technological and institutional demands,

I ran a ward where there was one nurse for every two patients. And we complained there weren’t enough nurses at the time! And that didn’t include the nurses’ aides and the orderlies as well. And so as the complexity increased as we were spending more money on technology and a lot of other things that were helping people, then the personnel… and the wages went sky-high compared to what they were, then we had to make modifications (I6, 440-443);

hospital accreditation, university accreditation, medical school accreditation – it does change palliative care, it makes it much more, in some ways, subservient to what the
hospital needs are…you can’t just play out in left field anymore, you need to be integrated into the system (I6, 596-601).

One interviewee mentioned what he saw as a link between pressures to find funding and the need to quantify the benefits of palliative care, and worried that this had led at times to “treating [palliative care] more like a car factory than working with human beings” (I8, 351-352), and in the words of another,

in the early days your research was at the bedside, I mean, that was really all, and part of our knocking at healthcare’s door is saying, ‘This is how you have to care for all dying people,’ so they’re saying, ‘Well, why would we give you resources if you can’t demonstrate to us, or prove to us, that your approach is better than ours?’ (I10, 282-287)

5.2.4) Evaluating Medicalization

Though an estimation of this medicalization was unasked for, the interviewees spontaneously expressed judgments about the change, both for and against. Sometimes the judgments were favourable,

We are in a, particularly in healthcare, in a domain fortunately dominated by biomedical sciences (I7, 127-129);
more of this palliative care field – and certainly upstream palliative medicine – takes more scientific rigour to truly find drugs, methods of care, that will hold up to trials, will hold up to analysis, and therefore [will] have a degree of higher confidence than does anecdotal, experiential (I3, 189-194);
I know there are new formulations of drugs and certainly if there’s anything we can do to help people in that way we should do it, but it would become mainstream, which is probably what had happened, which is good in some ways (I5, 439-444).

There was even a certain sense of inevitability seen in the change,

I hear it sometimes on the board of the CHPCA [i.e. Canadian Hospice Palliative Care Association]…‘medicalization of death’, what the hell are you talking about? Dying is a responsibility for all of us and its not medicalized – a lot of it happens in the hospital which is a medical dominion (I6, 654-658).
Sometimes there appeared a sense that palliative care was finding a ‘middle ground’
between its early ‘high touch’ beginnings and its growing emphasis on ‘high tech’,
finding for example ways of giving parenteral fluids that were taken as being less
intrusive,

IV poles and machines beeping and monitoring, whereas hypodermoclysis [i.e.
subcutaneous fluid administration] was easier, you could put a bag of fluid
subcutaneously. So it was interesting how you kind of worked into a middle ground,
and certainly people like Eduardo Bruera in Edmonton were very early explorers of
technology, but in a way that perhaps would fit better in not being so high-tech in
that sense. So I think it has drawn itself into that field [i.e. technology], with some
pushback (I3, 153-159).

This same interviewee spoke of the two types or styles of palliative care – understood as
the holistic and the scientific – as each presenting a potential, problematic ‘slide’. The
idea seemed to be that only by combining the two could a balanced approach to palliative
care be reached,

Well, I think both of them are about the whole person, and in fact both of them can slide
a bit if you’re excluding the other, so the holistic, although altruistic, may wind up
missing things that really would provide comfort to that patient because you’re holding to
a philosophical view that says it shouldn’t be…And on the other part of that, you know,
the more scientific, the explorative part, can slide into research and medicine, and ‘we
need the next study and the next trial’, and it can slide into this more criticized medical
model. But palliative care, as it stands, is holistic even though there is a rigour to it. But I
think both of them have run risks of sliding. (I3, 200-212);

they [i.e. two types of palliative care] can’t diverge or it really falls apart, they can be
parallel but at some places the road has come together, or at least criss-cross from time to
time (I3, 544-546)

Another interviewee considered the tension between “good-old, left-brain, rational,
outcome-measurement-driven science” and “non-quantifiable domains” of human
existence to have been part of palliative care from the outset, and commented this way,

I think there should be a tension, I don’t have a problem with that, but I think we need to
pause and look at the significance of each of the parts and why there’s a tension, what are
the presuppositions about the human condition that biomedical sciences bring to our
understanding of suffering, and our understanding of not just dramatic suffering at the end of life but of any healthcare (I7, 254-260).

At other times the judgments were unfavourable (sometimes for and against in the same interview). The concerns expressed included the worry that medicalization interfered with whole-person care and the very fact of the person’s dying, or that it was unnatural, or that palliative care was becoming just another medical specialty. I have included a great number of these criticisms to give a sense of their scope:

the upstream or the more medical gets called, ‘That’s the medical model and the medical model’s terrible for the end of life, what we need is a holistic model that is all about the whole person (I3, 196-199);
there’s a lack of the balance between the broader vision of issues that underlie the non-quantifiable domains that we need to bring (I7, 240-242);
when you have the technology to focus on you don’t look at the demise (I2, 820-821);
the more less-invasive it was, the more natural…and nobody likes needles, and being tied to an IV-pole (I1, 38-43);
it can be a slippery slope, you know, because if ever the investigation [i.e. medical test] becomes its own reason – which I think is the risk – or the physician satisfying their curiosity becomes the reason, then I think you’re moving away from patient-centred care (I10, 254-258);
I wouldn’t want to see palliative care become another service and it may be becoming that (I5, 237-238);
I remember at an AGM talking about the mainstreaming of palliative care and how, you know, we’ve been knocking at the door of healthcare for years to recognize that there are better ways to care for people who are dying, that we did have things to offer them, we were value-added. And I could remember saying, ‘But you need to realize that sometimes you have to be careful what you ask for, and there will be a cost to us for this’ (I10, 313-321);
within hospice programs there was a fair amount of angst, ‘this is not who we are, this is not what we do, we shouldn’t be doing this,’ and so there was a bit of pushback (I3, 135-138).
5.3) Professionalization

“is hospice-palliative care within end-of-life care or is end-of-life care within hospice-palliative care?” (palliative care pioneer, interviewee)

Palliative care’s shared ideas and ways of behaving were described by the interviewees as changing. The picture that appeared was of an initial smaller, fledgling movement, ambiguously but inescapably related to medicine, which then grew and defined itself both in association with and in distinction from the rest of medicine. In particular the changes were seen in: scope, spirituality and professional identity of palliative care.

5.3.1) The Changing Scope of Palliative Care

The scope of palliative care was seen to have changed since its beginnings in Canada. For some, the size of palliative care was the most apparent change. In the beginning,

there were just a few physicians in Canada when I started to get involved in 1980 (I3, 14-15);
these little pockets of people trying to find their way to provide a different kind of care (I10, 22-23).

But by the later period,

the first thing that comes to mind is it’s bigger (I10, 9);
I think it has grown dramatically (I3, 11);
I think we’ve accomplished enormous…you know, I see the number of physicians who are now entering into palliative care, the nurses, I think that interprofessional piece, the university presence, the presence in medical schools, and we’ve got to be proud of what we’ve done (I6, 740-745).
Growing now perhaps to the point that “a hospital now would be embarrassed to say they didn’t have a palliative care team” (I5, 444-445).

But the scope of palliative care changed also in another sense in that it moved beyond its roots in care for the dying, particularly the dying oncology patient, into caring for a variety of patients. Palliative care began with a focus around the dying patient, especially those dying of oncological disease,

I think it was a very critical place to start in terms of those who were somewhat imminently dying. In fact it was really fairly close to death was a lot of the initial focus…from a societal, denial, the hesitancy of physicians to stop treating, and if they did stop treating then they weren’t visiting as much, there was this huge kind of hiatus. So I think that was the call from the medical angle, and Kubler-Ross and others were calling from a psychosocial about recognizing death and death-denying society, etc. So it started very much around that (I3, 35-38);

Certainly in the early days, in many places…[palliative care] was oncology (I5, 301-302).

Later it became less so. One interviewee noted, “whether you call it change or growth…phrases like…‘palliative care’ began to have a broader meaning” (I3, 67-69),

it was very focused on that [i.e. dying]…although I think we’ve perhaps gone away from those thanatology type things and now we’ve focused on the physical (I6, 126-128);

Sometimes this expansion was discussed with a concern for this overlooking, or straying from, the original sense of palliative care,

Now there’s non-oncology patients, that’s for sure… at times get asked to see other people who aren’t palliative at all, so there’ll be non-oncology palliative people with complex problems who need analgesia or something for nausea. And that can run us into some issues there in terms of how… what we feel we can do, and we modify the role we’re having depending on the issues for a patient… we just have to keep an eye on that, that we don’t stray too far from what we’re meant to be doing (I5, 303-308).

Other times the change was noted favourably, with the suggestion that such expansion was precisely where palliative care needed to go, “Where we need to make the gains are...
the non-cancer palliative care, but we’re starting to” (I6, 345-346). Whether seen favourably or not, the interviewees seemed to agree that palliative care moved beyond its original focus on the dying patient. This change was exemplified in the shift from calling the movement one of ‘hospice’ to calling it ‘palliative care’,

when [Balfour Mount] coined the phrase palliative care all of a sudden there was a new flavour to it, and I think that was part of that road to broadening the concept, even though it was still centred around death and dying (I3, 52-54).

Part of the change resulted from thoughts that,

when you hear about people in different places with pain not being addressed or other symptoms not being addressed, or whatever it might be, it’s hard not to think, ‘Well, we could help that’ (I10, 329-332);

Also I think we learned a lot about care of the dying, not just about death and dying, we learned a lot about effective management, pain control and nausea control and I think as we learned those things [i.e. symptom control] then it was kind of like, ‘Well, okay, we’re doing this pretty good job, you know, right at the end, the last few weeks or last month or two of life. Gosh, you know, these principles could well be, and in fact should well be, applied at an earlier point (I3, 72-76).

For some, the question that such change animates is something like, “is hospice-palliative care within end-of-life care or is end-of-life care within hospice-palliative care?” (I10, 322-324). This change of scope leaves too some ambivalence, 

I know there’s home care nurses and family docs and other people out there who know more about end-of-life care now than they ever did before and they’re doing really good care. So you know, I think mainstreaming always has a cost – you can’t be this nice little family. We were a little family unit in the beginning (I10, 608-614);

I think [palliative care’s] home is not only death and dying, I think its home is principles, and compassion being an example of that. So we are growing, we are expanding, very valuably so, but there are some principles to hold onto (I3, 420-423).
5.3.2) Declining Spirituality

Related to the initial focus of palliative care on dying was its relation to spirituality. The sense emerges from the interviewees that palliative care has become less spiritually focused overall. Certainly palliative care was seen as originally spiritual, particularly Christian,

initially there was a fair amount of Christian religion that permeated some of [palliative care] (I9, 242-243);
in the beginning everybody was Christian (I10, 462-463).

One interviewee recalled asking herself, “I started kind of thinking, ‘Oh Jeez, I don’t go to church…do I even fit in here?’” (I10, 464-466). Another discussed palliative care as part of his spiritual formation, giving as an example an instance the way in which a patient discussed her illness,

here this patient is teaching me that there’s a whole other language in which stewardship is lodged, and it’s the language of spirituality (I4, 839-841).

But the emphasis on spirituality declined, as plainly put by one interviewee, “it is less spiritual (I1, 210). Summarized by one interviewee,

the roots are, I mean, you know it was very Christian, and then that sort of changed. It became more secular I think” (I10, 468-470).

The secularization seems to have occurred in two senses, both as a dilution of the presence of institutionalized religion and also as a drift toward a more ambiguous, subjective sense of spirituality,

we were in a hospital that was distinctly a Catholic hospital at the time – it’s less so now (I4, 851-853);
it kind of became, well, spirituality is part of what everybody does (I10, 498-499);
[spirituality became] more private for the individual (I1);
it felt to me like this inclusive milieu of everybody has spirituality that religion was lost (I10, 509-511).
5.3.3) The Changing Identity of Palliative Care

Apparent in these changes in scope and spirituality is a change in the identity of palliative care. In one sense, this could be seen as self-identity and in another sense identity as a relation with conventional medicine. Considering first self-identity, according to the interviewees, palliative care acquired knowledge and expertise, began to teach others, and became a specialty. The expansion of knowledge and expertise (see also medicalization) is the sort of thing that might be summed up in the words of one interviewee as

palliative care was almost, like, stereotyped as hand-holding and praying an it’s [now] much more than that, and we’ve learned that over the years (I8, 297-299).

Research was also an important part of this change in palliative care. Where initially, “there was almost no research, the research was all thanatology-based and descriptive” (I6, 614-616), there appeared a change over time,

That’s the other thing that’s really grown in this field of palliative care, is the research. I mean, there’s just much more research to know about, you know, what is the experience like for individuals and families, and what is our best way of providing that care (I8, 88-92).

The result, from this interviewee’s perspective was that, “I think we do feel a little more confident and feel that we’re getting a little more recognition” (I8, 130-132). And with this knowledge and confidence came more education,

I think we’ve done a lot over the years to educate many…having some exposure in all the medical schools, having just different nursing, social work, we’re all working towards having more input at those levels (I8, 431-436).

There has also come specialization, “palliative care is flirting with specialty and so it’s progressed in that manner” (I8, 146-147).
Considering palliative care’s identity in relation to conventional medicine, the interviewees describe a gradual loss of antagonism and growth of respect. One of the issues to begin with was whether there was recognition of palliative care at all,

In the early years they had no idea. They’d say, ‘What is it? What are you talking about?’ (I5, 530-532);

certainly, not having credibility, I think, was very big for physicians in the beginning, you know, how they were viewed by their colleagues (I10, 43-45).

Early palliative care, in finding a place alongside medicine could also at times be critical of it,

a lot of the thanatology stuff [in early palliative care]…was blaming versus helping (I6, 334-335);

it was really antagonistic. I mean, as I said, we were the white knight guys, and we thought everybody else was wrong. And it was a positioning sort of piece, at that point you had to stand up for yourself, but in standing up for yourself you sometimes made enemies (I6, 296-300).

At times interviewees used metaphors of competition,

we had to fight for that [i.e. recognition], you see, that’s what the fight was (I2, 458-459);

what were [the early practitioners] fighting? Just opinion, like the opinion of other physicians (I10, 39-40);

some people were kind of wary of us, as to what it was we were going to do (I5, 137-138).

Other times the interviewees used metaphors of battle,

sometimes we had to nudge people…you have to kind of ‘win the battle’ or what’s the expression, ‘lose the battle to win the war’(I5, 142-148);

my phrase has always been that good palliative care was good guerrilla warfare, where you infiltrated [the rest of medicine] (I6, 315-316).

And also metaphors of infection,

from the very first part of our mandate in our program…was to infect healthcare through the hospital, and was to be jousting for funding and beds and nurses with the head of the cardiac intensive care unit and the medical and surgical intensive care units. That was not an easy task, and it wasn’t one of those occasions where everything you did won friends
and influenced people. But part of the rationale was to do that, from the first. (I7, 299-306)

And even one interviewee, noting that the reception in her hospital was good, still felt the need to add, “we didn’t have the [difficulties], some centres I know…we would we’d hear of the difficulties they encountered” (I5, 164-166).

But over time recognition of palliative care grew, and conventional medicine and palliative care moved through an initial oppositional period into a more collegial relationship.

so we’ve gone from probably not being recognized to being recognized (I8, 170-171);
I think now people know palliative care exists, that’s for sure. (I5, 215-216).

It seemed to some that “what we found was we had neglected our colleagues” (I6, 307), so that “we learned to partner and collaborate and to understand where other people were coming from” (I6, 329-330), and “other parts of the healthcare field and the medical field, they began to welcome that you can perhaps work a little more alongside me” (I3, 142-144). One interviewee recalled a great drop in referrals to palliative care between the first and second years in a particular hospital, and realized that the palliative care service had alienated itself from other medical practitioners by being overly critical and antagonistic towards the rest of medicine,

We came in as saying, “You guys are doing things wrong. This is the right way.” The nurses wouldn’t refer to us because we just kept haranguing them around not giving the medication every four hours and that kind of stuff, you know? So we learned a lesson that when you’re trying to break down some of the walls you don’t try to run into the wall, you try to pull the bricks out from the bottom (I6, 308-316).

From uncertainty to acceptance, and even to influence,

we weren’t always popular with people…people look upon you as rather weird…[but later] I think that we weren’t thought of as weird, like we were when I first went there. It seemed to be – maybe it was just me – but that we were felt a little apart and not valued.
By the time, as the years went by we were valued and thought well of (I1, 184-189, 621-624);

It’s very different now, and very... you know, I walk into the elevators now and people greet me like they don’t see me enough, what am I doing, your service is doing really great, etc. (I6, 347-351);

I think the thing that palliative care has brought to the system is the goals of care. By speaking about that, I think we’ve revolutionized [the rest of medicine]. I hear other people now talking about that, even in tumour boards and stuff like that, ‘Well, what are the goals of care? What are we trying to do with somebody?’ and giving them more options for treatment (I6, 467-473).

5.4) Stasis – Interprofessionalism and Goals

“I think the purpose, quite altruistically, has always been to try to find the best ways to help people to be comfortable in the least intrusive way” (palliative care pioneer, interviewee)

The literature review and textual analysis intimated the themes of change seen above, but they also suggested other themes of change that did not appear in the opinions of interviewees. In particular, the notion of interprofessional care (e.g. role blurring) and the goals of palliative care were seen by the interviewees to have remained relatively constant.

5.4.1) Interprofessionalism

Interprofessional collaboration seems to have been and continues to be an important part of palliative care. One interviewer conveyed several stories describing the manner in which palliative care was in this way unlike the rest of medicine at the time, and in some of her stories it is notable that the nurse and nurse’s aides are the one to offer reminders of the importance of interprofessionalism (I1, 23-32; I1, 76-84; I1, 378-381). Some interviewees suggested that palliative care was somewhat less or more
interprofessional than originally, but did not do so with much conviction. For example, one interviewee said, “I think how we function together in the various aspects of teams, I don’t think that’s changed a lot” (I8, 40-41), but noted simultaneously that as a whole, palliative care is “more integrated, it’s much more collaborative, it much more holistic than it has ever been” (I8, 18-20). Another considered things this way,

So there’s been that kind of a shift and, you know, part of that is you kind of evolve as a team, and people get better at articulating what it is that they do, and understanding what one another does, so I think that’s made a difference. I think, you know, we’ve done a lot of work nationally in terms of advocating for different professions, and so there’s just a, maybe, a bit more inclusive environment…so it’s changed but it hasn’t changed, maybe. (I10, 91-117)

Regarding the so-called role blurring there was little sense of change, “we probably did [role blur]. We probably still do” (I5, 264-266), and “there’s this great difficulty with role blurring, and to some extent that continues” (I9, 152-153).

And yet, while there was no real suggestion that palliative care has become less interprofessional (to the contrary according to some), there was a sense from some of the interviewees that the tone of collaboration had changed. There did appear in the interviews a sense that the person-to-person relationship between colleagues changed.

Said one interviewee,

And when I visit with the staff, they say ‘Oh [interviewee’s name], it wasn’t like it was,’ and I say ‘What do you mean?’ – because I thought working like that would go on forever. It’s working as a team, questioning each other, laughing with each other. (I1, 43-47);

Wouldn’t you rather have somebody you work with tease you occasionally and treat you like a human being than salute you when you came in? I mean, I was trained in the days when if a senior nurse was coming from the elevator she’d have to go in before you. And the doctor, if a doctor came into the conference room, or the chart room, you’d stand up. Oh my, I’m glad that went out with high-buttoned shoes! (I1, 654-661)
5.4.2 Goals of Palliative Care

The goals of palliative care were seen to have remained the same, even in cases where a tension between the early and late styles of palliative care was remarked upon, Are there different goals? I think the overarching goal has always been comfort and support, and so... and compassion. I’ve always viewed and taught that in fact the most overarching is compassion, that we’re there to help as we can in whatever way will help, and so if we have an overarching compassion about caring for people I think that sits in both those... I don’t like to call them camps, but I think it’s ways of looking at care towards the end of life. (I3, 180-182);
compassion was the most powerful piece of philosophy that got this whole thing going. And it must continue to be in the programs, in the objectives, in the vision, the strategies, the budgeting. And as it slides its way out ...[quoting an article] “How far can a palliative program move upstream without losing its home?” (I3, 415-419);
I don’t think the sense of mission was any different [earlier to later], other than to make things better for dying patients in an institution (I6, 101-103);
I’d say no, I think we’re doing the same thing (I8, 422-423);
I think the purpose, quite altruistically, has always been to try to find the best ways to help people to be comfortable in the least intrusive way (I3, 146-149).

5.5 Summary of Interview Results

In the opinion of the experienced practitioners interviewed, palliative care in Canada has undergone changes, which I have collected under the terms routinization, medicalization, and professionalization. Palliative care developed from a smaller, informal, more spiritual, high-touch movement focused on caring for the dying into a larger, more clinical, medical specialty aspiring to provide palliation to a broad scope of patients.
5.4.1) Routinization

The practice of palliative care arose in response to the perceived needs of the dying and drew to it highly committed practitioners and volunteers hoping to address these needs. In the early days of palliative care most practitioners began with little direct experience in palliative care, and there was little clinical knowledge or interventions available. Spirituality was important to palliative care as an aid to understanding the place of death in life. The practice had not become formalized, and creativity and warmth and sharing time were valued in the relationship between patient and practitioner. Over time clinical knowledge grew, allowing for more and better symptom treatment. Spirituality receded in importance and became regarded sometimes more as a mode of therapeutic intervention than a life understanding. Visits between patient and practitioner became more expedient and focused on symptom control, leading some to question whether something of the ‘patient-centred approach’ of the early days had been lost along the way.

5.4.2) Medicalization

The idea of medicalization appeared in terms of mainstreaming or upstreaming as well as medicalization. With medicalization came a demand for scientific or evidence-based justification of interventions, something that was always a part of palliative care but later much more so. Such justification was accompanied by quantification of many aspects of care and a shifted focus onto the outcomes of intervention. The growth in scope and knowledge and the need to justify treatments clinically or economically were also part of an ongoing bureaucratization of palliative care.
5.4.3) Professionalization

The profession of palliative also changed from its early to late period in scope, self-identity and relation to medicine. As palliative care developed from a small movement to a much larger medical specialty, along the way it brought its knowledge in symptom treatment to a broader range of patients. It no longer focused so exclusively on the dying but began to provide care to those patients that might benefit from palliation, and with this shift from dying and death came also the reduced emphasis on spirituality, being as it was initially so tied with questions of mortality. With the gain in clinical knowledge came more emphasis on research and teaching and an eventual move toward recognition as a medical specialty. The relationship with medicine moved from an initially antagonistic one into a more collegial and mutually-respecting one.

5.4.4) Stasis

In two areas – interprofessionalism and the goals of palliative care – the interviewees expressed no processes of change.

The interview analysis agrees in many regards with the preceding historical and textual analysis. Within a centuries-long rationalization of dying and death, palliative care appeared initially as a rejection of the rationalized medical domain, but in time adopted aspects of that domain. The interview analysis suggests that in Canada, as elsewhere, palliative care has undergone a rationalization. In the Discussion chapter I will consider this process, introducing an understanding of rationalization, and proposing a revised palliative care ethics.
Chapter 6: Discussion

At the core, the response of this thesis to the questions of whether palliative care has changed is that it has undergone a rationalization. Intimations of this response appear in the Background reviews, and they are developed further through the textual and interview analysis.

This idea that palliative care has undergone and is undergoing rationalization first appeared in the literature only two decades after palliative care began, and within a few years it became an established debate. This thesis adds two new facets to that debate. The first facet has already been suggested and will be developed further in this chapter. That is, this thesis provides evidence that a rationalization of palliative care has occurred in the Canadian context, something suspected or assumed by some, but unsupported by data. Canadian palliative care developed from a smaller, informal, more spiritual, ‘high-touch’ movement focused on caring for the dying; to a larger, more clinical, ‘high-tech’, medical specialty aspiring to provide palliation to a broad scope of patients. The second facet, also discussed below, is a consideration of the ethics of palliative care and a reframing of this ethics based on these considerations.

The discussion is organized under the following headings:

6.1) The Change in Canadian Palliative Care
6.2) The Rationalization of Canadian Palliative Care Ethics
6.3) The Debate on the Rationalization of Palliative Care
6.4) Considering the Thesis Results – Rationalization and Palliative Care Ethics
6.1) The Change in Canadian Palliative Care

“Individual grass roots initiatives...have gradually evolved into a cohesive movement that aims to relieve suffering and improve quality of life for those who are living with or dying from an illness” (CHPCA, 2002)

In order to lay the ground for the following sections, which focus on palliative care ethics in particular, this section will summarize the processes of change as they appeared in the results. The summary will be purposefully brief and directed.

As indicated in the Methods section, when we consider the way Canadian palliative care in general has changed since its beginnings, we can discern two periods, an early and a late period. The early period comprises roughly the first fifteen years (i.e. approximately mid 1970s to early 1990s), and the later period comprises roughly the past fifteen years (i.e. approximately the late 1990s to 2010s). These periods lie on either side of an apparent watershed period (i.e. the 1990s) that coincides with the beginnings in literature of an ongoing debate about what palliative care is and what it should be. Comparison of these early and late periods suggested changes that I believe are best understood under the processes of routinization, medicalization, and professionalization.

6.1.1) Routinization.

As seen in the Results section, routinization refers to a formalization of care that was earlier based on more informal, intuitive and ad hoc approaches. These changes in palliative care practice appear as a diminishment in some aspects of care and an emphasis on others. The intensity of early palliative care – the volunteering, sacrificing, and struggle to improve care for the dying – diminished with time, and care became more routine, more of a career and less of a calling. The phrase ‘patient-centered’ initially
included the notion that the patient and the practitioner should relate as fellows contending with mortality, but later the phrase became more wholly clinical, focusing on the therapeutic relationship, therein also emphasizing the autonomy of the patient to direct their own care. The few persons who practiced palliative care early were creative and flexible in their approach to care, willing to make accommodations that sometimes contended with the medical and hospital environments – accommodations less common in the later period. The initial worry over institutional ‘depersonalization’ receded in palliative care. Spirituality moved from the centre to the margins, from something shared to a therapeutic option. The relationship between practitioner and patient became codified somewhat in the later period, with clearer boundaries, and sometimes with more of an algorithmic or ‘checklist’ approach, and overall came to possess a more contractual form, what for some resulted in the feeling that care had become ‘expedited’.

6.1.2) Medicalization

Closely related to routinization is the increased use of medical interventions and medical understandings in palliative care. Many more medical treatments became available over time, both those aimed at the disease and those aimed at symptoms, and the need for doctors to prescribe and nurses to enact these treatments helped to reassert the traditional hierarchy of medicine. The focus of later palliative care on symptom-control was associated with a shift from treating primarily dying oncology patients to treating symptoms wherever they might occur – such as earlier in disease, in other diseases, and occasionally in patients expected to survive their disease. There appeared increasing emphasis on research, and together with new therapies, this encouraged
quantification of symptoms and care. There also appeared an expectation that care needed more justification (i.e. therapeutic and economic justification), and that this justification should be primarily quantitative. Palliative care began an ongoing conciliation with the rest of medicine, and it also began to adopt the bureaucratic structure of this medicine.

6.1.3) Professionalization.

Both on an individual level for the practitioners, and on a larger level for palliative care in general, the later period became more professionalized. Routinization and medicalization led practitioners to identify more closely with traditional professions then they had done initially (i.e. nurses, doctors, social workers, etc.), and encouraged their self-identification as medical practitioners of palliative care. The early role of volunteers, which was as equal and essential members of teams, receded from prominence and became more of an optional addition to accepted ‘required’ services. There appeared more and more standards to direct the actions of practitioners. And as palliative care began the slow development toward specialty, there appeared the expectation that palliative care programs should conform in their operation to some overarching conception of palliative care.

These changes, in the manner in which care is given (i.e. routinization), the understandings underlying that care (i.e. medicalization), and the self-consciousness of those providing that care (i.e. professionalism), have been accompanied by a change in the ethics of that care as well. Hypothesizing the possible reasons for all of these changes
lies outside the scope of this thesis, but they are likely to be multiple, both internal and
external to palliative care, and to have occurred on many levels. The focus here and in the
next section on palliative care ethics is to develop a picture of the change that has
occurred, using the themes developed during analysis.

6.2) The Rationalization of Canadian Palliative Care Ethics

“There is a danger of goal displacement, with the core goal of effective, humane care of
dying people in danger of being partially displaced by other activities which were
initially subsidiary to this goal” (James and Field, 1992, p.1372).

The data suggests that palliative care ethics has changed along with the rest of
palliative care, meaning specifically that, associated with the routinization,
medicalization and professionalization of palliative care, have come changes in the goals
inherent to these palliative ethics. As I suggested in the Methods section, the ethical
instances that constitute the data for this thesis are diverse in form and topic and context,
and so I have chosen to focus in particular on the goals of palliative care. There are other
ways to consider the ethics of a practice, but the question of goals is a deeply
fundamental one.

On first glance it would seem that the overall goal has always been patient well-
being, but I think there are important changes in the way this well-being has been
understood – for instance, in what this well-being is thought to entail; in the way
palliative care should be given; and in ideas about who should receive palliative care. It is
in this sort of manner that, although the interview results do not show a change in the
overall (general) goal of palliative care toward patient well-being, they do show changes
in the (particular) understanding of what such well-being entails. In this section, I will consider the goals of the early and late periods, and highlight the differences between them.

6.2.1) The Goals of Early Palliative Care

The goals of early palliative care were several. The secondary literature, the texts, and the interviews paint a picture of the mid-twentieth century in which the dying were suffering not only from symptoms related to their disease, but also from a complicated abandonment. On the one hand, the support and meaning earlier provided by community was less. Society had become more individualistic and fragmented, and religious structures in particular had declined in influence. On the other hand, the biomedical understandings and structures that had to some degree taken the place of those of community and religion were focused on cure, and often had little to offer the dying. Palliative care arose as a response to the problems of dying and suffering and abandonment entailed in this predicament.

I believe that the goals of early palliative care in responding to this suffering and abandonment of dying patients should be understood using concepts of palliation, presence, and meaning – goals that interrelate, but are also somewhat distinct from one another.

From the start, one of the hopes of palliative care was to develop therapeutic means to palliate the suffering of dying. Palliation included efforts to treat physical symptoms such as pain, nausea and breathlessness, but also efforts to treat psychological symptoms such as anxiety and depression. There were also other sufferings experienced
by dying patients – such as loneliness, fear, sadness, hopelessness, and meaninglessness – that were seen as being less clinical in nature. In response to these other sufferings, palliative care sought to provide presence and meaning. Presence in this sense meant listening to the patient without necessarily seeking to treat but simply to accompany, it meant developing a relationship with the patient built on understanding her or him, it meant caring for the patient almost unconditionally. Meaning meant giving patients support to develop or deepen an understanding of the detail and worth of their lives, and it meant finding a way to accept dying and death as part of that life, often through spiritual or existential understandings.

These can be considered the goals of early palliative care, the particular way that palliative care sought to improve the living and dying of patients. There were also other goals instrumental to these ends, such as research, expansion of palliative care services, and the creation of a profession of palliative care for disciplines such as medicine, nursing and counselling. These goals themselves contained further instrumental goals such as efficiency and standardization that were important, but, in early palliative care, were weighed against their potential detrimental effects on the main goals of palliation, presence and meaning. There remained concern about the possible threat to authentic human relationships that efficiency and standardization presented. In the texts and interviews, none of this was explicitly understood or expressed in terms of ethical theory or the structure of palliative care ethics. Instead, in early palliative care the understanding of ethics was intuitive, informal.

Together the goals of early palliative care form part of what I will call ‘care-for ethics’, in the sense that practicing palliative care was constituted by a caring of concern,
warmth and humanity. In care-for ethics, the overarching goal of patient well-being is understood as the pursuit of *palliation, presence* and *meaning* for dying patients.

6.2.2) *The Goals of Later Palliative Care*

Later palliative care ethics differs from early palliative care in its understanding of patient well-being, and in the hierarchy of its goals. Early palliative care implicitly assumed that patients suffered not only because of physical symptoms, but also from the consequences of a societal abandonment, but later palliative care left more open the understanding of what might be causing patients’ suffering. Later palliative care thus moved away from the initial somewhat ‘objective’ understanding of patient well-being (i.e. that all patients require *palliation, presence* and *meaning*) toward a more ‘subjective’ one (i.e. that what patients require will differ from one to the next, depending thus on their perspective), often under the phrase ‘quality of life’. In this understanding the patient is seen as best situated to choose among the courses of action that might improve or least damage his or her well-being.

From the results, I think this subjectification of well-being is also closely associated with two other broad changes in palliative care. The first is the expansion of palliative care to patients not imminently dying, such as those earlier in the course of a fatal disease, or those with a ‘life-threatening disease’ (as opposed to a frankly terminal disease), and even those with symptoms stemming from treatable conditions or conditions of ambiguous etiology (e.g. chronic pain). In these situations, providing *presence* to such patients (who might not feel abandoned), or helping them find *meaning* (especially meaning in their mortality), might seem either paternalistic or inappropriate.
The second change is the rise of bioethics and the concepts of autonomy, which promoted the idea that patients should determine what would be best for them, and that others, including professionals should serve more to advise than direct.

Of the early goals, palliation remains then as the only assumed goal inherent to patient well-being. Where initially the patient’s well-being was to be pursued by providing palliation, presence and meaning in the face of suffering, now quality of life (i.e. well-being as determined by the patient) was to be pursued more directly through the palliation of suffering, especially palliation of physical suffering. The medicalization of palliative care facilitated this more clinical sense of palliation, resulting both in an emphasis on the palliation of physical symptoms and a move to view most practitioner-patient interactions as therapeutic in intent, rather than viewing these interactions sometimes as a shared experience of mortality. For example, a patient’s anxiety toward dying and death became more likely to prompt a therapeutic intervention aimed directly at lessening that anxiety (often pharmacologically) rather than necessarily including efforts to confront or accept dying and death (which might sometimes continue or deepen the patient’s anxiety even while promoting a deeper life understanding). The other goals of presence and meaning have remained available and sometimes important, but they have become optional, to be included as directed by the patient (given the abilities of the practitioners available). So, notions of steering patients toward death acceptance, or the valuation of relationship between patient and practitioner, have become instrumental to the goal of palliation and best quality of life.

There seems also to have been a partial inversion of the hierarchy of goals. Where the goals of research, expansion, and the creation of a profession, were in early palliative
care more clearly instrumental to the goals of palliation, or presence, or meaning – in later palliative care this became less clearly so. These goals seem to acquire more intrinsic worth, and other goals in turn associated with these, such as efficiency and standardization, also began to acquire more intrinsic worth. At the least, these goals are later sometimes presented as being important in themselves without any explicit justificatory link being made to presence, meaning, or even palliation (and quality of life).

Taken together, this later palliative care ethics can be considered ‘care-of ethics’, in the sense that care is taken to mean the management of the patient (especially management of the patient’s symptoms). And while later palliative care has become more explicit in its considerations of ethics overall, in the texts and interviews such discussion of goals was still conveyed indirectly, and appeared only with analysis.

6.3) The Debate on the Rationalization of Palliative Care

“There have been substantial achievements and significant benefits from the medicalization of death, but also unnecessary suffering and psychological harm of patients and those close to them...Thus, it is not surprising that the emergence of palliative medicine should have been greeted with ambivalence and concern by non-medical workers.”(Field, 1994)

My understanding of Canadian palliative care, as presented in this thesis, is that it has undergone changes of routinization, medicalization, and professionalization. The original questions of this thesis, the methods, and the analysis that led to this conclusion were influenced by existing discussions in the literature on rationalization in Western society and rationalization in palliative care. But I first encountered similar discussions in
clinical practice, where it seemed to me that two understandings of palliative care supported yet contended with one another. An earlier, more humanistic, more earnestly emotional palliative care that emphasized the importance of relationship existed alongside a later, more clinical, more formalized palliative care that emphasized the importance of therapeutic skill.

In exploring the history and sociology of the changes of dying in the West, I found ideas that seemed to cleave together under the idea of ‘rationalization’. The history of dying in Western society showed a prolonged background of rationalization, and the descriptive literature on palliative care likewise described a rationalization of palliative care (after an initial flourish against early twentieth century biomedicine). And in addition to these assessments of rationalization, I also found an evaluative debate on the rationalization of palliative care, which drew from concepts of rationalization by German sociologist Max Weber and related sociological considerations of medical rationalization. This evaluative debate about the rationalization of palliative care is a debate that is uniform in its presumption that palliative care has undergone some sort of rationalization, and it focuses on evaluating these changes, in most instances suggesting that there is something troubling about them.

Primed with these notions of rationalization, I found on an initial analysis of the texts a vague tension, or polarity. In both the early and later periods, underlying the pervasive and overt concern for the well-being of patients, there appeared divergent emphases on the more qualitative versus the more quantitative aspects of palliative care. This polarity seemed to fit quite reasonably into the existing discussions on rationalization mentioned above. The themes that I ultimately employed (i.e.
routinization, medicalization and professionalization) are mentioned throughout the above-mentioned discussions on rationalization of dying and palliative care, both in the more general descriptive literature and in the more specific evaluative literature.

I believe that this thesis adds several things to those discussions on the rationalization of palliative care. It provides a more nuanced view of Canadian palliative care than do existing discussions; it is able to contribute to the evaluative debate on the rationalization of palliative care; and it is able to suggest a way to reconsider the ethics of palliative care. I have elaborated already on the first contribution, and later I will focus on the other two. But first in this section, in order to show the foundation upon which this thesis is built, I will attempt to make clear the sociological foundations and evaluative position of the literature’s debate on the rationalization of palliative care.

6.3.1) Rationalization and Medicalization

The understanding of rationalization that the literature on palliative care employs makes reference to the literature of sociology and social theory, especially those perspectives with roots in the work of Max Weber. Rationalization, as the spread of means-end deliberative thinking into areas of life previously reliant on tradition for direction, was understood by Weber as a key element in the modernization of Western society. His conception was descriptive and analytic but also evaluative in a way that continues to resonate. Weber saw in rationality great possibility, but he saw also a perniciousness. The loss of the ‘enchantment’ of the world that myth and religion provided, and the ‘iron cage’ that rationalized bureaucracy threatened, were to him both deeply troubling. As I will discuss later, both these descriptive and evaluative senses in
Weber’s thinking on rationalization carry through into the debate on the rationalization of palliative care.

Weber saw practical rationality as deliberation that develops “the standards according to which acting subjects learn to control their environments” (Habermas, 1984, p.168), standards that are part of almost all modern fields and endeavours. Rationality can be considered as it animates the deepest layers of modernity in the state and the market (particularly its capitalist manifestations), in the middle layers as the particular instantiations of the state and market in existing societies, or at the layer of institutions and attitudes, these being the level of “structures of consciousness that find expression…directly in actions and forms of life” (Habermas, 1984, p.174). It is the third level with which the palliative care literature deals. At this level, rationality comprises according to Weber’s thinking, instrumental rationality, rationality of choice, and value rationality. Instrumental rationality refers to means-ends rationality as considerations of which means best achieve a chosen end. Rationality of choice refers to the selection of goals, “not blindly controlled by affects or guided by sheer tradition…[but]…inferred in view of given preferences, means, and boundary conditions” (Habermas, 1984, pp.170-171). And value rationality refers to underlying values by which choices can be made, or by which rationality of choice can be exercised. In this sense, rationality of choice appears as choices that can be shown to appeal to these ‘first principles’ of values, and irrationality appears as choices that conflict with these deep commitments.

In the literature on the rationalization of palliative care, the references to Weber’s ideas focus often on the play in the process of rationalization between charismatic and bureaucratic organization. Typically such literature frames the beginning of palliative
care as rooted in charismatic leadership, a leadership able to break up rationalized areas of life and introduce novel attitudes, understandings, ideals of action, goals, and so forth – the introduction of a new discourse or paradigm. In this thesis I was particularly interested in the goals of palliative care, and what a rationalization might mean for such goals. And from this perspective, the starting point for the literature on rationalization is the point at which palliative care, led by early pioneers, challenged the existing discourses of biomedical care. Using Weber’s ideas of rationality, we could say that in rationality of choice and value rationality there were substantive changes. Suddenly, normative appeals were being made to a new set of underlying values, most strikingly to the value of care in place of cure. This in turn meant that through rationality of choice, new attitudes and actions and goals began to displace former ones, so that the established ways of proceeding – the formalized results of instrumental rationality – were disrupted and were reconceived.

The literature also focuses on the ensuing operational and organizational rationalization that often follows charismatic leadership. Though I have collected the discussions of the literature on palliative care under the broad notion of rationalization, other terms such as medicalization, professionalization, routinization and bureaucratization are used as more specific instances of this rationalization. The terms are variously understood simultaneously, or as associated, or inter-related as parts or causes (Conrad, 1992; Williams and Calnan, 1996; Clark and Seymour, 1999; Sadler, Jotterand, Craddock Lee, and Inrig, 2009).

Medicalization especially has been the subject of an ongoing discussion in the medical sociology literature, and though much of it concerns areas outside the scope of
this thesis, the overall shape of that discussion informs the shape of the discussion regarding the rationalization of palliative care. Medicalization has been defined as the understanding, discussing, or managing of an area of life in medical ways, using the terms, frameworks, and interventions of medicine (Conrad, 2005). While this concept could be used in a primarily descriptive way – describing various conceptual, institutional or interactional changes – the concept began and continues as a highly evaluative concept, used almost exclusively in a critical sense (Conrad, 1992; Sadler, Jotterand, Craddock Lee, and Inrig, 2009). The suggestion that an area of life has become medicalized is usually entwined with concern, and with ideas for disrupting or decreasing such medicalization. The concerns over medicalization collect around fears of misplaced or illegitimate social control (Williams and Calnan, 1996; Strong, 1979), or the depersonalization possible in a “centralized bureaucratized and soulless hospital service” (Horobin, 1975), or the manner in which medicalization “individualizes what might be otherwise seen as collective social problems” (Conrad, 2005, p224), or the charge that emotional and physical well-being are jeopardized by medicalization (Illich, 1975).

6.3.2) Palliative care

In the writings on the rationalization of palliative care, these sociological writings on medicalization accent ideas of rationalization deriving from Weber’s work. The picture is presented of an established discourse of biomedical treatment, initially disrupted by the new values of palliative care that themselves then soon solidify into a new discourse – the cumulative effect of instrumental rationality working with the values of the new discourse.
In these writings, palliative care is often presented as eventually neglecting or deforming fundamental values of care and healing with which it began (Kearney, 1992; James and Field, 1992; Bradshaw 1996; Clark and Seymour, 1995, Floriani and Schramm, 2012). The idea seems to be that despite the acknowledged advances of palliative care – in the range of patients treated, in the increased number of patients treated, in the discovery and provision of improved symptom control, and in the strengthened position of palliative care in the medical world – that something has been lost along the way. In a paper of reckoning, Doyle suggests that, alongside the gains it had achieved, palliative care is at risk of losing its ‘uniqueness’ – that is, its acceptance of death, its acknowledgment of life’s uncertainties, and its commitment to truth, honesty, compassion and the dignity of each person (Doyle, 2003). Thoughts of the sort of foundation that has been lost include a loss of human connection between the practitioner and patient (James and Field, 1992; McNamara, 1994), a loss of the ability to find value and healing in suffering (Kearney, 1992), a loss of creativity and flexibility in care (Tehan, 1985; James and Field, 1992; McNamara, Waddell, and Coven, 1994), a loss of the ideals of the good death (Bradshaw, 1996), and a loss of a sense of urgency or calling (Bradshaw, 1996; James and Field, 1992). While the list of features is long and abstract, the tone is clear with which these papers warn against palliative care’s corruption.

Some of the results of this thesis agree with the literature’s description of the changes occurring under rationalization. This description include palliative care’s adoption of the biomedical discourse, whose emphasis on cure (e.g. in the new therapeutic guise of symptom control and psychological technique) returns to usurp the original palliative goals of care, and whose more antagonist attitude toward death returns
to challenge the palliative effort to normalize death. And they include the rise of a new, ‘palliative’ formalization of ideas and goals and norms seen in the growth of standards, guidelines, a research imperative, aspirations to ‘hard’ clinical skills and knowledge, and an overall emphasis on quantification. In addition, the literature also suggests that the notion of ‘the good death’ – which is one that occurs with little pain, in accordance with the patient’s wishes, at home, with acceptance, with personal conflicts resolved, and seen as part of the patient’s personal growth (Clark, 2002) – a notion so integral to early hospice, later becomes itself paternalistic and dogmatic (McNamara, Waddell, and Coven, 1994; Floriani and Schramm, 2012). This ideal of the good death is seen as promoting at times a sort of quantitative ‘scorekeeping’ (e.g. using standards and evaluation), and as encouraging an overly rigid understanding of palliative care.

These literatures present a certain picture and pose certain evaluation questions. Grounded in Weber’s ideas of rationalization and influenced by the discussions in medical sociology on medicalization, the debate on the rationalization of palliative care becomes primarily an evaluative, ethical one. A key concern animating this debate is the evaluation of this rationalization, and the corresponding definitions, and future directions, of palliative care. To this fundamental question, I believe this thesis has something to offer, something to which I will now turn to in the following section.

6.4) Considering the Thesis Results

“We saw there were people that were not well cared for” (interviewee, on early motivations).
The debate on the rationalization of palliative care draws implicitly and explicitly from sociology and medical sociology in a descriptive, analytical sense, and also in an evaluative, ethical sense. This thesis engages both senses, but recognizes that the heart of the debate is the ethical one. This section will expand on some of the descriptive features introduced above, and use these features to introduce an ethical reconsideration of palliative care.

6.4.1) Descriptive Ethics

In a descriptive sense, I have suggested that the thesis results describe a change in Canadian palliative care that can be understood as a rationalization. The existing literature on palliative care proposes that such a rationalization has taken place, but it does not focus specifically on palliative care ethics.

Above, I introduced a way of viewing the changes in Canadian palliative care ethics as a shift in the goals of palliative care. In this understanding, the goals of palliative care initially included the goals of *palliation, meaning* and *presence* – ‘care-for ethics’. These goals developed in response to the perceived needs of suffering, abandoned, dying patients. Over time the goals shifted toward an emphasis on *palliation* with an accompanying de-emphasis on *presence* and *meaning* – ‘care-of ethics’. In this care-of ethics, the goals of palliative care narrowed between the early and late periods to become primarily a response to suffering, especially physical suffering. Care-for ethics is concerned with providing humane care, built on a relationship between the practitioner and patient, which attempts to provide physical, emotional and spiritual support for dying patients. Care-of ethics is concerned with providing broad palliation, both in the sense of
types and numbers of patients treated, and in the sense of being primarily therapeutic in its outlook (i.e. as understanding interactions between patients and practitioners as aiming toward treatment), favouring a more clinical, contractual, medical relationship between the practitioner and patient. The rationalization of palliative care ethics then, can be understood as a shift in emphasis from care-for to care-of ethics. The shift is distinct enough to be visible, but it is best seen as continually partial. In the early and late periods I found elements of both care-for and care-of ethics. Because of this overlap, the goals of palliative care are perhaps best viewed as a continuum, with complete care-for ethics on one end and complete care-of ethics on the other. At any time, palliative has existed somewhere between these two poles.

Palliative care contains within it a tension between these discourses of care-for and care-of ethics. This tension suggests to me a deeper contention about the very definition of palliative care, for these discourses carry different ideas of who should be cared for and in the manner in which they should be cared for. Care-for ethics grew from a drive to care for the dying. During the rationalization of palliative care, in which time ‘end-of-life care’ moved from being the whole of palliative care to being a part, care-of ethics developed in response the new, broader mandates of palliative care toward patients other than those imminently dying. And so, evaluating the rationalization of palliative care also means to me considering how far palliative care can move from the original care-for ethics of *palliation, presence* and *meaning*, which grew as a response to the plight of the dying, and still remain coherent with its roots.

For a practice that has been described as an example of postmodern medicine – in the sense that it is defined not by an organ or by particular diseases, but instead by the
course of diseases, by symptoms, and by the experience of patients (Clark, 2002) – such questions emerge as highly relevant ones. What is palliative care, and what should it be? Some worry about defining palliative too broadly, so that it becomes difficult to know how to proceed, while others worry about defining it too narrowly, so that palliative care loses its position in modern medical care and society. Either way, the underlying questions concerning the ethics of palliative care and the identity of palliative care are deeply intertwined and important questions.

6.4.2) Prescriptive Ethics

The identity of palliative care is in an important aspect an ethical identity. And so the described shift in emphasis from care-for ethics to care-of ethics is also associated with a shift in the identity of palliative care. Each ethics carries different notions of what should be palliative care’s understanding of patient well-being and the scope of palliative care. And while, in analyzing the literature, the texts, and the interviews, I encountered views on the benefits of rationalization, I also encountered concerns about this rationalization. The critical view is concerned above all with the depersonalization of care – that with a clinical attitude, a medical bureaucratic structure, and a focus on quantifiable objectives – palliative care will lose its original human, caring, meaning-seeking focus. From the results of this thesis, I believe the criticism is founded, but I believe that it also lacks some articulation. I think a different framework is needed to see what has been lost in the rationalization of palliative care, and to see how palliative care might reintegrate its originating foundations into its present form.
If we adopt the care-for and care-of distinction, then an initial question becomes whether care-of ethics can accommodate care-for ethics. In other words, even if we accept on first glance that early palliative care had an important but now perhaps overlooked ethical imperative, we still need to ask whether care-of ethics, with its goals of palliation and quality of life (with its inherent emphasis on patient autonomy), cannot accommodate concerns about rationalization. My contention is that though to a large part care-of ethics can accommodate care-for ethics (and has done so), in certain aspects it cannot. Ultimately, each ethics has a manner of understanding that resists being fully translatable into the concepts of the other. I believe that the original challenges that led to palliative care’s emphasis on palliation, presence and meaning remain important and should remain defining of palliative care, but that these challenges lie in a new, as yet unclearly recognized direction. My contention will be that while palliative care continues to respond to the challenges of suffering and dying, it no longer responds to challenge of abandonment as it once did. In the section that follows I will try to make clear the way in which I think that abandonment should be ‘retrieved’ as a challenge and reincorporated into contemporary palliative care, a move that while further expanding palliative care will also make more secure the identity and goals of this postmodern practice.

Looking again at the literature on the history of palliative care, and at the early writings and the interviewee reflections on the beginnings of palliative care, it seems to me that an important motivation toward providing palliative care was to help abandoned patients. The interview data and the early textual data make clear that before palliative care, and during its beginnings, the suffering of the dying was made especially problematic by the abandonment of these patients by medicine and society. But there was
a historical contingency in the concurrence of these states of abandonment, suffering, and
dying, and this contingency has meant that it has always remained possible that suffering,
dying and abandonment could each become a compelling motivation of palliative care on
their own. And in fact, to some degree such an uncoupling has occurred. Suffering has
become the most important motivating concern of palliative care. In contemporary
palliative care we see an emphasis on palliation, which, because it isn’t exclusive to the
period of dying, has facilitated palliative care’s expansion into care for those who are not
imminently dying. As mentioned earlier, palliative care now provides palliation often
earlier in the course of terminal disease, sometimes during the course of life-threatening
disease, and sometimes during the course of treatable disease, and this for both malignant
and non-malignant disease.

Responding to the difficulties of suffering and dying continues to define palliative
care, even if responding to dying might define it to a lesser degree than previously. And
therefore for the most part, the patients referred to palliative care are either clearly
suffering or they are clearly dying from some progressive disease. But if palliation and
responding to dying have disengaged from one another enough to become more distinct
concerns of palliative care (though often still related), so too could responding to
abandonment be brought forward as an important concern. In this regard there are
persons, who if considered as patients, might be defined not primarily by their suffering
(though they do suffer), and not primarily by their impending death (though their life is
likely to be short), but might be defined also by having been abandoned to suffer and die
ambiguously. These are patients that fall outside palliative care’s present emphasis on
suffering and dying, but also fall outside earlier palliative care’s emphasis on promoting the ‘good death’.

There are persons who die what Kellehear has called a ‘shameful death’ (Kellehear, 2007). A striking example of such a patient is the debilitated elderly patient, the ‘frail elderly’, who may suffer from a collection of morbidities but no single terminal disease, who may have cognitive impairments, and who may suffer from a collection of vague unpleasant physical and psychological experiences. These patients fit poorly into the mandates of curative medicine or health-promoting medicine, but they also fit poorly into palliative care, and they are thus to an important degree abandoned. These patients are unlikely to partake in deep or lengthy discussion about the imminence of death, the meaning of their mortality, or to arrive at acceptance of death – partly because without single terminal disease prognostication is difficult, and often partly because of cognitive impairments – and in this regard they fall outside the understandings of presence and meaning as understood in early care-for palliative care ethics. But because their suffering is often vague and difficult to attribute to disease, and is without obvious treatment, and because they often lack the autonomous capacity to request and direct their care, these patients have also fallen outside of the typical understandings of palliation in both care-for and care-of palliative care ethics. The deaths of these abandoned, ambiguously dying, and ambiguously suffering patients are difficult to speak of in positive terms, and hence they carry the societal and professional shame of which Kellehear speaks.

That these patients are suffering to some degree, that they are close to death (even if not clearly dying of an identifiable process), and that they are often medically abandoned, makes it appropriate that they should become a greater part of palliative
care’s focus. They do fall under the original needs to which palliative care responded.

And even if they are not neatly included within the goals of *palliation, presence* and *meaning* as they originally appeared, it is possible to envision a reconsideration of these goals that would include these patients.

In fact, in practical terms there is already a beginning call to include such patients within the scope of palliative care. In the United Kingdom the ‘Gold Standards Framework’ began in 2011 as a national effort to develop and strengthen routes of care across disciplines and institutions, with a mandate to provide “care for all people in the final year, months and weeks of life, in any setting, with any condition, particularly the frail elderly, those with dementia and other disadvantaged groups” (GSF, 2011). The Framework aspires to enable this care to be delivered in large part by generalists, with consultation with palliative care specialists only where needed. In this way, the effort seeks to address the inability of too few palliative care specialists to deliver all the needed care.

In Canada, no such program has been developed, although the ‘Quality End of Life Care Coalition of Canada’ (QELCCC, 2012), a coalition of over thirty-five Canadian organizations involved with end of life care, is attempting to address the issue in advocating for change. The QELCCC has drawn its mandate from the reports of the several Canadian Senate commissions investigating palliative care on an ongoing basis, and asserts that “All Canadians have the right to die with dignity, free of pain, and surrounded by their loved ones” (QELCCC, 2012). What is still lacking is the elucidation of the underlying ethical argument urging palliative care to accommodate such patients. What this thesis adds to the practical call is an examination of an underlying ethical call. My suggestion is that the early care-for goals of *palliation, presence* and *meaning* were
not only a response to suffering and dying but also to abandonment, so that the dying patient of the 1960s needed palliative care not only in the sense of needing palliation and of needing an opportunity to create meaning in the face of mortality, but they needed these things precisely because they had been abandoned by medicine and society.

So we see that in the contemporary experience of the end of life, though much has changed in the past half-century, there are still some persons that fall outside the existing conceptions and structures of care. In particular, the frail elderly, who though they may die in the year before them, might not necessarily do so with profound or acknowledged suffering, and not necessarily at a predictable time. It seems to me that palliative care should understand the goal of presence more explicitly as including an imperative to care for those who are abandoned in their last year(s), and that doing so presents an ethical duty to respond to these abandoned, suffering patients who may die soon. Presented more explicitly, the goals of palliative care should be conceived along these lines:

The goals of palliative care are,
- above all to palliate the suffering related to disease;
  - especially (but not only) for those whom death is likely to be soon
  - especially (but not only) for those without other options
  - with an emphasis on presence* (as guided by the patient and family)
    - and with an emphasis on meaning** (as guided by the patient and family).

* Where presence is taken to mean listening to the patient without necessarily seeking to treat but simply to accompany, to mean developing a relationship with the patient built on understanding her or him, and to mean caring for the patient almost unconditionally.

** Where meaning is taken to mean giving patients support to develop or deepen an understanding of the detail and worth of their lives, and to mean finding a way to accept dying and death as part of that life, often through spiritual and existential understandings.
The initial look at definitions of palliative care in the Background section intimated a wide scope of definitions, and thereby left open many possible visions of the goals of palliative care. The conception above fits within these visions, but lends a particular emphasis. The literature on the history of palliative care, the literature on the rationalization of palliative care, the criticisms of this rationalization, all taken in light of the results of this thesis, suggest the goals above. This would be an ethics of palliative care that prioritizes palliation of suffering, but still keeps central the notions of presence and meaning developed through the early focus on dying, and tempers these latter goals with a vigilant concern for patient autonomy and a realization that palliative care now reaches beyond only care for the dying. It is a definition that acknowledges that palliative care has acquired abilities and strengths, such as the ability to palliate a host of symptoms and a familiarity with the practical and emotional difficulties of facing mortality, but also that palliative care initially appeared as a refuge for a certain group of abandoned patients.

During the rationalization of the past several decades, palliative care has continued to grow in scope and in technical prowess, but a look back to its origins presents a new opportunity and responsibility. Palliative care appeared as a response to dying, suffering, and abandonment. If the first wave of palliative care was about the abandoned dying, and the second wave has been about suffering, then the third wave should be about abandonment. This third wave could, while retaining the accomplishments and abilities of the first two waves, reconsider who it is that has been abandoned now.
In the conclusion, I will review the changes in palliative care as I have come to understand them through this thesis, commenting both on the limitations of this thesis and its intimations for further research. I will finish by summarizing my understanding of the ethical responsibility that lies ahead for palliative care.
Chapter 7: Conclusion

“The growing expansion of palliative care in the traditional healthcare system is challenging, and proposes constant reviews of the best strategies for this insertion.” (Floriani and Schramm, 2012)

I began this thesis began by asking three questions. The questions were conceptual and broad, and using qualitative methods, I responded with ideas that are also conceptual and broad. I asked whether Canadian palliative care and its ethics had changed since its beginnings, and if these ethics had changed, in what way had they done so. Using the concepts arising from the analysis of this thesis, I suggested that Canadian palliative care had undergone a rationalization that could be described under the processes of routinization, medicalization and professionalization. I suggested that the ethics of palliative care had also undergone a rationalization, a move from emphasizing what I called care-for ethics to emphasizing care-of ethics. Key to this move was a shift in goals, wherein the goal of palliation had been strengthened while the goals of presence and meaning had been diminished. These ideas offered a way to frame the discussion on the rationalization of palliative care ethics, a discussion that has been to this point fairly hidden within the larger discussions concerning overall changes in palliative care. I was able to present a new understanding of palliative care ethics that could both ‘retrieve’ some of palliative care’s foundations and strengthen palliative care’s identity.

In this thesis I’ve made four points in response to my initial questions. This concluding section will review those responses, consider the strengths and weaknesses of this thesis, and suggest some directions for further research in the area.
7.1) The Responses

First, the results of textual and interview analysis supports the idea that Canadian palliative care has undergone a rationalization. The literature on palliative care, drawing on Weber’s ideas on rationalization and discussions in medical sociology on medicalization, suggests that rationalization has changed palliative care. The results of this thesis suggest to me that such a process of rationalization has indeed occurred in the Canadian context as well – that Canadian palliative care has undergone routinization, medicalization, and professionalization. This has meant that care has become more routine, more of a career and less of a calling; has meant the increased use of medical interventions and medical understandings in palliative care; and has meant that practitioners identify more with traditional professions then previously and self-identify as palliative care specialists.

Second, the rationalization of palliative care has been accompanied by a rationalization of palliative care ethics. The concept of well-being and the goals of palliative care have changed. Initially, when palliative care focused on the dying patients that had been abandoned by society and medicine, the goals were: to palliate the symptoms of these patients (palliation), to form relationships and to accompany them through the dying process (presence), and to help them find some existential and spiritual meaning and acceptance in the face of their suffering and mortality (meaning). As palliative care grew in its ability to palliate, it expanded into care for other patients, and while the goal of palliation remained definitive, the goals of presence and meaning became less so. Palliation was understood as important for all patients, while, under the broader scope of palliative care and strengthening ideas of patient autonomy, presence
and *meaning* were left as important only to some. And even in cases where *presence* and *meaning* were considered important, they constituted less of a shared experience between the practitioner and the patient and more of a therapeutic one, a therapy consented to by the patient.

Third, the results of the textual and interview data not only support the fact of rationalization, but also contribute to the evaluative debate on the rationalization of palliative care. The literature is mostly critical of the rationalization of palliative care, suggesting that important foundations have been lost. The interview results present similar worries, that with the expansion of palliative care (both in the growth of the profession and in the scope and number of patients seen) and with the ongoing focus on technical proficiency in treating symptoms (especially physical symptoms), that the human aspects of care and relationship risk being undervalued.

Fourth, the thesis results, especially when considered in light of the history of palliative care, suggest to me that the effort to respond to abandonment was one of the fundamentals of palliative care. I suggest that reconsidering this ethical principle in light of contemporary care could strengthen the identity of palliative care. Understanding the goal of *presence* in part as constituting a response to abandonment means expanding the scope of palliative care to include those facing the so-called ‘shameful death’. Such patients include especially frail elderly persons, often suffering from multiple morbidities, often with cognitive impairment, and who, while likely to die within the near future, are nonetheless without a clear terminal diagnosis. These patients have fallen outside the early care-for goals of palliative care toward *palliation, presence*, and *meaning* that sought to provide to (unambiguously) dying patients an acknowledged,
palliated and meaningful and accepted death. These patients have also fallen outside of the later care-of goals of palliative care toward the autonomously directed palliation for patients either suffering from, or dying from, a life-threatening illness. But if presence is seen as being in part a response to abandonment, then these patients fall firmly into palliative care’s scope. Their dying may be unpredictable, and their suffering may be unclear, but when seen in light of their abandonment, their predicament becomes part of the responsibility of palliative care. Recalling and strengthening palliative care’s imperative to care for the abandoned should mean expanding the scope of palliative care to explicitly include such patients.

7.2) Limitations

This thesis used discourse analysis to create a picture of the change in Canadian palliative care ethics over several decades. The thesis has limitations regarding the topic, scope, and analysis.

One of the aims of this study was to investigate a circumscribed topic, and doing so required making multiple judgments, both explicit and implicit, regarding what data might be used for inclusion in the study. I have described the concepts of ‘palliative care’ and ‘ethics’ and ‘early’ or ‘late’ periods, but some of the myriad choices involved in setting the boundaries are not documented. Two textual sources were used for analysis from each of the early and late periods. The sources were selected for their comprehensiveness, and for their expression of, and influence on, palliative care at the time of their writing. The sources were selected based on my experience as a clinician and under advice from palliative care pioneers. Nonetheless, the choices present
limitations – for the early period the range of choices was very narrow, for the later period overly large. Similarly, the judgments concerning which portions of these texts to include and which to exclude was challenging. The close focus of the method of discourse analysis meant selection had to be made within the texts, and as with the other choices, these decisions were too numerous and intuitive to all be documented.

The interviews also presented challenges of topic and scope. At times the interviewees answered very briefly, or at length on repeated ideas, or moved to topics outside the study’s scope. I tried to find a balance between leaving open the area for discussion and closing it near to the topics most relevant to the study. There were few persons across Canada who had been active across the period in question, and their number was further constrained by practicalities of health, interest, and availability. In the end, I interviewed ten palliative care pioneers. I gave thought to either interviewing for longer periods or for a second time, but the challenges of obtaining the interviews to begin with precluded this effort.

As well as these limitations regarding topic and scope, the analysis presented other limitations. The goal of the analysis was to create a picture of some important themes of comparison between the early and late periods of palliative care, though not to find all themes of analysis. I made choices regarding how long to continue looking for themes. Some of these choices were practical (e.g. as in the number of interviews), and some were conceptual, such as the sense that new material seemed to fit into themes already noted. Using the two sources of textual material and interviews did allow for some ‘triangulation’, whereby the appearance of similar themes in both materials added some confirmation to one another. Lastly, while the nature of a PhD dissertation required
that I undertake virtually all of the work required to complete it on my own (with advice and direction from my committee), having others undertake parts of the study and bringing such efforts together for discussion and revision could have deepened the study.

7.3) Further research questions

There are many possible routes of research that could build on the present thesis. I will focus on two aspects of what I see as potential important contributions. Following on the suggestion that palliative care should retrieve its roots in sheltering and caring for abandoned persons suffering through the end of their lives, it would first of all be helpful to know more about these ‘frail elderly’ that I considered in particular, and secondly it would help to consider what response of palliative care might look like.

Who are the abandoned frail elderly and what are their experiences? In particular it would be helpful to understand who would reasonably fall under the scope of palliative care were it to accept the proposed retrieval. It would be helpful to have a sense of the course of their last year of life: the feasibility of prognosticating based on their conditions; their experiences of illness and of their lives; the experience of their families and caregivers; and an idea of what care was available to them. These questions could provide a great number of possibilities for qualitative and quantitative research.

How should palliative care respond to the needs of the abandoned frail elderly? This question carries practical and ethical implications. I have introduced an ethical view of the question, but much remains open for further discussion. Is some sort of retrieval of earlier ethical foundations actually necessary? Is palliative care the best mode of care for such patients? What are the ethical theoretical implications of the suggestion of this
thesis? The practical questions are also many and varied, for if it is true that palliative care has some responsibility to care for these patients, how could this be undertaken? The number of patients who might potentially fall under the new scope of palliative care is likely to be large, and well beyond the ability of palliative care practitioners to accommodate. How could palliative care help facilitate the care of these patients by other practitioners?

7.4) Conclusion

Palliative care has changed since its beginnings. It has become more of a medical career and less of a social calling. This has meant that more patients receive treatment for their suffering, but it has also meant that palliative care has drifted from its original deep focus on the person, on their life and death. It seems to me that palliative care has been moving through waves of identity. It began as a response to the suffering and abandonment of the dying, it developed into a multifaceted response to the sufferings of illness, and now it sits perched on verge of a third wave. If palliative care can incorporate in its understanding the new face of dying and suffering in the frail elderly and others abandoned to a ‘shameful’ death, and can see therein the founding call to care for the abandoned, then it will mature into yet another form. In this third wave there will be practical challenges, but undertaking them will be made possible and perhaps easier with the view that through the waves, palliative care has always been about the well-being of patients – about responding to dying, suffering and abandonment.
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Appendix 1: Interview Guide

Thanks to the interviewee.

Introduction to project (reminder):

Like any endeavour or profession, palliative care has a way of being. In particular, it has ideas on how practitioners should practice, what values and goals are important, what virtues should be aspired to, and so forth. This collection of norms I am considering the ethics of palliative care. “Ethics” here is a much broader term than that of bioethics, medical ethics, or professional ethics in general. It is a term meant here to encompass the general mores or ethos of palliative care.

Many have suggested that palliative care has had and continues to have its own distinct ethics, and many have also suggested that this ethics has changed over the past several decades. The hope of this project is to discover what the ethics of Canadian palliative care has been and is, and whether this has changed since its beginnings. I will be reviewing texts and I will be conducting interviews with experienced practitioners.

Introduction to interview (reminder):

I’ve intended this interview to be “semi-structured”, that is, I’ve written some questions to remind and guide me. There is much room to explore other related topics and please feel free to discuss what seems important to you. Some of the questions may seem vague, but these open questions will often be followed by more directed questions. I can clarify any questions that seem ambiguous or confusing. You should feel free to decline to respond to or come back to any questions.
Initial, open questions:

1) When you think of the way palliative care was understood and practiced in the 1970’s and 1980’s in Canada (the early period), what would you consider its salient features?

2) When you think of the way palliative care has been understood in the last decade in Canada, what do you consider its salient features?

3) a) Do you think palliative care has changed since its beginnings in Canada?
   b) If you think it has changed, can you talk about this change?

Questions concerning themes:

4) From my readings, the notions of self or personhood or humanness seem to figure prominently in palliative care.
   a) Could you comment on the importance of these notions to palliative care?
   b) Do you see any change in the way these notions are understood or used in contemporary palliative care relative to the early period?

Probes: depersonalization, relationship

5) From my readings it seems as if palliative care was, especially in the early days, consciously trying to shape and define itself.
   a) How do you think palliative care saw itself, early on? Relative to the rest of medicine; the rest of society?
   b) Do you think that the way palliative care sees itself has changed since its beginnings?
6) In the early days of palliative care, what do think practitioners were hoping to achieve, what they were helping their patients to achieve?
   a) Do see any changes in what the contemporary palliative care practitioner hopes to achieve?

Probes: death/dying, autonomy, dignity, suffering

7) Some have suggested that palliative care has become more professionalized, more medicalized, and more secular?
   a) In your experience, has this been the case?

Probes: standards/guidelines, outcomes, funding, research
Appendix 2: Consent form

CONSENT TO PARTICIPATE IN A STUDY OF PALLIATIVE CARE ETHICS

**Title of Project:** The conceptual structure of palliative care ethics in Canada.

**Principle Investigator:** Dr. Victor Cellarius (PhD candidate, Dalla Lana School of Public Health, Faculty of Medicine, University of Toronto)

**Supervisor:** Dr. Ross Upshur

**Committee Members:** Professors Ann Roberson, Wayne Sumner, and Mary Vachon

**Purpose of Research:**

Psychologists, sociologists and historians have suggested that the conception, the experience, the meaning of dying and death varies tremendously across persons, cultures and times. As part of my PhD thesis, I propose to study the shape of dying in Canada through examination of palliative care ethics.

Palliative care practitioners have a certain “ethics” guiding and expressing their relation to the dying – an explicit and implicit understanding of what is right, valuable, worthy, acceptable, and so forth. The hope of the proposed study is to divine this palliative care ethics, to see how it has appeared and changed, and to offer other ways of moving forward. The proposed study will use discourse analysis to examine textual sources and interviews regarding palliative care ethics in Canada. It will have a historical and contemporary focus, seeking to root the present state of palliative care ethics in developments of the past several decades.
The idea is to analyze the discourse in the early period of Canadian palliative care, and to contrast this with the contemporary period, which my preliminary understanding shows to be less “revolutionary” and less of a grassroots movement and more “medicalized”. There seems to have occurred a shift in the aims, values, norms and self-understanding of palliative care, and the aim of the proposed study is to discover if this is actually the case. The analysis will also serve as a point of departure for developing a theoretical picture of, and a practical future direction for, palliative care ethics.

**Funding:**

This study has been funded by the Canadian Institutes for Health Research.

**Procedure:**

You have been identified by your colleagues as a “key informant”, a person with an extensive history working in palliative care, and it would be a great pleasure to interview you regarding your experience of palliative care in Canada. At most I hope to interview fifteen palliative care pioneers, though the actual number is likely to be less than ten.

I’ve intended this interview to be “semi-structured”, that is, I’ve written some questions to remind and guide me. There is much room to explore other related topics and you will be free to discuss what seems important to you. The interview should take less than one hour and will be recorded on audiotape, which will later be transcribed into
electronic and paper text formats. You may choose to skip questions, return to questions or to stop the interview at any time. You may ask that certain remarks be excluded from the study either during the interview or any time prior to the completion of the study.

Benefits:

The benefits of this study to you relate to the interview process and the findings. I hope the interview itself will be enjoyable for you, but I hope also to provide you with some interesting insights into palliative care as the study progresses. I will be available to discuss my ongoing findings as I analyze the data.

Risks:

The risks inherent in this study are minimal, and include any discomfort that may arise from the interview process. From my medical practice, I am experienced at interviewing persons, and I expect that the interview should be a pleasurable experience.

Confidentiality:

All the information collected as part of this study will be kept secure either at the Temmy Latner Centre for Palliative Care or at my home office. The information will be stored on audio tapes, on paper and in computer files. The only persons who will have direct access to your interview will be the researchers (i.e. me, the thesis committee members and the transcriber). The only person who will be able to identify which interview is yours will be me. I will employ a professional to transcribe your interview from audiotape to a text form (electronic and paper). The transcriber will know you only
by number, and I will keep a separate record of your identity. The committee members will have access to the transcribed interview only and will not be able to identify you as the source of any comments other than by the content of your replies.

When the study is presented to others, either in the thesis itself, in talks, presentations or in publications, I will not mention your name, unless you would prefer that I do so. Otherwise, no information will be given out which could identify you as the source of any particular data. The information will be presented as an aggregation based on your interviews and on key texts, with some quotes to highlight important themes.

THIS STUDY HAS BEEN REVIEWED AND APPROVED BY THE HEALTH SCIENCES RESEARCH ETHICS BOARD AT THE UNIVERSITY OF TORONTO.

Compensation:

There is no specific compensation for participating in this interview study, however I would be happy to cover any costs that you might incur related to the interview (e.g. taxi, parking, etc.).

More information:

If you would like to be informed of the findings and presentations of this study I would be happy to arrange this.

If you would like more information on this study, please feel free to contact me, Victor Cellarius at:

(home) [deleted for publication]
You may also contact the Office of Research Ethics for more information:

ethics.review@utoronto.ca, 416-946-3273.

**Confirmation of Participation:**

I have read this consent form and understand that my participation is voluntary. I agree to participate in an interview as described above. I have had my questions answered and have been given time to consider my participation. I understand that I may ask questions in the future also at the contacts listed above.

Interviewee’s Name_______________________________________________

(please print)

Interviewee’s Signature__________________________________________

Date____________________________________