

Negotiated Practices: Understanding Hospitalized Palliative care as an Affective Economy

by

Marian Theresa Krawczyk

M.A. (School of Communication), Simon Fraser University, 2004

B.A. (Anthropology), University of British Columbia, 2001

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Approval

Name: Marian Theresa Krawczyk
Degree: Doctor of Philosophy (Anthropology)
Title: *Negotiated Practices: Understanding Hospitalized Palliative Care as an Affective Economy*
Examining Committee: Chair: Wendy Chan
Professor

Jane Pulkingham
Senior Supervisor
Professor

Dara Culhane
Supervisor
Professor

Sharon Koehn
Internal Examiner
Professor
Department of Gerontology

Kelli Stajduhar
External Examiner
Associate Professor,
School of Nursing,
University of Victoria

Date Defended/Approved:

July 6, 2015

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Abstract

This dissertation is an exploration of contemporary hospital-based palliative care informed by ethnographic research in two large hospitals in Western Canada. My objective was to explore how the concept of an “affective economy” contributes to understanding the ways in which the dying process is currently negotiated in these spaces. Through extending existing scholarship on discourse, emotional labour, affect, affective economies, and literature on institutionalized end-of-life care as a form of social governance, I define an affective economy of hospitalized palliative care as a discursive formation, which is understood and explained through its emotional labour practices, and which attempts to organize the dying process in order to facilitate a good death. Primary attention is given to three aspects of clinicians’ emotional labour practices: therapeutic relationship building, addressing total pain, and offering of the dying role. Through interviews, fieldnotes, and case studies, I trace how these are relational practices of knowledge and power that circulate and privilege clinicians’ understandings of the emergent physical states of the patient, along with clinicians’ cultural authority to define the appropriate emotional orientations to these understandings. I also explore how these orientations are negotiated, validated, and/or contested through claims to narrative authority by all involved parties. I propose that, within an affective economy framing, hospitalized palliative care is best understood as constituted by two, not always complementary, discourses. These discourses both construct and reflect tensions within care provision, including: the evolution and mainstreaming of care, the requirement for rapid patient transitions, the rise of business modeling, and increased patient and family member involvement in clinical care decisions. This research contributes to the study of dying in three key ways. First, no one has yet conceptualized hospitalized palliative care as an affective economy. In doing so, the specific moments and networks of relations that constitute this form of care are understandable as a cultural system that attempts to make human capacities productive, even at the very end of life. Secondly, I forward an understanding that clinicians’ privileged position is one that often occurs within active and sustained negotiations, where emotional orientations to dying process are generated, validated, and/or contested within the perceived rights and obligations of all involved parties. Third, this framing encourages an understanding of hospitalized palliative care in contemporary Canadian hospitals as necessarily fluid and ambivalent, defined as much by negotiation and disjuncture as by mutuality and cooperation.

Keywords: affective economy; hospital palliative care; emotional labour; therapeutic relationships; total pain; dying role

Dedication

*For my parents, my grandparents, and all of those
who came before me. For Barbara and Joe who
left before me. And for Justin.*

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Chapter One: Organizing Death

Death is terrifying because it is so ordinary. It happens all the time.

(Susan Cheever)

Shortly after her 30th birthday, my sister died in a palliative care unit, 16 months after being diagnosed with a virulent form of breast cancer. Six years later, my 56-year-old brother died in an acute care unit five months after being diagnosed with brain cancer. Although they both had the same disease, and both died within a hospital setting, each had very different end of life experiences. While my sister chose palliative care and a “comfort” only approach, my brother refused any discussion of end-of-life care and stated he “wanted to fight at any cost.” For a significant time after my brother’s death, I was far too exhausted and in shock to attempt any comparison between these experiences. Yet as time passed, I noticed my whole family—myself included—talked about these deaths in a certain way. The collective grief my family gave expression to seemed to focus on the choices my brother and sister made about their treatment paths once they had been designated as having a short time to live. We ruminated on our support, but also on the difficulties, of respecting my brother’s right to choose the way that he died, while agreeing that my sister’s choices had led to a much better death even given her young age. In short, we created narratives: cohesive stories to make sense of these traumatic moments that we collectively experienced as a family, and as individuals within the family. The way that we told these stories made us feel better about the seeming senselessness and chaos of early death, about our inability to change or control what was happening to those we loved, and about our own existential anxieties of mortality. The narratives that we jointly created, contested, and negotiated invoked particular emotional states meant, both consciously and unconsciously, to help us continue in our lives.

As these conversations became less frequent and our grieving took other (less public) forms, I started to wonder what was it that made us all know and agree that my

sister's death was "better" than my brother's. Curious, I began to seek out others who had experience with hospitalized dying. In doing so, I noticed specific language and terms were commonly used to describe experiences with palliative care in hospitals. As I listened to, and created stories with, others as to how palliative care helped us to "accept" death rather than being in "denial," I realized that a common factor uniting all our narratives was praise of palliative clinicians' ability to transition our problematic emotions about dying into a desire for a "good" death. My curiosity was piqued. I wanted to know more about how palliative clinicians accomplished this seeming emotional alchemy, particularly within a culture—and more particularly within an institutional context—that has been labelled death denying. Given that the majority of Canadians will spend their last days, and die, in a hospital, these institutional settings are a critical geography to explore how we give meaning to, and thereby socially order, the experience of dying.

What is Hospitalized Palliative Care?

While our cultural "common sense" narrative constructs the preferred location for a good death within the private home space, this contrasts with the reality that the majority of Canadians die within an acute-care hospital after a protracted illness (Bell, Somogyi-Zalud, & Masaki, 2010; Wilson et al., 2009). Currently, a good death in these institutions frequently requires a specific form of medical expertise—palliative care. Originating in Canada in 1976, palliative care practices were borrowed from the free-standing hospice model that was emerging in England at the same time. Although location of care differed, palliative care had the same philosophy and mandate: to focus on quality of life, open communication about diagnosis and prognosis, comfort rather than curative efforts, relief of physical and emotional suffering, facilitation of patient autonomy, and help with bereavement, all achieved through a multi-disciplinary approach (Mount, 1976; Saunders, 1978).

In the proceeding 40 years, palliative care has emerged as the contemporary *ars morendi*—the art of dying well, regardless of location.¹ Currently, the World Health Organization defines palliative care as:

[...] an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO, 2014, para. 4)

Advocates of palliative care conceptualize it as a set of compassionate, flexible, individualized, responsive medical practices for those in a liminal state of health. In this narrative, palliative care can solve concerns about resource use within an overburdened health care system, for an aging population with more complex and chronic illnesses who are used to consumer choice and patient autonomy, and for individual medical practitioners who are trained to keep patients alive at all costs (Kelly & Meier, 2010; O'Mahony, Blank, Zallman, & Selwyn, 2005; Teno et al., 2004). It is also seen as a way to facilitate acceptance, meaning, and self-fulfillment during the later stages of the disease process, all the while receiving expert pain and symptom management, allowing people to “live until they die” and facilitating “death with dignity” (Chochinov, 2002, p. 2253; see also Breitbart, Gibson, & Poppito, 2004; Romanoff & Saunders, 1978; Thompson, 2006). Within medical discourse, palliative care is therefore understood as a set of practices that simultaneously addresses the concerns of critically ill individuals, their relations, the professionals that care for them, the institutions in which these professionals labour, and the larger society within which all are located.

¹ More recently, the provision of palliative care as the pathway to a good death has been publically challenged by the right-to-die movement. In this latter discourse a terminally ill individual has the inalienable right to choose the time, and manner, of their death. Palliative care proponents rebut this position by arguing that requests for terminating life usually emerge from existential angst and uncontrolled symptoms, and that palliative practices can address these concerns without hastening death. However, what is often overlooked within these competing discourses is the unifying understanding that values the autonomy of the dying person—what is disagreed on is how to safeguard that autonomy.

Research Context

To better understand the practices of hospitalized palliative care, I spent 11 months in 2008-2009 engaged in ethnographic research at two large tertiary care hospitals² in Western Canada observing physicians, nurses, social workers, therapists and other allied health professionals who specialized in providing palliative care. These clinicians³ worked in dedicated palliative units as well as in palliative consult teams with patients throughout their respective hospitals. In addition, I conducted more than 40 interviews with both palliative and non-palliative clinicians, as well as with hospital administrators. I also followed 36 patients and their family members to the point of death or discharge; sometimes this occurred within days, other times weeks and even months passed.

During this time I observed how a diversity of patients, their family members, and clinicians negotiated the dying process together.⁴ At times these negotiations were relatively straightforward, and a good death was achieved for everyone involved. I also observed a range of shifting, ambivalent, and context-dependent understandings of appropriate end-of-life care practices, including a diversity of narratives of what it means to die well within this setting. I witnessed critically ill individuals and their relations resist

² Tertiary care hospitals are defined as large institutions focused on specialized health care, including advanced and complex medical investigations, treatments, and interventions.

³ I define a palliative clinician as a medical professional working in the hospital who directly and substantively provides palliative-specific health care to patients. In my work I use the term clinician to encompass physicians, nurses, social workers, and therapists. I use this generic term rather than formal professional distinctions to: (1) emphasize the interdisciplinary teamwork in palliative care and clinicians' assertions of the equal importance of each profession required in care planning and delivery; and (2) the field of hospital-based palliative care is relatively small, and masking professions facilitates the anonymity of the clinicians I observed.

⁴ The dying process within hospitalized palliative care encompasses: (1) a medical understanding of a person's unfolding physical state as one of terminal decline; (2) the organization of their care during this time; and (3) the social and emotional impacts of this work on everyone involved in the provision and uptake of care. In defining the dying process, I borrow from Strauss, Fagerhaugh, Suczek, and Wiener's (1982) encompassing term "trajectory" to "refer not only to the physiological unfolding of a patient's disease but to the total organization of work done over that course of illness plus the impact on those involved with that work and its organization"(p. 257).

conceptualizing dying as a time for growth, instead choosing a narrative grounded in warfare where they had to “fight” the “enemy” at all costs. There were patients and family members who exhibited acute distress when dying was referenced, and who demonstrated a continued refusal to acknowledge impending death. Others tacked between potentially conflicting narratives of what they understood to be a good death for themselves or their loved ones, seemingly reaching out for life and death simultaneously.

On a practical level, the dying process was often difficult for clinicians to chronologically order, regardless of the ongoing development of prognostic indicators, particularly for patients with chronic or multiple illnesses. I observed instances where the evolution of medical treatments and expansion of practice in the name of quality of life continued to further problematize the division between living with an illness and dying from it. There were clinicians who rarely spoke openly about the possibility of death until it became physically clear that the patient was imminently dying. Complicating matters further, these hospitals both modeled, and were shaped by, business framing rules and organizational mandates that construct the good death as either occurring in the community or as institutionally “quick, cost-efficient, [and] no risk” (Mor, Greer, & Kastenbaum, 1988, p. 3). This lived “messiness” of care provision often required sustained—and at times contested—negotiations by everyone involved, as patients, family members, and clinicians all worked to construct, resist, and/or legitimize understandings of the dying process within uncertain contexts and ambivalent priorities. In short, I found that implementing a good death in hospitalized palliative care was often an uncertain practice, where the desired outcome of care was not always coterminous between the patients, their family members, clinicians, or the institutions of care within which all were located.

Research Purpose

The purpose of this dissertation is to explore how the concept of an “affective economy” contributes to understanding the ways in which the dying process is currently negotiated in Canadian hospitalized palliative care. Within an interdisciplinary framework that borrows from social theory, critical cultural studies, political anthropology, the

sociology of emotions, and psychoanalytic philosophy, I define an affective economy of hospitalized palliative care as a discursive formation understood and explained through clinicians' emotional labour⁵ practices. I suggest how these practices attempt to order and make productive the affective experiences of dying through the co-production of emotional orientations that create individual meaning, provide collective social order in the face of loss and mortality, and increase the ability to govern the biological processes of dying for the population as a whole. Collectively, I understand these emotional orientations as generating the good death. With this focus, I address the following concerns. First, I explore how clinicians' emotional labour practices operate within, and as, relations of power and knowledge. Second, I trace how these practices constitute the dying (and their conduct) as an object of interest. Third, I examine specific relations, behaviours, and actions that make up clinicians' emotional labour practices. Fourth, I explore the desired and actual outcomes of clinicians' emotional labour practices. At the end of this chapter I provide a summary of the contents of the remaining chapters, and outline how my work may contribute to existing understandings of the dying process in hospitalized palliative care. I now turn to an overview of contemporary Western understandings of the good death from a diversity of perspectives: historic, academic, populist, and medical. I use this discussion as the foundation from which to explore how these narratives have informed current practices of dying well, with particular reference to the development of hospitalized palliative care.

The Good Death

There is a wealth of anthropological and sociological studies as to how cultures construct meaning-making systems to regulate responses to death and dying. Too numerous to include all, well-known examples include Earnest Becker's Pulitzer-prize winning *Denial of Death* (1973), Barney Glaser and Anselm Strauss's famous study *Awareness of Dying* (1965), Nancy Scheper-Hughes' *Death without Weeping* (1993),

⁵ I broadly follow Arlie Hochschild's definition of emotional labour as the work "of trying to change in degree or quality an emotion or feeling" (1979, p. 561) in oneself or another in order to "produce the proper state of mind in others" (1983, p. 7). I discuss emotional labour more fully in Chapter Two.

Clive Seale's *Constructing Death* (1998), Claudio Lomnitz's *Death and the Idea of Mexico* (2005), *Celebrations of Death* by Peter Metcalf and Richard Huntington (1991), and James Green's *Beyond the Good Death* (2008). Regardless of scholarly perspective, all these authors agree that awareness of death requires affective systems—culturally sanctioned systems of meaning-making that organize and make knowable the experiences of death and dying. The psychologist Robert Kastenbaum (1972) termed these “death systems” to encompass all of those processes that teach us what to think about death and dying, how to feel about it, and what to do with regard to it. These affective systems manage individual existential angst, prevent social nihilism, and order the biological conduct of populations. In the contemporary Canadian secular context, a critical element of our affective system is generated within the narratives and practices that are collectively known as the good death.

Evolution of the Good Death

Philippe Aries is perhaps the most prominent historian interested in the social evolution of the good death. In his books, *Western Attitudes towards Death* (1974) and *The Hour of our Death* (1981), he exhaustively traces the social changes of death and dying from the Middle Ages to the mid-20th century. His central argument is that our current collective understanding of the good death has been primarily influenced by broad social changes; within religion, the community, family, and medicine. This thousand year transformation in turn influenced ways of dying. He asserts that in the Middle Ages death was familiar, universal, and a part of the social fabric of everyday life. This understanding slowly began to be replaced by an emerging distinction of the individual self capable of good or evil, and as concepts of biography and individuality gained dominance over a universal, collective destiny. He argues that by the time of the Renaissance, the dying individual was required to *preside* over his own death (1974, p. 538). The dying process continued its slow transformation and by the 17th century it was affected by communal fragmentation caused by the Industrial Revolution, the waning of religion to frame meaning in everyday life, and progress in the field of medicine that replaced death with illness and persistent disease. The dying process was no longer identifiable or under complete control of the individual and their families. These changes eventually led to a social denial of death and sequestration of the dying within hospitals. What is now required in these institutional spaces for an ostensible good death is “an

acceptable style of dying” that does not invoke a “chain of sentimental reactions that would bring out a loss of self-control” for everyone involved (p. 543). Aries concluded that late-modern Western civilization is death denying and he articulated a personal, social, and cultural meaningfulness to our current forms of dying. Yet he also expressed cautious optimism, citing emerging research as a reflection of larger social transformations organizing new ways of understanding death and dying. He felt that this signified “a complete reversal of attitudes” prompted by professionals and researchers who “[have] become aware of the pitiful situation of the dying and decided to defy the taboo [of talking about it]” (1981, p. 589). Due to this emerging attention to the dying, Aries’ belief was that a good death might again be possible by making terminally ill individuals culturally visible and allowing them control over meaning-making processes at the end of life.

A particularly famous example of this “emerging social transformation” is evidenced in the work of psychologist Elizabeth Kübler-Ross. Her research on the experiences of dying in hospitals lead to the publishing of *On Death and Dying* (1969), which was followed by *Death: The Final Stage of Growth* (1975). Together, these books summarized 500 interviews with dying patients and provided a series of scholarly essays meant to guide “the search for meaning of life and death” (Kübler-Ross, 1975, p. xii). Kübler-Ross asserted that dying patients in hospitals were isolated, ignored, and seen as medical failures. She argued that most of all, what these patients wanted was to talk; they wanted to review their lives, their deterioration, and their imminent death. Her central thesis was that when clinicians and patients could talk openly, patients could be supported to move through the stages of accepting their death, and thereby achieve personal growth. Through this open and honest communication process, a dignified death that recognized the individual’s experience of dying could be achieved. In short, by giving patients a voice—and therefore an identity—a good death necessarily followed. While Kübler-Ross’s work has subsequently been subject to intensive scrutiny and critique (Bonanno & Boerner, 2007; Copp, 1998; Hart, Sainsbury, & Short, 1998), her concepts of “The Five Stages of Grief,” “death with dignity,” and “death as the final stage of growth” have powerfully shaped the mainstream discourse on the good death, created a series of bestsellers, and her books are often cited as key to popularizing the topic of dying as a subject for general social commentary.

A more recent example of this discourse of the displacement of death, and a corresponding desire to reclaim it, is echoed by the sociologist Tony Walter in *The Revival of Death* (1994). While critiquing Aries' assertion that contemporary death and dying are culturally taboo, Walter also relies on an individuality-created-by-general-social-transformation thesis as his core argument. Pointing to the current lack of ritual to regulate death and dying, Walter argues that death and dying are not problematic to contemporary culture as a whole, but rather are problematic for the *individual* within this culture. He goes on to extrapolate that the current "revival" of death is due to a post-modern "expressive revolution" generated by ordinary people who demand to express their emotions freely and to celebrate their individuality in resistance to the calculating rationalism of early and mid-capitalism. In post-modern society, people have been deprived of support from established traditions and stable networks, yet paradoxically they are now—for the very same reasons—finally free to die and grieve as they wish. However, unlike Aries and Kübler-Ross, Walter sounded a note of caution in asserting the primacy of therapeutic communication, where psychology may be replacing religion in providing the normative framework of the good death. He was also careful to articulate possible confluences between consumerist notions of identity and autonomy within this revivalism.

All three of these authors have participated in the creation, and are reflections, of contemporary understandings of the good death. Although they emerge from divergent disciplinary perspectives and interests, each construct a good death as one which requires that the dying process celebrate, and give control to, the "expressive" individual concerned. This discourse of emerging public reclamation of the dying process in conjunction with the rise and celebration of the expressive individual has led to a "common sense" understanding of the good death as one in which autonomy and the ability to construct meaning of the dying process is inextricably intertwined. This understanding is further naturalized in contemporary medical textbooks, professional literature, and in popular culture. A particularly powerful form of this narrative is one that Walter (1994) has termed "pathography," where personal experiences of death and dying recounted are not presented as historically located but "on one hand as personal and on the other hand as universal" (p. 127). A prime example of this is *Tuesdays with Morrie* (1997), which topped the New York Best Seller List in 2000, remained on the list

for four years, and was subsequently made into a movie. Written as a series of conversations between a dying older man and his former student, the book traces the wisdom imparted by the former on acceptance, communication, love, values, openness, and happiness, all of which are rendered more poignant against the backdrop of the older man's deterioration. This construction of the dying process as a "natural" time for personal growth (both of self and others) is also echoed in a multiplicity of clinician-authored how-to books, including: *Dying Well: Peace and Possibilities at the End of Life* (Byock, 1997); *The Needs of the Dying: A Guide for Bringing Hope, Comfort, and Love to Life's Final Chapter* (Kessler, 2000); *What Dying People Want: Practical Wisdom for the End of Life* (Kuhl, 2002); and *Peaceful Dying: The Step-by-Step Guide to Preserving Your Dignity, Your Choice, and Your Inner Peace at the End of Life* (Tobin, 1998). Although many of these authors, scholars, and clinicians identify autonomous and individual "styles" of dying, what is not addressed in these diverse narratives is the underlying assumption that the subjective experiences of dying have an essence or unity that can be given voice and validated through an "expressive death."

Dying well, or what I term a good death, requires an enormous amount of emotional and physical labour, by all involved parties. In addition to being physically pain-free, a good death is also one that has a minimum of emotional *suffering*. It requires the dying person to: openly acknowledge their impending death; conceptualize their remaining time as an opportunity for personal growth; have their personal conflicts and unfinished business resolved; be surrounded by family and friends in a care location of their choice; and have the whole process respect and reflect the dying person's individuality (Clark, 2002; Kuhl, 2006). For the terminally ill individual, dying becomes a "moral career" (Field, 1996), replete with a specific "social script" (Seale, 1998; Timmermans, 2005) regarding the feelings, understandings, and actions of what it means to die well. In adhering to this script, those who take on the dying role are re-inscribed as valuable and generative members of society through their teaching-by-example of what it means to die well. In turn, this enactment ensures that the process and outcome of dying generates meaning, thereby reducing individual and collective anxieties about non-existence. Therefore, while the experience of dying is physically located within the body of the dying person, the experience is mediated through social relations of meaning making. In short, a good death is not a single act but the outcome

of a series of social processes and relations (which I term “the dying process”). Yet how did this social script of the good death come to be the dominant contemporary frame for the processes and relations of dying within Western institutional acute care settings? To further explore how these beliefs emerge from, and are interwoven with, the evolution of the hospital, I now turn to a brief history of hospitalized dying.

The Evolution of the Hospital and End-of-Life Care

In Medieval Europe, hospitals were organized and staffed by religious orders, and practices of care focused on the social and moral regulation of the poor as much as on physical well-being (Foucault, 2007; Humphreys, 2001). Through religious conversion of their patients, caregivers believed that the care/convert model would ameliorate the problems of crime, poverty, civil disorder, as well as ill health. During the Renaissance, these practices (evolved as religious philosophies underpinning Salvationist care) began to wane with the emergence of secular scientific discourses, organized in part by new ways of seeing the human body. Foucault (2003) conceptualizes this new way of visualizing the body as “the gaze” (p. ix). Arguing that the gaze marks the move from one epistemological era to another, Foucault asserts that this new way of seeing bodies made possible a new domain of experience and structure for its rationality (p. xv). In this new way of seeing, bodies became more than vessels for souls; they also became mechanical organisms with aberrations. This marked a powerful epistemic change within the hospital, which was evidenced in the transformation of medical practices and the spatial re-organization of the hospital. Patients became individualized and distributed in space where they could be overseen and recorded, where “one could also modify the air they breathed, the temperature of the environment, the water to drink, the regimen, so that the hospital panorama imposed by the introduction of discipline had a therapeutic function” (2007, p. 148). As clinical experience increasingly became a mandated part of medical certification, hospitals became the primary location for this specialized training. In turn, practices of medical specialization became central to the production of new forms of knowledge about “healthy” and “unhealthy” bodies (Armstrong, 1987; Cassel, 1982; Foucault, 2003; Gagan & Gagan, 2002; Weisz, 2003).

The processes of dying within these institutions also underwent radical transformation. Foucault argues that the new way of seeing “opened” the body to the gaze of medicine, in part due to the practice of autopsy (2007). Through autopsies, the search for the “true” cause of death was literally written on the body in the form of physical pathology. The imprint of the disease left on the body’s interior could now be exposed, pointing to its original locus. This required individualizing bodies as bearers of the truth as the gaze transformed death into an individual biological event. This understanding generated new forms of knowledge, both about the processes of dying and the processes of living. *Death became productive* of new knowledge, of new practices, and therefore of new fields of power.⁶ In this manner, the ability to pathologically locate death within individual corporeal form also led to practices of totalization in the documentation of death and its causes for the benefit of the living. This included the requirement for death certificates, as well as morbidity and mortality statistics for managing pathological health “risks” in aggregates of populations (Armstrong, 1987; Rose, 2001).

As I highlighted earlier, many scholars interested in thanatology have asserted that the increased concern for the dying is primarily a contemporary humanist response to the “silence” of those dying in hospital settings. While this narrative has appeal, what is overlooked in this perspective is how new forms of knowledge about death translates to new forms of regulation of the dying process. In the burgeoning medical specialities generated by the organization of the gaze, idiosyncratic anecdotes of terminally ill patients were replaced with systematic observation. These practices begin to demarcate specialist needs for those located within a discrete, medically defined phase—dying. This represents a shift from the passive observation of death’s traces in the pathological

⁶ A particularly clear example of this connection between autopsies and new forms of knowledge emerges from the history of chemotherapy. In *The Emperor of All Maladies* (2010), Siddhartha Mukherjee recounts how the pathologist Stanley Farber became focused on cancer. As a coroner Farber “would try to use the knowledge he had gathered from his pathological specimens to devise new therapeutic interventions” (p. 13). For Farber to understand cancer, he must “first describe it; to describe it objectively, he must first measure it. If cancer medicine was to be transformed into a rigorous science, the cancer would need to be counted somehow” (p. 19). Using this biomedical “gaze”, Farber would go on to patent several of the first chemotherapy drugs, as well as become one of the first advocates for the now ubiquitous “war on cancer.”

corpse to active medical intervention with *living bodies*. Consequently, the rise of palliative care as the dominant knowledge framework to manage the dying process can be conceptualized as the logical extension of the emerging biomedical⁷ model of disease, which requires specialized practices, specialized space, and specialized bodies. As Parsons and Lidz (1967) have argued, death has not been denied by the medical profession but rather an overall acceptance of the scientific reality of death and a rational attempt to control its occurrence by scientific means. This “medical-rationalist” understanding of the dying process highlights that rather than a sequestering and/or silence marked by the *withdrawal* of active intervention, now it is the *application* of specialist knowledge that constructs a dying patient’s identity and course of care. Within these new practices, everyone involved must be mutually aware and openly communicate the “truth” of the dying process. These truths are in turn generative of specific forms of appropriate conduct for those bodies, both for those who give care and for those who receive care in these institutions. Hospitals are now a place of formation and transmission of specialist end-of-life care knowledge, and therefore for the creation, circulation, and distribution of specific relations of power regarding the regulation of these bodies. In exploring hospitals as a critical site within which contemporary practices and understandings of what it means to die well are negotiated, however, it is also necessary to examine how this evolution both informed, and was informed by, the emerging ideas and practices of hospice care.

The History of Hospice Care

Dame Cicely Saunders is widely credited for organizing the first contemporary hospices. The oft-quoted origin story begins in 1948 in England when Saunders—a social worker and ex-nurse—was caring for a young man dying from cancer. As their therapeutic relationship developed, they discussed alternatives to pain control and dying in a hospital ward. Saunders stated she wanted to open a care facility specifically for the

⁷ Following Hahn and Kleinman (1983), I define biomedicine as the predominant sociocultural system for medical theory and practice among Euro-American societies, based on the principles of the “natural sciences” such as biology and biochemistry, whereby the body is the primary, and often only, relevant environment for the understanding of the disease causation.

dying, a place where terminally ill patients could receive better care. On the man's death, he bequeathed her a small amount of money with the famous epitaph: "I will be a window in your home" (Saunders, 2001). This culminated in the opening of St. Christopher's Hospice in 1967. Now a physician, Saunders described the hospice "as something between a hospital and a home—combining the skills with one with the warmth and welcome that belong to the other" (St. Christopher's Hospice, 1967, p. 169). Her goal was to have patients "live their lives as fully as possible" while stimulating "the growth of skill and interest in the care of these patients" (p. 169). Saunders (1978) explicitly included spiritual goals drawn from the Christian faith—the expression of God's love through skilled nursing and medical care—while simultaneously focusing on clinical expertise for symptom relief. Through this work, Dame Saunders became the first clinician to publically succeed in linking expert pain and symptom control, compassionate care, education, and clinical research as critically interrelated components for enabling a good death. As such, this framework of care not only explicitly reinscribed the dying individual as inherently valuable in and of themselves and to society, but also to medical inquiry and expertise.

Focused on the end-stage cancer patient who had a relatively defined prognostic trajectory, Saunders' hospice model emerged from conventional biomedical understandings of the dying process and the need for specialist expertise. This understanding, however, was uniquely tethered to, and articulated through, humanistic considerations of therapeutic relationship building that addressed total pain and facilitated entry into the dying role. Saunders' principal goal was to address the suffering of dying patients or, what she termed, their "total pain." Total pain is defined as the entirety of the individual's suffering—the physical, psychological, social, spiritual, and practical struggles at the end of life, each of which she believed must be addressed in order for the patient to productively explore the journey of dying (Clark, 1999; Saunders, 2001). While innovative medical management of physical symptoms was championed as a core component of the ethical care of the dying, the concept of total pain is what defined this type of care as separate from, and superior to, mainstream medical care. Total pain dissolved traditional divisions between the physical and spiritual care of the dying; as Saunders' (1996) explicitly stated, "the whole [hospice] approach has been based on the understanding that a person is an indivisible entity, a physical and spiritual

being” (p. 1600). In order to address the multi-factorial needs of an “indivisible entity,” then, the therapeutic relationship between clinicians and the dying patient became critically important. While there is no one definitive definition of this relationship, current practitioners construct it as a continuous coproduction between clinicians, patients, and their relations that include feelings of safety, comfort, familiarity, openness, and trust that clinicians are working for the overall well-being of the patient (Canning, Rosenberg, & Yates, 2007; Li, 2004; Mok & Chui, 2004; Solomon & Browning, 2005). The therapeutic relationship ideally facilitates generation of what sociologists Glaser and Strauss (1965) famously coined an “open awareness context,” where everyone is aware that the patient is dying and act openly towards this knowledge (p. 11). With full disclosure of diagnosis and prognosis, open awareness allows the dying individual and their families to acknowledge and accept the impending death, be involved in decisions regarding how remaining time is to be spent, establish goals of care, and engage in activities of closure (Emanuel, Bennett, & Richardson, 2007; Glaser & Strauss, 1965, 1968; Prigerson, 1992; Seale, 1998). Although Saunders never used the term “dying role” to describe this emotional orientation and concomitant activities, she spent a great deal of her time focused on how to best facilitate patients’ and family members’ acceptance of impending death. The importance of this labour is highlighted in her seminal 2001 review for the *British Medical Journal*, where she concluded, even with all the scientific advancement in the field of palliative care, practitioners must remain aware that:

Professionals’ own search for meaning can create a climate, as we tried often helplessly to do all those years ago, in which patients and families can reach out in trust towards what they see as true and find courage and acceptance of what is happening to them. (p. 1601)

I have chosen to define this bundle of patient and family member behaviours, actions, and emotional orientations as constitutive of a “dying role,” and I suggest that Saunders’ implicitly legitimated and gave value to this role in her emphasis on therapeutic relationship building and attention to concerns of total pain.

Within the emerging hospice care framework, the social, emotional, and spiritual dis-eases of dying were now explicitly constructed as the domain of clinicians specializing in caring for terminally ill patients. Again, the dying process became

productive in a new way. It became productive for the dying individual who could now generate a sense of self and social identity even as they faced radical dissolution. It became constructive for their relations and the broader society through the creation of meaning and purpose of the dying process as it provided a model for a good death. It became productive for clinicians who, through compassionate care, developed further specialist knowledge and a specific population upon which to practice their expertise. These care practices also constructed the dying process as generative through new ways of organizing, regulating, and making productive the biological aspects of dying for whole populations.

As the burgeoning practice of Western hospice care increasingly became a model for appropriate end-of-life care, an examination of its history highlights how these institutional practices were coterminous with evolving hospital practices and public understandings of the contemporary good death. In advocating the potential capacity for personal growth within an “indivisible entity” in the process of medicalized dying, Saunders’ opposed the idea that death is predominantly something that just happens to us. The hospice discourse of individual agency gave some control to the process of dying, framing it as one where we can participate and be involved in constructing a good death. In championing the dying process as “the last stage of growth” focused on both “quality of life” and “death with dignity,” the hospice model quickly became a popular medical framework through which to enact a good death in contemporary Western society. Both in the UK and in North America, Saunders’ hospice movement became a touchstone for other medical professionals interested in end-of-life care. One of these clinicians was Dr. Balfour Mount, the future “founding father” of palliative care in Canada.

The Origin of Palliative Care in Canada

In 1974, after reading Kübler-Ross’ (1969) book *On Death and Dying*, the Canadian oncologist Balfour Mount undertook a study of the dying within his own hospital. Finding that his results replicated Kübler-Ross’ assertion that care provided was of “abysmal inadequacy,” Mount began studying the principles of hospice care and even travelled to Dame Saunders’ hospice. While wanting to replicate this form of care in Canada, he felt that the free-standing independent hospice model would be too

expensive to implement, and instead proposed a hospice unit within his hospital. He justified this location in his belief that it would better meet the needs of existing patient populations, facilitate the integration of hospice practices into mainstream medical care, allow for the observation of patient symptoms, and erase the negative stigma of dying (Mount, 1976, pp. 120-121). To facilitate this erasure, he coined the term “palliative” to replace hospice. Taken from the Latin word *pallium*, an outer garment or cloak, the word also describes a protective or ameliorative *action*: how this form of care can cloak the symptoms of terminal illness.

Mount opened the first palliative units in Montreal and Winnipeg in 1975 amidst much administrative reservation. The staffing was based on an interdisciplinary team model and included consult teams to work in other units as well as in home support teams. The patient population for these services were the terminally ill in the last stages of cancer (Mount, 1976; “A Moral Force,” 2005). As defined by the Palliative Care Foundation in 1981, focus of practice centred on the:

[...] active compassionate care of the terminally ill at a time when they are no longer responsive to traditional treatment aimed at cure and prolongation of life and when the control of symptoms, physical and emotional is paramount. It is multidisciplinary in its approach and encompasses the patient, the family and the community in its scope. (quoted in Canadian Hospice Palliative Care Association, 2012a, para. 4).

The two-year pilot programs were deemed a spectacular success. Echoing Saunders’ belief that her evolution of medical expertise was key to generating interest in hospice care, Mount also credited his expertise in oncology for the success of palliative care units within a hospital setting. He stated that his medical background allowed his work to be taken seriously “in a way that it would never have been...had I come out of psychiatry or psychology, even internal medicine” (“A Moral Force,” 2005). Saunders’ ideal of a seamless, interdisciplinary continuum of care at the end of life that was able to encompass all aspects of the embodied dying experience had now officially been imported and operationalized within a Canadian hospital and championed by a surgeon oncologist. As a new category of “palliative” patients emerged from these new practices, this population was further constructed as having specialized needs and so specialized

expertise became increasingly integral to ensuring a good death for this institutionalized demographic.

Palliative care programs quickly spread across Canada and rapidly developed as a medical speciality and academic discipline closely linked to (and even embedded within) oncology programs in teaching hospitals and universities. In little more than two decades from the start of the first palliative units, there were three designated academic chairs in palliative medicine, and seven recognized academic divisions within the 16 medical schools in Canada (MacDonald, 1998). By 1981 there were definitions and regulations of practice at both federal and provincial levels, including self-regulation through the Canadian Hospice Palliative Care Association. By 1998 palliative care had its own awareness and research week in the same way as other diseases and medical causes. Two Senate Reports were released in 2000 and 2005, *Quality End-of-Life Care: The Right of Every Canadian* and *Still Not There: A Progress Report*. While there is no current national strategy on palliative care in Canada, federal and provincial institutions govern aspects of the dying process through legislated programs such as the Employment Insurance Compassionate Care Benefits Program and provincial Palliative Care Benefits Programs.⁸

As palliative care became an established medical specialty, its practices expanded well beyond the discrete concerns of a good death for end-of-life cancer patients. Practitioners now routinely advocate the necessity for their skills to reach a much broader “underserved” population of both hospitalized and non-hospitalized patients. The Canadian Hospice Palliative Care Association (2012b) states that “90% of Canadians who die can benefit from palliative care” (p. 3), yet “only 15-30% have access or receive end of life services” (p. 1). This narrative simultaneously makes visible patient’s previously unattended needs and provides the solution—palliative expertise—to ameliorate them. Clinicians from diverse medical specialties have added their voices to this assertion, including those in neurology (Borasio, Voltz, & Miller, 2001), nephrology

⁸ In Western Canada, interest in extending the reach of palliative care continues with the development of Ministry of Health initiatives such as British Columbia’s integration of palliative care indicators in performance agreements within healthcare regions (Fraser Health, 2007) and Alberta’s Ministry of Health formal recommendation of 36 initiatives for improving access to palliative care (Alberta Health Services, 2014).

(Cohen, Moss, Weisbord, & Germain, 2006), cardiology (Field & Addington-Hall, 1999; Gibbs, McCoy, Gibbs, Rogers, & Addington-Hall, 2002) and pulmonary medicine (Seamark, Seamark, & Halpin, 2007). From its relatively modest origins, palliative care has now become a mainstream medical speciality requiring rules, regulations, and state intervention, and is understood as a social justice issue of basic human rights. Accordingly, similar to its progenitor hospice care, palliative care both advocates and naturalizes specific practices that shape the good death. As the following sections will highlight, however, the practices of hospitalized palliative are both enacted within, and create, complex relations and contexts that do not necessarily and unproblematically facilitate this ideal.

The Expansion of Hospitalized Palliative Care

Increasing Interventions in Conventional Patient Populations

While the palliative patient profile is increasingly diverse, cancer patients continue to be the traditional population for hospitalized palliative care (Luddington, Cox, Higginson, & Livesley, 2001; Ostgathe et al., 2011). There are several reasons for this trend. Many forms of cancer have become relatively identifiable and measurable with established diagnostic and prognostic indicators. There is a multiplicity of treatments available that potentially provide a cure, or at minimum, extension of life. Cancer symptoms are also often responsive to medical intervention, even in the very last stages of life. Yet individuals with cancer also require frequent hospitalization due to the side-effects of these treatments, as well as for symptoms from disease progression. These factors make most cancer-related deaths within the hospital relatively controllable and therefore predictable—key aspects of a good death. By focusing on this population, specialist knowledge about pain control in late-stage cancer, particularly about opioid use, became a defining hallmark of palliative care. This expertise allowed palliative practitioners to become legitimate specialists within the institutional context of the hospital. Specialization both allowed and required ongoing development of “palliative medicine,” comprised of ever-advancing medical interventions for physical symptom management. It is now common to use palliative chemotherapy and radiation as symptom management tools even for those in the last few weeks of life. Equally

common are complex pharmacological regimens (Bell, 2004; Inturrisi, 2002), surgery (Kvale, Simoff, & Prakash, 2003), regular blood transfusions (Glesson & Spencer, 1995; Tanneberger, Melilli, Strocchi, Frenquelli, & Pannuti, 2004) and artificial hydration and nutrition procedures (Dunn, 2007; Steiner & Bruera, 1998). These treatments can allow very sick people to live longer, and at times with more symptoms, which thereby require further interventions in the name of symptom management. Consequently, in the pursuance of quality of life, palliative care has also had an important role to play in *extending* life (Temel et al., 2010).

New Patient Populations

As death and dying are the least prestigious aspects of medical care, the institutional validation of palliative expertise has also required that clinicians show their relevance to patients who are not imminently dying. Consequently, as a naturalized extension of the emerging skills, techniques, and interventions for end-of-life populations, palliative care is also increasingly constructed as “appropriate” for a broad range of patients. In turn, this understanding is both a reflection of, and impetus for, new forms of medical knowledge and expertise that are emerging from the specialty at an ever-increasing rate about all diseased bodies, not just the body with terminal cancer. While cancer still remains the dominant disease for those receiving palliative services, a patient no longer needs to be at the end-stage of cancer to receive this form of care, and the word “terminal” is now rarely used to describe appropriate patient populations. Patients with organ failure, cardiac problems, dementia, ALS, Parkinson’s, and other chronic or life-limiting diseases are all now constructed as benefiting from palliative expertise. Care has even expanded to address symptoms among those still seeking curative treatment. One media article articulates the benefits of this expansion by proclaiming in its title “Palliative care not just for the dying” (Fayerman, 2009). Focused on a 36-year-old cystic fibrosis patient with a double-lung transplant and a correspondingly high symptom burden, the article traces a woman’s struggle to accept palliative care, not for end of life issues, but for pain relief. The clinician interviewed stated that “there are a lot of misconceptions because of the previous focus on dying,” and articulated that while palliative care is about “treating the suffering of patients...we’ve [also] developed broader visions of our roles...the high symptom burden

[of other diseases] makes them suitable to be addressed by palliative care specialists” (2009).

Earlier Interventions

Corresponding to this broadening of pathological breadth is intervention earlier in patients’ disease trajectory. According to the Canadian Hospice Palliative Care Association (2014), palliative care is now understood as a practice that “may be combined with therapies aimed at reducing or curing the illness” (“FAQ”, para. 3). In part, this extension of the temporal scope of care is due to the frustration many clinicians express as they are commonly referred when a patient has only days or hours to live (Cheng, Willey, Palmer, & Bruera, 2005; Mintzer & Zagrabbe, 2007). Advocates of palliative care also have argued that intervening earlier in the disease trajectory provides multiple benefits including superior pain and symptom management (Higginson et al., 2002; Temel et al., 2010); allows for patient and family familiarity with the concept of palliative care (Harding & Higginson, 2003); encourages advance care planning (Morrison & Meier, 2004); minimizes patient and family distress in care transitions (Greer, Jackson, Meier, & Temel, 2013); facilitates stronger therapeutic relations (Craven, 2000; Luker, Austin, Caress, & Hallett, 2000); and, as suggested previously, may even increase length of life. Within the hospital setting, earlier involvement of palliative consultants also allows “in-time” teaching with non-palliative medical staff (Hanratty et al., 2006; Walker, Mayo, Camire, & Kearney, 2013). In short, incorporation of palliative care earlier in chronic and potentially life-limiting disease trajectories is understood as facilitating patients’ quality of life and of a good, if now eventual, death.

The expansion of care, not only in disease breadth but also in temporal depth, requires that palliative expertise does not focus solely on the terminal phase of an illness but is better conceptualized as an “approach.” Although the term is increasingly used by clinicians, there is no mutually agreed definition of the term. Clinicians Kristjanson, Toye, and Dawson (2003) have stated that a palliative “approach” entails “early identification, assessment and treatment” (p. 18), where other practitioners have constructed it as appropriate for those still seeking curative treatment (Schofield, Carey, Love, Nehill, & Wein, 2006) or who do not need specialist palliative services (Street, 2007). Yet with a palliative approach being used when curative options are still being actively explored, as

Wilson and Seymour (2007) have argued, receiving this type of care can mean that a patient still has 15 years to live. More commonly, advocates have stated that the palliative approach is appropriate for those located within a medically liminal zone, or what Bern-Klug (2004) calls “the ambiguous dying syndrome,” where patients are at a greatly increased risk of death, although the timing is highly uncertain (p. 55).⁹

Implications of Practice Expansion

While advocates of palliative care expansion assert that their practices are appropriate for a broad spectrum of diseases, for all their symptom burden similarities to cancers, they are not coterminous. Many of these diseases do not have a stable trajectory, making end-of-life prognostication (and therefore planning) difficult if not impossible (see Appendix A). Patients with “life-limiting” diseases may live with their symptoms for many years, experience several near-death episodes, and, with medical intervention, once again stabilize for significant periods of time. Based on these past experiences, they may expect this cycle to continue indefinitely. Many, if not most, have not had a physician tell them, in clear language, that their disease is considered terminal (Brickner, Scannell, Marquet, & Ackerson, 2004; Edmonds & Rogers, 2003; Mack & Smith, 2012). Based on these understandings, non-cancer patients may often assert an autonomous “right” to continue pursuing curative, experimental, and/or investigative treatment, regardless of prognosis or efficacy. While late-stage cancer patients may also claim this right, palliative clinicians’ detailed knowledge of cancer trajectories translates to a (relative) certainty in determining appropriate treatments and care pathways. Finally, patients with multiple illnesses may fundamentally challenge clinicians’ ability as to how to best address the complex symptoms that can arise as each disease can have differing and, at times, contradictory treatment needs.

Complicating matters further, many practitioners have asserted that less emphasis is being given to therapeutic relationship building and practices of addressing

⁹ For example, palliative clinicians are now encouraged—and encourage other clinicians—to use the “surprise question,” asking “Would I be surprised if this patient died in the next twelve months?” (Harris, 2007; Moss et al., 2010; Murray & Boyd, 2011; Weisman & Meier, 2011).

total pain as priority increasingly is centred on physical symptom management, medical goals of care, and rapid transitions (Field, 1994; Kristjanson, Toye, & Dawson, 2003; McNamara, 2004). Concerned clinicians have highlighted how attention to patient and family member suffering is often understood to be the responsibility of specific (less prestigious) professions, commonly done off “the sides of their desks,” such as nurses, part-time social workers, and pastoral support, than by the emotional labour skills embodied in daily practices of all palliative clinicians (Clark, 2002; Field, 1994; Kearney, 1992; McNamara, 2004). In a revealing audio interview with the noted palliative specialist Dr. Meier, for example, when questioned about her belief that emotional and existential issues are best addressed by pastoral care rather than as part of the training and responsibility of a palliative care physician, she responded “I think that’s the ideal. The real...the development...is a work in progress” (Heffner, 2011). This understanding has led to some clinicians to assert that palliative care in hospitals is primarily palliative medicine—the provision of symptom management with little emphasis on any other aspect of care. Consequently, the spiritual, emotional, and social distress that early practitioners’ understood as integral to their practice may either be marginalized, or alternatively, rendered solely through a medical lens as a pharmacological issue.

The assertion of a growing medicalization in palliative care is not new (Abel, 1986; Georges, Grypdok, & Dierckx De Casterle, 2002; James & Field, 1992). As suggested in my review of Foucault’s evolution of death within the hospital, a perspective echoed by other scholars, the medicalization of palliative care should be seen as the *expected* rather than unintended outcome of its growth, where medical practitioners have been central to its development (Clark, 2002; McNamara, 2004). As biomedical evidence-based practices and research emerge as the benchmarks for best practices in palliative care, this framing ensures that measurable components (i.e., pain and symptom management) are given priority. Non-physical interventions then are forced to either compete for visibility in the same biomedical and institutional language or languish. Hibbert et al. (2003) frame this as the prioritization of the “determinate” aspects of palliative medicine’s technical contributions over the “indeterminate” expertise represented by practices of addressing total pain. Taken to the extreme, advances in palliative medicine in the name of quality of life can shift attention entirely away from dying, and, in “talking about and focusing upon palliation [of physical symptoms], people

may stop talking about and confronting the fact that the individual is going to die” (Biwas, 1993, p. 135).

Further, in focusing on acute physical symptom management, stabilization, and rapid discharge, the impetus for care may be prioritized by the institutional needs of organizational efficiency regarding the biological processes of dying. This business modeling valorizes a “bureaucratic model” of task-based care over therapeutic relationship building, where palliative clinicians are institutionally rewarded for adopting system characteristics as the determining factor than patient or even clinician preferences in end-of-life care (Bruce & Boston, 2008; Drought & Koenig, 2002; Georges et al., 2002). In their study of hospitalized dying published 40 years ago, Glaser and Strauss (1968) detailed the empty space of days and in some cases weeks “when nothing is happening to the patient” (p. 197) except waiting for death. This once-valid clinical practice and temporal space no longer exists in the hospitalized care for the dying; in order to remain hospitalized, a patient must be receiving some type of specialized treatment unless they are clearly in the last hours of life. The requirement for efficient transitions through the institutional care pathway for palliative patients—what I term the “terminal care pathway”—requires clinicians to spend a significant amount of their daily work, whether successful or not, focused on discharge concerns: strategizing where the patient will be discharged to (home, hospice, or long-term care), what services need to be in place for discharge, and how to stabilize the patient for this transition. Alternatively, if this external transition cannot be facilitated, focus then centres on how to best withdraw treatments and facilitate death efficiently within the hospital.

Taken individually and as a whole, these aspects of practice expansion can complicate the desired outcomes of an affective economy of hospitalized palliative care, where the ability to facilitate a good death may be in tension with the realities within which they deliver care. Clinicians attempting to juggle earlier and increasingly complex interventions, expanding populations of care, and the rise of business modeling may therefore work within irreducible tensions in their ability to simultaneously meet the needs of their patients, the patients’ networks of relations, fellow clinicians, and the institutions of care. This complexity both constructs and reflects two contradictory, but not necessarily antagonistic, discourses of truth that constitute hospitalized palliative

care. The first is that palliative care is a specialty designed to meet the unique needs of those at the end of life while *at the same time* is appropriate for those who are not at the end of life. The second discourse champions empathic claims to patient and family member autonomy *and* clinicians' medico-cultural authority to define direction and outcome of care. These potentially differential priorities and discourses can then trouble the capacity of all involved to enact the good death. In these instances, a significant investment of clinicians' emotional labour is then required to negotiate the tensions that both reflect and construct the ideal of an individualized good death, the expansion of expertise and audience, and the practical maintenance of the hospital as an institutional organization.

Organization of Dissertation

This introductory chapter focused on providing an overview of contemporary understandings of the good death from a diversity of perspectives. I explored how these narratives have informed current practices of dying well, making particular reference to the development of hospitalized palliative care. I further examined this rise through increasing specialization, the expansion of appropriate patient populations, and bureaucratic mandates. This discussion lays the foundation for Chapter Two, where I delineate my own iteration of an affective economy by combining the work of Michel Foucault on discourse and governmentality, Arlie Hochschild's scholarship on emotion work and emotional labour, and Brian Massumi's thoughts on affect. I also borrow significantly from Sara Ahmed's work on affective economies, and Analiese Richard and Daromir Rudnyckij's discussion on economies of affect. This second chapter also details my own understanding of an affective economy specific to hospitalized palliative care. This understanding is informed by a review and synthesis of literature on institutionalized end-of-life care as a form of social governance, through which I identify six (idealized) outcomes of hospitalized palliative care. Through these desired outcomes of care that ideally result in the good death, I trace how the dying process is given structure and made productive.

Chapter Three turns to an ethnographic description of my fieldwork, including discussion of the ethical and personal challenges of doing research with institutionalized

terminally ill populations and the clinicians that care for them. This chapter also details my emerging understanding of hospitalized palliative care as an often uncertain practice, even in “ideal” situations where the patient is clearly at end of life and expresses open awareness. I build on this discussion to suggest that the key currency in negotiating this ambivalent and uncertain affective economy is the ability to claim narrative authority to define understandings of the patient’s emergent physical state. This authority is ideally negotiated through narrative processes of coauthorship, which naturalize truth claims about, and emotional orientations to, the dying process. However, I suggest that these negotiations may both generate and reflect a range of understandings, and result in a range of outcomes that I have termed the seamless “good death,” the visibly negotiated “good enough” death, or a continually contested process that can only result in a physically “peaceful” death.

In the remaining chapters I examine three emotional labour practices of palliative clinicians that work to facilitate the six idealized outcomes of care: therapeutic relationship building, addressing total pain, and offering the dying role. Chapter Four focuses on therapeutic relationship building as the central domain of practice that defines palliative care. I describe what constitutes therapeutic relationships at the end of life, how clinicians describe this work, how these relations are enacted *in situ*, and the challenges present in developing these relationships. I reference Foucault’s thoughts on contemporary “confessional society” to suggest how therapeutic relationship building can be understood as an emotional labour practice that shapes appropriate forms of conduct for everyone involved in the provision and uptake of hospitalized palliative care. Chapter Five centers on palliative clinicians’ emotional labour practices of addressing total pain. With particular reference to the work of Cicely Saunders and David Clark, I explore how addressing total pain attempts to collapse problematic experiences of dying into specific emotional orientations and outcomes for the benefit of all involved. This exploration occurs through my use of interviews, fieldnotes, and three diverse examples where the concept of total pain is invoked to assign specific meaning to a patient’s experience. I also discuss the social, professional, and institutional tensions within which clinicians attempt to address total pain. Chapter Six describes a third central emotional labour practice of palliative clinicians: their use of specific narrative techniques to orient patient and family member to behaviours and activities that collectively constitute the dying role.

Similar to the previous chapters, I explore how this occurs using examples taken from interviews, fieldnotes, and an extended account to highlight how these emotional labour practices both create and reflect a complex affective environment that often requires continuous negotiations by all parties.

Collectively, Chapters Four, Five and Six provide specific moments to explore how hospitalized palliative clinicians' emotional labour practices are enacted and negotiated *in situ*. In analyzing the moments that constitute these practices, I highlight the specific narrative techniques—framing rules, feeling rules and rule reminders—that circulate and privilege certain understandings of the emergent physical states of the patient. I suggest how these relational enactments can be understood as governmental in their attempts to solidify and order the dying process, while simultaneously naturalizing specific emotional orientations to this process. In sum, these chapters give flesh to an affective economy of hospitalized palliative care where clinicians' emotional labour practices are understood as socio-historical relations of power/knowledge that condition capacity and conduct at the end of life in ways that attempt to maximize the social productivity of institutionalized dying. In this sense, my research echoes previous studies that have found clinicians to be privileged “cultural brokers” in the coauthorship of “appropriate” emotional orientations for purposes of governing the dying process (Timmermans, 2005; see also Field, 1996; Kaufman, 2005; May, 1991; Perakyla, 1991).

At the same time, my research contributes to the study of dying in the following ways. First, no one has yet conceptualized hospitalized palliative care as an affective economy. In doing so, the specific moments and networks of relations that constitute this form of care become understandable as a cultural system that attempts to make human capacities *productive*, even at the very end of life. Secondly, in using this framework, I am able to forward an understanding of clinicians' privileged position as one that often occurs within *active and sustained negotiations*, where emotional orientations to dying process are generated, validated, and/or contested within the perceived rights and obligations of all involved parties. This then requires that attention be given to the specific moments and techniques within which emotional labour is enacted. Third, this framing encourages an understanding of hospitalized palliative care in contemporary Canadian hospitals as necessarily *fluid and ambivalent*, defined as much by its practices

of negotiation as by mutuality and cooperation. Through these contributions, I suggest how conceptualizing the collective emotional labour of those providing, receiving, or otherwise involved in hospitalized palliative care as an affective economy may add to our understanding of the dying process within these institutional settings.

Chapter Two: An Affective Economy of Hospitalized Palliative Care

We are not at all concerned that a patient or family should come to think as we do but that they should find strength in their own inner values. (Saunders, 1992, p. 4)

The last stages of life should be seen...as life's fulfillment. It is not merely a time of negation, but rather an opportunity for positive achievement. One of the ways we can help our patients most is to learn to believe and expect this. (Saunders, 2006, p. 79)

Introduction

This chapter defines an affective economy, and explores how it might be useful in describing and understanding hospitalized palliative care. First, I begin with a review of Michel Foucault's work on discourse, governmentality, and technologies in order to conceptualize how historical relations of power/knowledge shape human capacity and engender specific forms of conduct. I move from this macro-level interest in discursive formations to a micro-level interest in emotions through Arlie Hochschild's work. In her understanding, the central feature of subjectivity is the work we undertake to regulate our own and others' emotions within these relations of power/knowledge. I then review scholarship on end-of-life care that constructs care practices as relations of knowledge/power that shape capacity at the end of life. This review also encompasses those studies interested in how clinicians' emotional labour is employed to evoke particular emotional orientations to the dying process, and thereby produces both subjects and subjectivities. From this literature I synthesize six ideal outcomes of care, providing a theoretical pathway in which to combine Foucault's and Hochschild's concerns, and to understand hospitalized palliative care as a set of practices for ordering the dying process that attempts to generate both individual meaning and social order. I then suggest how this body of research may be complemented and extended by

conceptualizing these practices and desired outcomes as part of an affective system. This assertion is grounded within a discussion of affect originating from the work of Spinoza, and includes Brian Massumi's thoughts as to how affect can be analyzed through its solidification as emotion. This leads to an examination of emotions within the affective economic frameworks offered by Sara Ahmed, Analeise Richard, and Daromir Rudnyckj. In the final section of this chapter, I combine all of these ideas into my own delineation of an affective economy specific to hospitalized palliative care. As I synthesize this scholarship in a unique way, the final section delineates a theoretical framework that builds on and extends existing literature on affective economies, as well as applying the concept to a new context—hospitalized palliative care.

Foucault – Discourse, Governmentality and Technologies

Discourse

Foucault (1972) invokes the term “discourse” to describe the organization of particular sequences of signs that enable “specific repeatable relations to objects and subjects” (p. 140). Foucault uses the concept of discursive formations in relation to his analysis of large bodies of knowledge such as science, medicine, and political economy. Discursive formations (also known as discursive practices) are a set of potentially contradictory but stable practices of organization that produce the historically-specific truth conditions of people's lives and the categories of their epistemology. In discursive practice, “the exercise of power consists in guiding the possibility of conduct and putting in order the possible outcome” (Foucault, 1983, pp. 220-221). These practices of guidance construct, naturalize, and (re)produce what can be knowable. Discourse is the medium through which power relations condition the possibility for acting and being acted upon.

Discursive power is not a repressive force but a positive and generative one, “presupposing rather than annulling [peoples'] *capacities* [emphasis added] as agents” (Gordon, 1991, p. 5). For Foucault, then, the capacity to act is “the source of dynamism in social life” (Li, 2007, p. 276). I find the term capacity to be a particularly useful one in understanding how relations of power simultaneously create subjects and subjectivities. I

therefore borrow from and extend Gordon's (1991) use of the term. I define capacity as the relational ability to act; to be able to do, experience, or understand something. Capacity is a reflexive term as it describes a condition that develops through relations of power where the ability to act emerges through the ability to be acted upon. In this sense, capacity describes both the ability to perform or produce an action, as well as the ability to receive, hold, or absorb actions. This understanding of capacity provides a pathway to understand how, within discursive formations, the one over whom power is exercised is "thoroughly recognized and maintained to the very end as a person who acts; and that, faced with a relation of power, a whole field of responses, reactions, results, and possible interventions may open up" (Foucault, 1983, p. 220). As the ability to "act on actions," the exercise of power then engenders (instead of decreases) a subject's or object's capacity to act, albeit in particular ways, at particular times, for particular outcomes. Therefore, for the purposes of this work, I define autonomy as an individual's personal and social capacity to consider, decide, and pursue a course of action. An analytics of discourse, therefore, requires inquiry into the mutual constitution of knowledge and power that grounds the socio-historical conditions for, as well as the expression of, these capacities. In relation to understanding the practices of hospitalized palliative care as a discursive formation, the following questions emerge: First, how can these practices of care be understood as manifestations of socio-historic relations of power and knowledge? Second, what are the particular forms of power and knowledge that emerge from this discursive practice? Third, how do these practices generate specific forms of capacity for everyone involved?

Governmentality

As the definition of the term evolves somewhat in the course of his work, I use an interpretation that arises from Foucault's later writings and references other scholarship on governmentality. For the purposes of this work, governmentality describes all the practices that guide conduct resulting in the mutual formation of modern subjects (populations) and modern subjectivities (individuals). Governmentality is:

[...] all those ways of reflecting and acting that have aimed to shape, guide, manage or regulate the conduct of persons—not only other people but also oneself—in the light of certain principles. What makes these forms of reflection governmental...is their wish to make themselves

practical, to connect themselves up with various procedures and apparatuses. (Rose, 1996, p. 287)

Foucault (1991) argues that the exercise of this contemporary form of governance is primarily a consequence of external sovereign and disciplinary mechanisms becoming internalized mechanisms of self-governance, and generated through neoliberal discourses that constitute governance at a distance. This includes the shaping of desires, habits, aspirations, and beliefs within specific discursive practices that he interchangeably termed techniques or “technologies” (O’Farrel, 2006). These technologies set the conditions of possibility for action in a certain way, at certain times, for certain outcomes, thereby “arranging things so that people, following only their own self-interest, will do as they ought” (Scott, quoted in Li, 2007, p. 277).

The concept of governmentality encapsulates how specific discursive formations are aggregated practices that organize the capacity of individuals to self-govern. The analytic of governmentality then requires attention to two seemingly disparate, but simultaneous, processes. First, it asks us to examine the technologies through which we generate and self-govern our subjectivities based on “common sense” knowledge(s) and personal aspirations. This includes inquiry as to how discursive practices generate individuated subjects and domains that are differently formed and positioned, assembled with specific powers, and with particular capacities for action. Second, the analytic of governmentality asks how these practices of individuation also operate as technologies of totalization, where we are constituted as governable and administrable on the level of aggregate populations (Dean, 2002; Li, 2007).

Technologies

Foucault defines technologies of power as practices for administering society that are designed to shape individuals into populations, and to regulate the conduct of those populations (1988). In contemporary Western society, technologies of power primarily reference all the practices that shape the reproduction, health, living, and working conditions of groups of people that are designed to increase the capacity of the population as a whole. These practices include statistical analyses and modeling, institutional administration policies, legal codifications, and other constructions of

individual-as-citizen with rights and duties. Foucault (1988) asserts that these technologies determine the capacity of individuals and submit them to certain ends through forms of conduct that are totalizing, “objectivizing the subject” (p. 18). Within an examination of hospitalized palliative care, technologies of power would then reference all the practices that construct patients as part of a bifurcated population: those that are appropriate for palliative services (and who accrue benefits from this designation) from those who are not. In this context, technologies of power reference clinicians’ use of specific terms, phrases, and descriptors, chart notes, admission and discharge policies, medical meetings, care plans, advance care directives, criteria for financial assistance, prognostication tools, and other care protocols developed by regulatory bodies such as Canadian Hospice Palliative Care Association.

Technologies of the self, alternatively, are undertaken by individuals in the ostensible self-formation of identity. Foucault (1988) argues that these technologies:

[...]permit individuals to effect, by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality. (p. 18)

Technologies of the self are the practices through which we generate our individuality and sense of increased capacity. At the same time, these practices are regulatory—they are the ways in which we self-organize our bodies, our thoughts, and our conduct. Everyday examples would include exercise, therapy, and any of the other myriad forms of individuated self-improvement. In the context of hospitalized palliative care, it may seem paradoxical to examine techniques designed to increase the capacity of individuals when the expected outcome for that individual is death (or the end of capacity). However, by engaging in techniques such as building therapeutic relationships and acceptance of the dying role, patients may come to understand themselves as facilitating personal growth and meaning, even as their previous capacities to act within day-to-day life wanes.

Foucault (1988) asserts that neither technologies of power nor technologies of the self operate independently; it is the interrelation between the two that constitutes an

understanding of governmentality within particular discursive formations (p. 20). These modes of action and thought become governmental when they are expressed as procedures and mechanisms that establish them as scientific facts and taken-for-granted “common sense.” Hospitalized palliative care may then be examined as a productive intersection between these technologies to understand how they form a type of governmental “transactional zone” (Rose, 2001); a place where concerns for regulating population-level processes of morbidity are symbiotic with the rise of palliative care as a medical speciality and personal processes of self-development at the end of life. In other words, these technologies are specific forms of activity that make contemporary hospitalized dying “thinkable and practicable” to both practitioners and upon those who it is practiced. Our experience of life, or in this instance dying, is then understandable as an interrelation between knowledge, “types of normativity,” and subjectivity in a particular culture at a particular time (Foucault, 1990, p. 153). An examination of hospitalized palliative care through Foucault’s framework of technologies examines both care provision and uptake as discursive practices that shape capacity through relations that are simultaneously totalizing and individualizing.

Foucault’s system of inquiry about the conditions of possibility through the concepts of discourse, governmentality, and technologies is useful to examinations of hospitalized palliative care in the following ways. First, hospitalized palliative care can be understood as a specific socio-historical discursive formation that conditions capacity at the end of life through relations of knowledge/power that have generated the dying process as an object of medical expertise for the governance of populations. Second, practices of specialist palliative care are understood as an intersection of technologies of the self and technologies of power as they are governmental in their attempt to shape certain forms of conduct at the end of life. Third, a focus on technologies highlights how this discursive system is enacted. As technologies of the self, clinicians’ sharing their knowledge and expertise of the emotional requirements of dying ideally leads to forms of self-governance (conduct) that makes the dying process productive for both individual patients and their social networks as “the last stage of growth.” As technologies of power, these practices generate new forms of knowledge and expertise that engender the ability to regulate the dying process of the population as a whole. Hospitalized palliative care should be understood as both grounded in, and generative of, specific

socio-historical relations of power/knowledge that shape the conditions for capacity (i.e., the subjective ability to experience, understand and act) and conduct (i.e., management of self and others' behaviours and expressions) at the end of life.

As noted by many critics, however, Foucault privileges discourse over experience, and his thoughts can be read as over-deterministic (Dumas & Turner, 2006; Simons, 1995). Foucault (1991) himself did not shy away from this characterization of his work, agreeing that his analysis does not refer to consciousness or “speaking subjects” but the terrain that make experience possible (p. 58). Consequently, as I am also interested in how these subjectivities are *experienced* and *expressed* within the institutional organization of dying, I now turn to the study of emotions, using the work of Arlie Hochschild.

Hochschild – Emotion Work, Framing and Feeling Rules, and Emotional Labour

Emotion Work

I include Hochschild's writings on emotion work to understand how we enact the discursive practices that shape the social organization of dying. Hochschild (1979) defines emotion work as “the act of trying to change in degree or quality an emotion or feeling” (p. 561). Emotion work, therefore, is the attempt to reconcile any difference between what a person feels and what they believe is the appropriate feeling response for themselves or another. Her account of emotion is a theoretical position which she describes as located between Goffman's focus on consciously designed appearances and Freud's insistence on unconscious intrapsychic events. While her perspective of the self as “an emotion manager” borrows from both theorists, in her words “it squares completely with neither” (p. 555). Here the regulation of emotion is a core component that constitutes both the self as well as all social processes the self engages in. This active structuring of feeling(s) means that emotions are “open-ended”—they are not static, they differ between individuals, and they are constituted through interaction where “social factors enter not simply before and after but interactively during the experience of emotion” (Hochschild, 1983, p. 211).

Framing Rules and Feeling Rules

There is an assumption in Western society that our own (and others') feelings have rights and duties directly applied to them. Hochschild asserts that these assumptions arise from "framing rules," the implicit social norms of what a person ideally understands they should feel within specific contexts. It is through these framing rules by which "we ascribe definitions or meanings to situations" (1979, p. 566). These framing rules create social cues—"feeling rules"—of how these understandings should be appropriately organized and expressed. Drawing on Durkheim, Geertz, and Goffman, Hochschild (1979) explains these rules as the "underside" of ideology, where ideology is "an interpretive framework...[that] can be described in terms of [emergent] framing rules and feeling rules" (p. 566). The direction and content of these rules reflect patterns of social membership and are subject to change as ideological changes and political conflict occur, where the individual adopts new rules for reacting to situations based on the acceptance or rejection of the ideological changes. If these positional cues are misunderstood or ignored, there may be an invocation of "rule reminders," which she conceptualizes as public "claims and callings for an account [of these feelings]," in order to shape the appropriate extent, direction, and duration of emotions (p. 564).

Hochschild argues that through adherence to these rules, individuals induce or inhibit feelings so as to render them appropriate to a social situation. Consequently, these feeling rules are socio-emotional frames, where subjectivity is constructed through emotional responses generated by expectations that inhere in specific social situations. However, she asserts, emotion work does not necessarily have one unitary direction. Emotion work can be done by the self on the self, by the self on others, or by others upon oneself, and it commonly involves multiple considerations across a range of relations. Further, Hochschild (1979) constructs three types of emotion work to illustrate her point. First, emotion work can be cognitive in its attempts to change images, ideas, or thoughts in the service of changing the feelings associated with them. Second, this can be embodied work, in an attempt to change somatic or other physical symptoms of emotion. Third, this work can be expressive, in an attempt to change expressive gestures in the service of changing inner feelings (p. 558). She argues that these types of emotion work are distinct only in theory—in practice they often go together as a collective response to feeling rules.

Emotional Labour

Hochschild (1983) extends her concern with the purpose of emotion work in exploring the management of emotions by others, including institutions and, more specifically, commercial enterprises. Here she designates emotional “labour” as distinct from emotional work, where the former requires an economic incentive “to induce or suppress feelings in order to sustain the outward countenance that produces the proper state of mind in others” (p. 7). She uses a Marxist definition to distinguish emotion work as a private act (based on its use value) from emotional labour as a public act (based on exchange value) (p. 7). In the most general sense, emotions are currency in that they are the expressible property of belonging to a particular episteme, and the result of engaging in specific forms of emotional labour. They are currency in a more literal definition as well—both the labour involved in generating specific emotions, and the outcome of this labour, can be valued and exchanged between individuals and/or groups as a form of social payment (Hochschild, 1979; Lutz & White, 1986). Here both the process (i.e., labour to produce specific emotion) and the outcome (i.e., expression of the specific emotion) are valued. And, as Hochschild (1987) highlights, at the most extreme end of the economic spectrum emotions gain quasi-commodity status, valued and traded within an impersonal financial framework (see also James, 1989).

In defining emotional labour, Hochschild’s focus centres on this labour as a commodity, and how the worker becomes alienated from their labour for the ultimate benefit of others. As powerful as this analysis is, it does not leave much conceptual room for the understanding that, in most contexts, to paraphrase Goffman (1959), emotions are a form of cultural currency that connect and transect both the public “front stage” and private “back stage” personal spheres. Hochschild attempts to address this complexity with her concepts of “surface acting” and “deep acting” (1979) but her examples primarily relate either to the public business sector (e.g., paid, usually low-wage, employees) or the private sphere (e.g., relations between family members). While Hochschild addresses how emotional labour is valued for both its processes and outcomes, what remains underdeveloped in her work is the conceptual treatment and analysis of forms of employment that may require people to engage in emotional labour

simultaneously on all three levels—on the self, on others, and by others on the self within contexts that are neither purely public nor private.¹⁰

Using Hochschild's work to examine the practices of hospitalized palliative care as a discursive system provides specific terms for the relational practices that constitute this form of care: emotional labour, feeling rules, framing rules, and rule reminders. These terms generate a vocabulary from which to trace specific human processes—relations, behaviours, and actions—through which conduct is shaped for everyone involved in the provision and uptake of hospitalized palliative care. As Hochschild understands emotion work to have use-value to the individual and emotional labour to have exchange-value to collectivities, her thoughts provide a theoretical pathway to comprehend how emotions at the end of life (and the regulation thereof) are governmental. The emotional expression of patients and family members is then understood as a form of work in response to these framing and feeling rules, which ideally result in “naturalized” understandings and actions that shape direction and outcome of care. The relational components of these concepts highlight that there is no unitary direction to this work—patient and family members' labour may be directed externally towards clinicians as well as inwards towards the self. By focusing on the multi-directional aspects of these practices, Hochschild's thoughts can also be used to explore how engagement shapes clinicians' own emotional orientations to their work. As Hochschild (1979) states, her perspective provides “a lens through which to inspect the self, interaction and structure” simultaneously (p. 551). Consequently, while others have used the term emotion “management” to encompass both the use-value and the exchange-value components of Hochschild's differential terminology, I consciously use her term emotional labour to render visible the Marxist foundations of her awareness. This framing of emotional labour as having both use-value and exchange-value also draws attention to how this work is done within contemporary health care institutions that

¹⁰ Hochschild implicitly acknowledges, but does not resolve, this problem. In her 1983 publication of *The Managed Heart*, she argued that employees in positions requiring independence and training such as social work, law, and medicine are not emotional labours “due to the level of control they have over how emotional labour is performed” (p. 153). In the 20th anniversary edition of this same work, while she acknowledges that these, and other professionals, do carry out emotional labour, Hochschild (2003) does not pursue this change in thought any further (p. 200).

are manifestations of the interface between public and private spheres. Further, the term highlights how, as is in any discussion of economies, labour is a fundamental concept; that is, the measure of work done by human beings. In this understanding, the relations that constitute hospitalized palliative care are an embodied articulation of the intersection between technologies of power and technologies of the self. As such, they enable humans' capacity to do, experience, and understand the dying process within historically contingent framing and feeling rules that emerge from palliative expertise. Through this labour, all parties are involved in negotiating, validating, and/or contesting these rules that collectively work to orient and legitimate understandings of hospitalized palliative care.

End-of-Life Care Practices and the Organization of Dying within Institutional Settings

To further explore hospitalized palliative care as a discursive formation constituted by governmental practices of emotional labour that organize the dying process, I now turn to an interdisciplinary review of scholarship that identifies specific outcomes of these practices. The researchers I include in the following sections offer productive bridges from the theories of discourse, capacity, and emotion as set out by Foucault and Hochschild to a more specific consideration of end-of-life care practices. A review of this work highlights how relations of power/knowledge shape the conditions of possibility for capacity at the end of life, as well as how we labour to evoke particular emotional states within these relations. In this literature, the need to organize and regulate the dying process is understood as the central function of end-of-life care, and the emotional orientations to this process are generated and experienced within these practices of organization. Collectively, I synthesize this research within a framework of six (idealized) outcomes of palliative care that work to organize the dying process within institutional settings. First, patients and family members willingly acknowledge the dying trajectory and take on the roles and responsibilities that accompany this open awareness. Secondly, due this acceptance, patients and family members, together with clinicians, are able to coauthor meaningful end-of-life narratives to understand the dying process as the last stage of personal growth and as the “natural” culmination of life. This

then leads to the third outcome: ensuring a minimum of social disruption that the dying process can generate. Fourth, these practices naturalize the direction and outcome of care, thereby providing both efficient workflows and patient transitions through the terminal care pathway. Fifth, by meeting the above criteria, clinicians are simultaneously able to identify as compassionate *and* efficient care providers. Sixth, these practices work to generate knowledge about the biological aspects of dying process and the emotional needs of those involved in it, making certain that further specialist intervention is both required and desired by all parties. Through clinicians' emotional labour practices designed to facilitate these desired outcomes, the dying process is given structure and made productive by achieving the goal of a good death.

Acknowledgement of the Dying Trajectory

In a hospital setting, the ways in which dying patients and their social networks understand and express their experiences are subject to framing and feeling rules that are never entirely within their control. The authors in this section understand hospital clinicians as the central social group that provide the rules for ordering the uncertainty and fragile hope offered by medical interventions at the end of life, and for mediating the moral anguish of dying (Field, 1996; Holmes, Perron, & Savoie, 2006, Kaufman, 2005; May, 1992; Perakyla, 1991; Timmermans, 2005). These scholars focus on how, in the desire to order this uncertainty, hospital clinicians provide a set of social expectations around what it means to be "dying," how one comes to be dying, and, especially, what one is to do upon being labelled as dying. Examination centres on clinicians as "moral entrepreneurs" that shape the "moral career" (Field, 1996) of the dying patient, where focus is given to the ways in which medical professionals present patients with information designed to impact a patient's decision in a particular desired direction. Subsequently, these authors explore the rules and reminders that are generated through therapeutic relationships, including examining specific emotion management techniques and conversational tactics that "reconstruct" sick patients as dying patients. These practices are then understood as naturalizing both the process and outcome of this emotional labour.

Perhaps the most detailed study as to how this process is organized in Western hospitals comes from sociologists Barney Glaser and Anselm Strauss (1965) in their

work, *Awareness of Dying*. They construct emerging awareness of an impending death as a step-wise progression of increasingly shared and explicit “awareness contexts.” They assert that these contexts are primarily constructed through interaction with hospital staff who control the flow of relevant medical information. Addressing how these contexts—and the interactions that construct them—are evolving and dynamic, Glaser and Strauss suggest that in the strategic management of difficult news, clinicians order a coherent “dying trajectory” that provides a “non-scheduled status passage” to facilitate emotional acceptance of the dying process by regulating the emotions of patients, family members, and staff. Building on this seminal work, others have examined the ways in which open awareness context functions as a “role” that works to reinscribe the dying person as a continuing, valued member of society. In this body of literature, by acceptance and public acknowledgement that they are dying, patients are accorded a dying role with specific rights and obligations, including the requirement to model a good death (Emanuel et al., 2007; Prigerson, 1992; Seale, 1998).

Others have used different descriptors while concerning themselves with the same relations being described. Timmermans (2005) articulates construction of desired subjectivities at the end of life as a function of “death brokering,” which is a collective term for all the activities hospital clinicians undertake to make death meaningful. This work is accomplished by patterned interactions of talking, or what he terms “cultural scripts,” that guide the relational negotiations necessary for a “culturally acceptable passing” including practices that “rationalize the inevitability of [death’s] occurrence with a classification of its causes” (p. 993). However, he also adds to Glaser and Strauss’ (1965) understanding of how awareness contexts are negotiated by suggesting that *emotional* ways of knowing need to be recognized as equally important as cognitive and psychological constructions. In Timmermans’ (1994) framework, emotional orientations to the dying process need to be included as “[t]he disclosure [of knowledge of an impending death] causes an emotional crisis which undermines all taken-for-granted definitions of self and identity” (p. 329). He therefore adds three possible stages to open awareness: the first stage is “suspended” (where the information is disregarded by patients and families); the second stage is “uncertain” (when the worst parts of the information are disregarded); and the third is “active” (when there is full acceptance of the diagnosis) (p. 332). Similarly, Mamo (1999) argues for the need to address how

emotions influence awareness contexts as there are multiple “interactants” who create meaning of the dying process through “webs of conscious knowledge *emotional responses*” [emphasis added] (p. 33). Regardless of terminology, in examining the emotional labour practices that both construct and reflect awareness contexts, these authors construct the ideal dying process as requiring open acknowledgement, constructed as a “natural” corporeal phenomena (even if occurring in an institutionalized context), and as emotionally productive.

Within an open awareness context, a patient’s courage in accepting impending death is the one realization that is the most admired as making life easier for everyone and that implicitly positions courage a means for reframing and reducing emotion (Seale, 1995, 2002; Treweek, 1996). Patients (and family members) who do not conform to this emotion ideal are often labeled using psychological language, such as being in “denial” (Fischer, Tulskey, & Arnold, 2000). Therefore, any “unresolvable” anxieties or uncertainties inherent in facing one’s mortality can now be defined in terms of psychosocial problems in need of resolution through the emotional labour expertise of palliative clinicians (or other medical specialists). This process is one in which obligates the dying individual and their social networks to take these sense-making narratives (and accompanying subject positions) as their own understanding of the experience of dying. In this way, patients are socialized to accept and participate in a preexisting definition of their own dying process while still claiming it as their own. The pedagogy of open awareness is therefore also pedagogy of desired behaviour and subjectivity (McNamara, 2004; Perakyla, 1991; Timmermans, 2005).

Scholars interested in the pedagogy of the dying role differ somewhat in their understanding of this work in constructing desirable subjectivities. At one end of the spectrum, primarily from those who invoke a Foucauldian framework, these practices are fundamentally repressive (Holmes & Gastaldo, 2002; Holmes et al., 2006; May, 1992; McNamara, 2004; Perron, Fluet, & Holmes, 2005). At the opposite end of the spectrum, represented primarily in professional literatures, there is a privileging of the benefits to ameliorate suffering associated with the social and physical stigma of dying (Byock, 1997; Kuhl, 2006; Mount, 2005). Others, most commonly from the disciplines of anthropology and sociology, provide a more nuanced understanding of these practices

as containing the potential to both enable and proscribe identity and concomitant expressions (Clark, 1999, 2002; Seale, 2002; Timmermans, 2005; Walter, 1994). However, where these diverse perspectives intersect is in a mutual understanding that these practices generate and reflect normative behaviours that create a “role” for the dying, require collaboration between patients and their social networks, and are designed to facilitate a good death.

Coauthorship of the Good Death

While clinicians, in facilitating open awareness contexts, may function as the primary social actors for pedagogy of the dying role, a good death within institutional settings requires collaborative relationships amongst all parties. This collaboration occurs through the therapeutic relationship and it enables coauthorship of specific narratives that work to make the end of life meaningful. Within examinations of narrative construction in end-of-life care, a particularly well-researched practice is “hope work.” This research highlights the ways in which patients’ and family members’ hope operates as a powerful emotional orientating device for framing understandings of the direction and purpose of care, and as an emotion that requires active reworking by clinicians. A diversity of studies have examined how clinicians work to replace narratives of hope for a cure with narratives of hope for physical comfort, a dignified death, and emotional closure (Benzein & Saveman, 2008; Fanos, Gelinas, Foster, Postone, & Miller, 2008; Penson, 2000; Perakyla, 1991).

The reworking of the hope narrative constructs dying as a “peaceful” process, with the possibility of emotional and spiritual growth, all while championing individual “styles” of dying. Many authors address how these narratives are invoked in genuine, caring attempts to help terminally ill patients come to terms with their impending death. However, scholarship has also explored this form of emotional labour as one that can be used to contain choices, where these narratives and practices of “common sense” close off other forms of dying. Several authors address how, within the traditional end-of-life narrative, there is both an implicit and explicit assumption that individuals and their families should be able and willing to accept death with courage and dignity; if they are unable to do so, there are several patterns of interaction that attempt to “facilitate” this desired movement (Kaufman, 2005; May, 1992; Moller, 1996; Timmermans, 2005).

These authors then highlight some of the ways in which narrative practices may be a consciously deployed tactic to actively change the emotional orientations of palliative patients and their families for instrumental acceptance of the dying role. The subsequent changes in the expression of hope, ideally, constructs patients and their families as amenable to changes from curative treatment to a less intensive resource-utilizing care plan and/or care location.

Research has also traced how processes of coauthorship also function to order the affective environment of care. Glaser and Strauss (1968) define this affective ordering of hospital units as “sentimental order...the intangible but very real patterning of mood and sentiment that characteristically exists on each ward” (p. 14). In particular, Sara Li’s (2004) work on “symbiotic niceness” highlights how specific forms of emotional labour by both patients and staff function to create a specific environment of “niceness” that naturalizes specific desired behaviours. Li’s findings address how “niceness” is a desired and defining characteristic of end-of-life care, which is invoked for purposes of identity by both patients and nurses. Through coenactments of “impression management,” both patients and staff are perceived as charismatic, friendly, informal, understanding, and concerned. This emotional labour therefore requires coproduction, where through the combined emotion work of all involved parties, specific behaviours are negotiated, validated, and/or contested. The successful outcome of these practices ensures a “mutually shared advantage” for ordering both individual nurse-patient relations as well as operating as “a mechanism for constituting moral identities and for maintaining social order” (Li, 2004, p. 2573; see also Copp, 1998; Hockey, 1990). While specific emotional orientations are malleable to institutional needs and social order, these outcomes are negotiated, championed, and rescinded through the emotional labour of all parties involved (Good, 1994; Perakyla, 1991; The, 2002; Timmermans, 2005).

Ensuring a Minimum of Social Disruption

The previous two sections have traced how end-of-life care shapes expressions of open awareness that lead the dying patient and their social network through a defined dying trajectory that functions as a status passage. This work both creates and reflects specific affective environments and orientations that naturalize specific understandings

of a good death. Although this work centres on the dying individual, these practices are also designed to suture the radical disjuncture that dying and death can create for everyone involved. This framework of care understands the patient's closest social networks as part of the "unit of care," where family and friends are involved in care planning, and are themselves constructed as potential recipients of care (Kristjanson, Aoun, & Oldman, 2006). Consequently, the patient is only one nodal point in this relational work to ensure a minimum of social disruption (Árnason & Hafsteinsson, 2003; Armstrong, 1987; Kaufman, 2005; Mamo, 1999; McNamara, 2004; Timmermans, 2005; van Brussel, 2010). In reference to coauthorship, Perakyla (1991) addresses how these social meanings about the dying process are organized by a form of suturing work which she terms "dismantling hope." She proposes:

The point of dismantling hope is that it helps the participants to collectively orient to the death of the patient before it actually happens. In this way, work for dismantling hope presents the patient's death as a social fact before the patient dies in the biological sense. When the social goes before the biological, then the biological, when it is time for it, can no longer threaten the social. Consequently, the medical frame, as a social arrangement, remains unchallenged. (pp. 428-9)

Several scholars of contemporary Western experiences of death and dying have also explored how, within these transitional states, normative processes work to contain the potential social disorder signified by the emotionally and physically "leaky" dying body. In this understanding, the dying process requires careful negotiation and monitoring as it threatens the permeable boundaries between life and death, nature and civilization, and order and disorder. For example, Lawton (1998), in her ethnographic study of hospice, wrote about how discharge protocols depended on "bounded" and "unbound" bodies, where unbound bodies required sequestration as "matter out of place" (p. 128). In their work with terminal cancer patients, Waskul and van der Reit (2002) highlighted how diseased bodies are conceptualized, both individually and collectively, as "abject" and disordered. Here the abject is not merely an absence of health, but an absence of corporeal boundaries that disturb identity, system, and order "provoking horror both in those who experience and witness it" (p. 499). As the transition between life and death is a socially and biologically "liminal" space of transition, end-of-life care practices can be conceptualized as a complex set of ongoing negotiations to reinscribe

the diseased individual body as an ordered social body for the benefit of all (Peelen & Wojtkowiak, 2011; Philpin, 2007; Seale & van der Geest, 2004).

Naturalizing the Direction and Outcome of Care

Glaser and Strauss (1965) assert that hospital dying is a temporal process with an institutional trajectory, where the management of the medically constructed dying trajectory is done in the interests of both institutional and social order. Using this lens, they explore how clinical practices work to naturalize a specific care pathway once it has been determined that “no more can be done.” They term this labour “trajectory work,” which they define as all clinical work over the course of illness (p. xii). In particular, they focus on the emotion work of staff and relatives when expectations about the time taken to die are not fulfilled, and the consequences for ward routine, which they conceptualize as a disruption of its sentimental order. In these moments, “identity work”—the “working with patients on matters of personal identity...what is sometimes referred to as ‘psychological problems’” (Strauss, Fagerhaugh, Suczek, & Wiener, 1982, p. 264)—becomes a critical labour for naturalizing the direction and outcome of the dying trajectory. This then serves to efficiently order task-based work and the affective environments in which this work is undertaken. Glaser and Strauss (1965) suggest that identity work is not empathic work performed as compassionate gesture, but enacted primarily in service of other trajectory work. When identity work fails, it leads to “the blocking of trajectory tasks, ineffective trajectory work, and the disintegration of the patient in the face of both physical deterioration and seemingly ineffective medical interventions” (p. 263).

Almost 40 years later, Kaufman’s (2005) ethnographic study of contemporary hospitalized dying explores how this work continues to be a constitutive part of the everyday work of clinicians. She articulates two competing discourses currently shaping hospitalized practices of care for the critically ill: the good death and medicine’s promise to extend life indefinitely. She traces how the conflict between the two can create “zones of indistinction” where patients are neither actively dying nor medically stable, and how physicians then work to resolve these zones with technologies and specific forms of rhetoric. Referencing the work of Glaser and Strauss, she asserts that these practices of resolution stem from the desire to move patients into the category of “dying” and

therefore efficiently time death for institutional order. She suggests that in order to achieve this goal, clinicians invoke specific phases as powerful orienting devices for patients and family members, which serve to create specific forms of experience and emotion. This work uses:

[...] a vocabulary of pragmatism that emphasizes problem-solving and decision-making. Such language ignores or redirects incoherence, anxiety, breakdown, diffuse suffering, and *any other expression of affect that lacks rationality* [emphasis added]. Similarly, the talk about “control” and “dignity” as death approaches, about “the good death,” that is common among staff, patients, and families can only be known through institutional activity that organizes how these terms are given shape within the hospital world. [...] Emotional understanding of dying and grieving is shaped through phrases such as “being ready to die,” “knowing it is time to die,” and “accepting death” phrases that delimit emotions as an instrumental and organized—not inchoate and overwhelming—experience. (p. 17)

Perakyla (1991) also examines how clinicians’ narratives work to shift patients from the liminal zone of indistinction to one where they are publically identified as dying. She asserts that these narratives function by marking patients as “exceptions to the principle of medical mastery,” wherein the patient becomes a visible signifier demarcating the boundary between life and death, and thereby operates as a socially ordered tactic for giving these patients up to “nature” (p. 429). Echoing both Kaufman’s and Perakyla’s interest, Timmermans (2005) also examines how the activities of death brokering require the use of technologies (both mechanical and linguistic) to socialize patients and relatives to die well in the name of institutional efficiency as much as for compassionate care and social cohesion.

As touched on in Chapter One, this understanding of end-of-life care is not new. In 1992, James and Field expressed concern about the “institutionalization” of the good death as antagonistic to the originary goals of palliative care, where issues of bureaucracy, professionalization, evaluation, and audit have increasingly gained predominance in order to facilitate the needs of governance instead of the “authentic” needs of the individual. Near the same time, McNamara, Waddell, and Colvin (1994) explored the institutionalization of the good death narrative in hospice care, again suggesting that it has evolved into a discourse of control over the lives of dying people

for the facilitation of institutional goals and certain forms of professional expertise. Floriani and Schram (2012) reassert these concerns almost 20 years later, stating that the conceptualization of the good death, and the practices to achieve it, are “apparatus” that aim to manage death more effectively on an aggregate population level, including shaping the professional behaviours of those providing care. They argue that activities of care that shape institutionalized dying now primarily serve “as an instrument to consolidate public health policies and social control politics, that is, biopolitical policies, as mechanisms of bio-power that ensure a systematic and permanent regulation” (pp. 299-300). The key difference between these authors is that Floriani and Schram understand institutional governance of dying as integral to the work of palliative clinicians, whereas James and Field (1992) and McNamara et al. (1994) construct it as a corruption of this work.

Identification as Compassionate and Efficient Care Providers

Through practices that naturalize the direction and outcome of care, clinicians attempt to ensure a minimum of social disruption of the cultural fabric that can be caused by death and dying. In doing this “trajectory” work, clinicians are able to efficiently order both work environment and routines. In this sense, palliative clinicians attempt to govern the conduct of patients and their social networks to meet institutional expectations and mandates. However, this labour is also done in the name of personal compassion and professional ethics (Byock, Caplan, & Snyder, 2001; Mount, 1976; Saunders, 2001).

While the majority of research on the regulation of conduct at end of life focuses on issues of governance for patients and family members, a few scholars have begun to explore how this work impacts clinicians themselves. Timmermans (2005) suggests that the outcome of death brokering renders dying meaningful not only for the patient and their social networks but for the patient’s care providers. Perakyla’s (1991) work briefly addresses how end-of-life care practices work to shape a clinician’s professional and moral identity as someone who helps the patient feel better, even when curative treatment is no longer possible. Li (2004) articulates how the ability to manage “interactional problems” at end of life also represents a core component of professional identity. She suggests that the emotional labour constituting these relations is not only a mechanism for generating social order but also a way that care providers produce an

impression of nice professionals, and, consequently, of “nice organizations” (p. 2572). Symbiotic niceness, then, not only maintains local social order and is generative of identity for nurses and patients, but it also functions as a way to advance personal, professional, and organizational aspirations. These few studies evidence that the provision of hospitalized end-of-life care is one in which the affective environment generates meaning and identity for all involved, including care providers and the institutions within which they are located.

New Forms of Knowledge and Increased Specialist Intervention

There is some scholarship that has begun to address how biological governance is articulated and regulated through the rise of specialist end-of-life care. Here, the evolution and institutionalization of expertise has been integral to the development of governmental tactics for organizing the dying process. For example, da Silva and Kruze (2013) have explored the World Health Organization’s definition of palliative care as a discourse shaping the creation of new subjectivities. They assert that the WHO Palliative Care Guide works as a bio-political strategy in order to defend society by producing a different rationality, building instruments of truth that subjectify and govern caregivers, patients, families, health professionals, and administrators. Similarly, in her work examining the discursive struggles between palliative and euthanasia advocates in defining the good death, Lisa Van Brussel (2010) explores how “new discourses of truth” emerge through these debates, leading simultaneously to new forms of biopolitical governance on a population level and to new forms of identity for the dying individual. Although these authors offer examples that are primarily theoretical “sketches” rather than indepth analyses, they invoke the profitability of exploring how specialist end-of-life care emerges from, and depends on, ever-growing needs for new knowledge and increased specialist intervention.

Currently, there is no research examining how care practices generate new forms of specialist knowledge in the context of a palliative-specific hospital setting. There is interest as to how the dying process within a general hospital setting solidifies the need for continued specialist mediation, as well as increased intervention, which is taken up in the work of Perakyla (1991) and Timmermans (2005). They both address how the practices of end-of-life care require specialist cultural mediation that, in reference to

biomedical discourse, generate new forms of knowledge about, and therefore new forms of relations with, the dying. In particular, Timmermans highlights how the creation of knowledge occurs even in adverse circumstances. He suggests that, in spite of all efforts, some hospital deaths will be “bad.” Instead of these deaths destabilizing the need for medical intervention, however, problematic deaths are productive of development of further expertise in the dying process, where the hope is that increased interventions will improve future deaths. In this way, specialist knowledge of the dying process is both a product of, and a response to, requirements for “flexibility and institutional reflexivity to respond to scepticism and new informational and technoscientific developments” (2005, p. 994). Like Perakyla, he concludes that this produces a “self-reinforcing circular process” whereby clinicians’ *clinical* authority to mediate death emerges and accrues from their *cultural* authority to define “the probability that particular definitions of reality and judgement of meaning and value will prevail as valid and true” (p. 994).

Each of these authors provides critical pathways to connect Foucault’s interest in discursive practices and Hochschild’s focus on emotional labour to a more specific consideration of end-of-life care. Examining this body of literature highlights how the provision and uptake of end-of-life care governs conduct through emotional labour practices that are given value within specific relations of power/knowledge that constitute the institutionalized (if not necessarily palliative-specific) dying process. These authors establish a vocabulary by which I am able to identify specific palliative care practices and outcomes, including: awareness contexts, trajectory work, status passage, sentimental work/order, zone of indistinction, death brokering, cultural scripts, hope work, and symbiotic niceness. Further, by synthesizing and framing this research as six idealized outcomes of care, I am able to identify how these practices function *collectively* to organize, regulate, and give meaning to the good death for all involved by generating individual meaning, social cohesion, and medical knowledge that increases the capacity to govern the dying process. This literature highlights that, in working to facilitate these outcomes, clinicians’ thereby enable the conditions for a good death whether or not the patient actually dies in their care.

In particular, the combined work of Glaser and Strauss (1965, 1968), Kaufman (2005), Timmermans (2005), Li (2004), and Perakyla (1991) begin to orient our attention as to how the hospital setting may be understood as a structured affective environment with a specific order that is organized by the emotional labour of the staff. However, a specific focus on affect and affective environments remains under theorized within examinations of specialist palliative care practices, and there is no research that has conceptualized end-of-life hospitalized palliative care as an affective system. The following sections therefore delineate how applying the concepts of affect and affective systems, culminating in an “affective economy” framework, may complement and extend existing understandings as to how palliative practices work to organize the dying process.

Defining Affect

Scholars have termed the increased interest in affect and affective systems as an “affective turn,” where these concepts are increasingly used to trouble understandings of experience as either wholly reducible to biology or language (Clough, 2009; Cromby, 2012). While this interest is evidenced in a range of disciplines, including psychoanalysis, psychology, philosophy, political science, feminist and cultural studies, as well as various histories of emotion, there is no cross-disciplinary, generalizable theory of affect (Gorton, 2007; Gregg & Seigworth, 2010). Given the heterogeneity of perspectives and disparate application of affect to a wide range of interests, I cannot do justice to the richness of possibilities this concept encourages. In recognition of this diversity, the following discussion of affect is bounded by the definition and attendant concepts as originated by the 17th-century Dutch philosopher Baruch Spinoza, as well as by others who have interpreted and expanded his work.

Spinoza (1985) first used the term affect to describe the ability to influence or effect change (to affect and to be affected): “By affect I understand affections of the body by which the body’s power of acting is increased or diminished, aided or restrained, and at the same time, the ideas of these affections” (I1D3). Spinoza postulated affect as an embodied intensity that emerges from the pre-conscious will to strive, an inherent desire that is characteristic of all living things (I1D6). From his perspective, the concept of affect

brings attention to four interwoven aspects of being. First, we are always undergoing transitions between one embodied state and another (i.e., a perpetual becoming). Second, these lived transitions are relational, as they are generated through continual interactions between bodies. Third, these relationships either increase or diminish the potential capacity of the individual body to act. Fourth, these relations are experienced as emergent physical states coterminous with certain modes of thinking than a prioritizing either of mind or body (Spinoza, 1985; Deleuze & Guattari, 1987; Hardt & Negri, 2004). Collectively speaking, affect defines the *terrain through which the preconscious intensities that arise from the will to strive generate the capacity to act and to be acted upon*. In turn, these intensities are perpetually coming to be through ongoing relations between bodies that increase or diminish capacity, and result in emergent physical states accompanied by certain modes of thinking.

Analyzing Affect

Affect is intangible and therefore it cannot be analyzed directly. Nevertheless, various scholars state that the *effects* of affect can be analyzed. The psychoanalytic philosopher Brian Massumi (1995) argues that affect, “while unformed and unstructured, is nevertheless highly organized and effectively analyzable as effect” (p. 237). Communications scholar Eric Shouse (2005) articulates this as a “dissolving of affect into subjective experience, “thereby rendering experiences of affect amenable to analysis through examination of subjectivity (para. 11). Interest in how to analyze the effects of affect is also found in the work of Jon Beasley-Murray (2010) on posthegemonic relations of power, as he suggests that the concept of affect is useful in “redescribing the constant interactions between bodies and the resultant impacts of such interactions” (p. 127).

The analyzable traces of affect emerge in our attempts to express the experiences of affect. In these moments, there occurs a “concretization” through the “socio-linguistic fixing [of] the quality of an experience which is from that point onward defined as personal” (Massumi, 1995, p. 221). This allows Massumi (2002) to state that “perceived experience, articulated as emotion, can be understood as the narration of affect” (p. 25). Through its expression, our experience of affect comes to be qualified and experienced as subjective emotional content, shaped within predefined socially

constructed categories of expression. Massumi then defines emotions as “[affective] intensity owned and recognized,” emerging from relations of cultural mediation (p. 28). Understanding emotions as the narration of affect constructs emotions as the articulated, momentary, shifting, but legible traces—the describable experiences—of affect. Following Massumi, I define emotions as *the embodied expressions of the experiences of affect, emerging through relations of cultural mediation*. Emotions are expressions of momentary “concretized” capacity, the continually emergent physical states coterminous with certain modes of thinking that increase or diminish the potential capacity to act. As Foucault (1988) points out, however, while these embodied feeling states are experienced as personal, they are generated through discursive relations that have wider histories, contexts, and even geographies. In this sense, emotions are historically, socially, and politically contingent, which emerge within specific political and social interactions, as well as personal, deeply held, private events (Freund, 1990; Hochschild, 1979 & 1983; Scheper-Hughes, 1992). Affect becomes subjective emotion when it is captured and fixed at specific moments in specific bodies, and when encounters between bodies in flux are represented as interactions between fixed stable subjects. While emotions are not synonymous with affect, affect becomes emotion when it is delimited through expression and thereby establishes subjectivity. This is why followers of Spinoza’s philosophy of affect argue that while ideas and resultant emotions are not affect, they are necessarily, and always, intertwined (Deleuze, 1978, p.5).

Defining emotions as affective solidification provides an analytic pathway to combine Hochschild’s interest as to how emotions “come to be” with Foucault’s interest as to how technologies of the self intersect with technologies of power to result in self-governance. This definition provides a framework to understand how emotions both enable and delimit expression, and how their expression works to establish legible, if temporary, emergent physical states accompanied by certain modes of thought. This understanding also addresses how emotional states operate both within and as an index of power, resulting in either an increase or decrease in the capacity to act. In applying this framing of emotions to an examination of hospitalized palliative care, however, we also need to ask *who* are involved in these processes of shaping affective expression, *when* and *where* these processes occur, *how* are they negotiated, and *what* are the outcomes of this labour specific to this institutional context. In order to do so, I envision

these processes within scholarship that addresses how affective solidification is both a product of, and (re)produces, larger affective systems.

Affective Systems and Economies of Affect

My examination of affective systems is interdisciplinary, echoing the diversity found in perspectives theorizing affect more generally. However, scholars interested in the solidification of affect also state that existing work often naturalizes the concept of affect without providing a specific explanatory framework or language (Blackman & Venn, 2010; Massumi, 1995). With this awareness, I focus the following discussion on scholarship of affective systems through authors that connect their interest to one or more of the four components that Spinoza postulated as core to the concept of affect. For these authors, affective systems work as a theoretical frame to better understand: how we are always in the process of becoming even within specific moments and relations, to explore how these relations either increase or diminish our capacity to act, and to examine how these relations generate subjectivity that results in emergent physical states accompanied by certain modes of thinking. In framing these components, the authors below invoke concepts of the “economic” to conjoin the production, distribution, and use of affective solidification within specific socio-historical examples of affective systems.

Perhaps the best known delineation of an affective system comes from cultural theorist Sara Ahmed. In her work *Affective Economies* (2004), she begins from the position that emotions “do things...they mediate the relationship between the psychic and the social, and between the individual and collective” (p. 119). Her understanding of affect emerges from the psychoanalytic perspective that subjectivity “lacks a positive residence” and from a Marxist interest as to how the movement between commodities and money creates surplus value (pp. 119-120). Ahmed synthesizes these ideas in her use of the term “economic” to describe how emotions circulate and are distributed across a social as well as physic field. She then uses the term “affective economies” to describe how subjects are bound into collectivities through the circulation and exchange of emotions, and suggests this use of the term allows an understanding as to how “emotions work as a form of capital: affect does not reside positively in the sign or

commodity, but is produced only as an effect of its circulation” (p. 124). Ahmed applies her “economic model of emotions” to public rhetoric in order to explore the ways in which this circulation occurs between bodies and signs to align individual and collective bodies, an effect she calls “surfacing” (p. 121). She examines how “sticky” words (e.g., hate, love, dirt, and sewage) and signs (e.g., national flags) align and bind certain bodies together through “othering others...this stickiness occurs as characteristics of one figure get displaced or transferred onto the other. Through this association between figures they acquire a life of their own” (p. 123). Ahmed’s framework emerges from several examples, including the analysis of white supremacist propaganda to explore how racial hatred becomes Aryan proclamations of love of a beleaguered nation, which therefore bind the imagined white subject with nation. In another, she examines British politicians’ speeches to show how global economies of fear are constructed in discourses that align asylum seekers with terrorists. In these examples, hate and fear do not reside within a specific subject or object, but rather “circulate between signifiers in a relationship of difference and displacement...without positive value” (p. 119). However, these emotions can become temporarily “stuck,” experienced and expressed in individual bodies, and have corporeal consequences, where “fear works to restrict some bodies through the movement or expansion of others” (p. 127). Consequently, emotions seem to be located within individual bodies only as “an effect of a certain history, a history that may operate by concealing its own traces including histories of production (labour and labour time), as well as circulation or exchange” (p. 119).

Ahmed’s understanding of affective economies has been influential, and applied widely in critical cultural studies (Bissell, 2010; Conradson & McKay, 2007; Rich, 2011). Referencing her “economic model of emotions,” scholars highlight the usefulness of her framework to examine how emotions are generated and given value through circulation than as residing within specific bodies. In exploring what constitutes affective systems, there are three additional aspects of Ahmed’s work I find particularly useful. First, she constructs a fully formed framework of an affective economy, including its purpose (to align certain bodies in collectivities by othering others), its currency (emotions), its practices (the creation and use of “sticky” words and signs), and its mechanisms of reproduction (continuous relations of circulation and exchange). Further, she applies this framework to specific examples to understand how affective economies both operate

within and as socio-historic fields of power. Second, Ahmed's assertion that emotions have particular (if obscured) histories of production through circulation and exchange highlights that, while they may be claimed as personal, they are only constituted through ongoing relations. This then requires that analytical attention focus primarily on relations rather than individual feeling states. Third, her foregrounding of circulation necessitates an understanding that there is no "end" point to affective economies. Affective systems are then understandable as continuously reproducing individuals and collectivities even as they are experienced as concrete, subjective personal emotion. In applying this framework, Ahmed is able to theorize how subjectivities are generated within specific historical moments of "socio-linguistic fixing" (Massumi, 1995), where the outcomes are particular emergent physical states (individuals and collectivities) accompanied by certain modes of thinking (e.g., hate and fear). At the same time, she addresses how these becomings either increase or decrease the capacity to act.

Her interest as to how affective economies shape both individuals and collectivities resonates with Foucault's interests in discursive practices and how they are generated through the intersection of technologies of power and technologies of the self. Ahmed's model may then be understood as describing governmentality in action, where the production and circulation of emotional states guide the conduct of persons. In relation to Hochschild, Ahmed's work intersects in their mutual interest in tracing how emotions emerge and circulate through relationships, and how emotional orientations come to be naturalized within specific practices of framing by which we ascribe meanings to situations.

Along with these strengths, there are some challenges in attempting to apply her concepts in relation to hospitalized palliative care. First, Ahmed (2004) does not define or differentiate between affect and emotion; at several points she even collapses the two together (see for example pages 119, 121 and 124). This elision is by no means unique. As Massumi states (1995), scholars interested in affect may differentiate between affect and emotion, state that they do and then conflate the terms in use, or even use affect as a loose synonym for emotion. This elision creates more than definitional confusion as what remains unclear is, if emotions are the object of interest, what benefit, if any, does using the term affect have? For the purposes of exploring the practices of hospitalized

palliative care, a clear distinction between the concepts is critical (as will be evidenced in the final section of this chapter). Secondly, while Ahmed asserts that “emotions do things,” she remains explicitly focused on the rhetorical production and circulation of emotions. While she suggests that signs which constitute a body as an object of fear may become temporarily “stuck,” her focus is on the movement between signs that allows others to be attributed with emotional value. I suggest that the situated reception and temporary “uptake” of the signs can also be understood as an uptake of the emotions themselves. In turn, these temporary emotional states may have important effects in negotiating and shaping the continuous unfolding of affective economies. For the purposes of my work, rather than assume that these moments of temporary solidification are a side-effect of an affective economy, I suggest that it is these very “moments” of emotional concretization that both construct and reflect specific instances of an affective economy, as well as generate future iterations. Therefore, in examining an affective economy of hospitalized palliative care as both a medium of ongoing circulation *and* as specific moments of emotional “stickiness,” we may be able to better understand how individual experiences and understandings of dying can emerge coterminous with concerns of efficiently governing the conduct of populations at the end of life. Finally, as Ahmed does not significantly address moments of uptake, her understanding of an affective economy does not address how these economies are always necessarily permeable, incomplete, and open to negotiation. While specific emotional orientations to the end of life, such as courage, dignity, and acceptance, enable certain forms of capacity and foreclose others, the mediated outcome of any deployment of emotional labour to guide these forms of conduct is never assured and emotional orientations are never completely determined.

There are no examples of Ahmed’s work being applied to hospital settings or patient care. The closest application to my research is in the recent work of Buchbinder and Timmermans (2014) who use her framework to examine newborn screening (NBS) policy debates in the United States. A review of their work highlights some of the strengths and challenges of using Ahmed’s understanding of affective economies within a medical context. With backgrounds in medical anthropology and sociology, Buchbinder and Timmermans’ interest is to explore how parents faced with their children’s life-

threatening genetic disorders have mobilized affect as a political resource to accomplish advocacy goals. They utilize Ahmed and her understanding of an affective economy to:

[...]reference the circulating networks in which emotion, feeling and sentiment...[are] systems of exchange in which people enact and elicit emotional responses for social and political ends, such that affect comes to serve as its own currency and yield its own profits and costs. (p. 104)

In their examination as to how parent advocacy narratives were carefully crafted in an attempt to produce a particular emotional response in policy makers, Buchbinder and Timmermans detail three aspects of an affective economy specific to their context. First, advocates drew on publically accessible emotional experiences to evoke a compassionate, urgent response. Second, these narratives constructed their audience as uniquely capable of taking political action. Third, advocates claimed authority based on intimate experience, which they juxtaposed against traditional forms of scientific authority (p. 104). Buchbinder and Timmermans assert that parent advocates focused on narrative and performance, first performing their emotional distress and then evoking similar emotions in their audience:

[...] using affective language and terror imagery to amplify a sense of collective fear about the hidden dangers facing the nation's children that could erupt and attack with little warning...advocates drew on some of the same language that has been used to describe disasters, epidemics, and human rights atrocities to victimize babies, thereby altering the landscape of suffering as well as the stakes of political inertia. (p. 111)

Applying the concept of “emotional institutions” to this public discourse, the authors argue that the “institution” of NBS advocacy is not a structured environment for the airing of pre-existing emotions, but a space which constitutes “socially situated discursive practices that variously evoke, represent, and transform emotional experience” (p. 105). In their conclusion they state that, while the invocation of emotions within advocacy movements is not a new phenomenon, their framework for affective economies “emphasizes the *orchestrated, discursive* enactment of affect towards political aims” (p. 118).

Buchbinder and Timmermans invoke key aspects of Ahmed's affective economy. They, like Ahmed, understand an affective economy as a discursive system which works

to publically orchestrate emotional experience. They, like Ahmed, examine linguistic practices as the primary mechanism for the production of emotions. They also follow Ahmed's understanding of affect as its own currency, where value is generated through its circulation. Additionally, in their assertion that the role of affect in public discourse works as a form of "sublimation," they echo Ahmed's concern that emotional states hide the histories of their production (Buchbinder & Timmermans, 2014, p. 104). Like Ahmed's interest in the "alignment" between signs and bodies through the use of "sticky" signs and words, Buchbinder and Timmermans address how seemingly unrelated emotional-moral orientations, such as to natural disasters and newborn screening policies, become connected by narrative association. They also move beyond Ahmed's framework as they construct an affective economy as emerging through the conscious agency and cultural brokering of advocates for specific political ends. In doing so, Buchbinder and Timmermans are able to trace how these narratives work to increase the capacity of their audience (i.e., by constructing them as key power brokers), albeit in specific ways. A further extrapolation is also evidenced in their suggestion that advocates *performed* emotions. This terminology implicitly assumes that the emotions expressed were a form of acting that required a conscious labouring process (although it remains unclear if this was understood as shallow or deep acting by either the advocates or the researchers). Additionally, Buchbinder and Timmermans highlight how individual agents collectively utilized their personal experiences as the basis on which to claim authority. In their use of Ahmed's affective economies framework, as well as building on it, they are able to address key theoretical and methodological elements by exploring how specific discursive relations between bodies either increase or decrease their capacities to act, as well as provide examples as to how embodied performances of emotion work to shape emergent ways of thinking.

I have reviewed Buchbinder and Timmermans' (2014) research as their use of Ahmed's work addresses some of the benefits that accrue from applying her concepts to a medical context. I also do so because this research highlights some of the key challenges that may emerge in referring to Ahmed's framework, and not to others, to examine the practices of hospitalized palliative care as an affective system. Perhaps most critically, Buchbinder and Timmermans do not find it necessary to define or differentiate between affect and emotion other than to generally state that they use the

term affect over emotion “to emphasize the expressive dimensions of feelings and sentiment” (p. 104). This elision then leaves the reader assuming that affect is merely a descriptive device to address the expressive aspects of emotion. Additionally, they also imply that affect can be a medium for the exchange and validation of emotions when they state that “affect operates socially by resonating with and reinforcing broadly felt public sentiments” (p. 106). In this understanding, there is seemingly no differentiation between an affective economy as a space within which emotions circulate as objects between subjects based on conscious orchestration, and as a specific environment within which all subjects circulate, both capable of acting and being acted upon. Second, while Buchbinder and Timmermans highlight that their interest in the expressive dimensions of emotions requires a real or imagined “other,” they, like Ahmed, do not take up how these expressions are negotiated and understood by their audience. The strength of their work then lies in examining how the preconstituted emotion of suffering is mobilized by specific actors to forward a specific political project through narrative alignment and the production of affective displays. In contrast, my goal in employing an affective economic framework to understand the practices of hospitalized palliative care is to be able to explore how the capacity to act *for all involved* is negotiated. This requires differentiating, as I do, between affect as a preconscious medium within which we all circulate and emotions as temporary moments of affective solidification that render experience expressible. Consequently, in the context of palliative care, the use of an affective economic framework is meant to address how patients, family members, and clinicians are simultaneously (if differentially) made capable of acting, and being acted upon, and highlights that emotional orientations to the dying process occur within specific moments and contexts that require ongoing relations of mediation and negotiation.

My interest as to how an affective economy of hospitalized palliative care can describe the simultaneous emergence of subjects and subjectivities at the end of life is critically informed by the work of anthropologists Analeise Richard and Daromir Rudnycky (2009). They coin the term “economies of affect” to explore how affect is mobilized to produce subjects within the context of international neoliberal transformations. Their analytic framework explicitly draws on Foucault and is grounded in ethnographic research of two contemporary economic transitions. Importantly, they

begin constructing their framework by first differentiating between emotions and affect. They argue that while the concept of emotions implicitly continues to reference psychological individualism, the concept of affect foregrounds reflexive actions that both “affect others and oneself, either materially or otherwise” (p. 57). Furthermore,

[affect] resembles the reflexive quality of what Foucault refers to as “conduct,” which is simultaneously a means to lead others...and a way of behaving within a more or less open field of possibilities. The exercise of power consists in guiding the possibility of conduct and putting in order the possible outcome. (p. 61)

Richard and Rudnycky use affect as a way to bring together Foucault’s work on relations of power, governmentality, and subjectivity to understand how affect operates as “a means through which people both conduct themselves and conduct others by structuring possible courses of action...a means of subjectification that simultaneously produces those who enact it and those upon who it acts” (p. 61). As a result, they suggest that the transitive and reflexive capacity of the term make it better suited than emotion to document how subjects and subjectivity are mutually constituted.

For Richard and Rudnycky, affect describes the reflexive actions generated through relations between individuals that shape capacity in certain ways. Affect then becomes central to establishing “the continuity of government between the self, the family, and the state that is characteristic of modern polities” and is the process “through which a subject of government is constituted” (p. 58). They also provide two further delineations of affect. First, they emphasize that affect is not an object that circulates between subjects, but is a medium within which subjects circulate (p. 59). Second, their interest is in both the linguistic and non-linguistic aspects of affect, where embodied practices are visible both within and outside language (p. 61). Having defined their understanding of affect, they then conjoin it to the concept of an economy. They use the term economy in two overlapping ways: to describe “a zone for the production of certain types of subjects and practices” as well as to connect the “affective transactions” within these zones to economic transformation (p. 57). I now turn to their ethnographic research in some detail, where their understanding of economies of affect becomes both cogent and compelling.

Richard's¹¹ (2009) work addresses how affect is mobilized within relations between Mexican and Northern non-governmental organizations (NGOs) in a time where Mexican NGOs have become increasingly responsible for the provision of services formerly offered by the state. She explores the origins of the Mexican NGO Rural Development of Hidalgo (RDH), and how its leaders specifically focused on youth in popular education initiatives, inter-village exchanges, workshops, and community-building retreats, and were centered on consciousness-raising and generating relations of an extended family using metaphors of siblinghood. Richard traces how these youth then became contemporary RDH staff and how they currently work to create ties with foreign organizations through a similar economy of affect consciously designed to cultivate and convert the foreign representatives of these organizations into "solidary subjects." She examines how RDH staff engage in multiple tactics that are explicitly framed to "open...warm...[and] administer a change of heart" of these foreigners by the cultivation of personal friendships and responsibilities (p. 66). Through invitations to work in impoverished villages, extended stays in villagers' homes, encouragement to participate in daily life, as well as keeping in contact by letter writing after they have left, RDH staff intentionally use shared physical labour ("muscular bonding") to elicit fellow-feeling that is consolidated over time through incorporation into domestic family life to build enduring "bridges of love" (p. 68). These representatives then ideally become personally connected to the RDH organization so that even after their departure they continue to demonstrate a commitment to act on their behalf and offer resources and help when called on. In this way, a caring personalized relationship is built between subjects reminding them of their bonds with, and responsibilities to, a collective.

Rudnyckyj (2009) examines the role of affect in the project of spiritual reform within the Krakatau Steel company (which is the largest steel factory in Southeast Asia, employing 6,000 workers). By the time of Rudnyckyj's research, the company was facing dramatic economic restructuring, including the end of state subsidies, the elimination of protective national tariffs, and planned privatization. This led to a reframing of current practices such as insider contracts becoming seen as "corrupt" and employment of lower

¹¹ While Richard and Rudnyckyj coauthor the 2009 work referenced here, they also use individual voice in separate sections to address their specific projects.

level workers no longer being assured. In response, managers of the company and union leaders worked together to contract the provision of spiritual training sessions (ESQ) in order to cultivate an “Islamic work culture.” By enhancing their own religious practice and that of other employees, the goal was to prepare everyone at the company for privatization by eliminating “chronic” corruption and advocating work practices that would make the company more internationally “competitive.” In these religious workshops, the enactment of affect and the production of affective ties were exhibited by managers and union leaders as much as by lower level employees, and “taken to be critical to eliciting the new worker deemed necessary at Krakatau Steel” (p. 68). In the training sessions, employees connected affective practices such as the ability to cry, embracing, and other public expressions of grief, joy, and shame, “to producing oneself as a labourer amenable to changing norms and forms of economic practice” (p. 69). In particular, Rudnyckyj focuses on “ritual weeping” within Muslim religious practice as a public corporeal manifestation of atonement for sins, as well as evidence of the effort to achieve purity of the heart in the ESQ training. This form of affective expression was understood both by those engaging in the weeping and those who witnessed the weeping as “a material representation of the transformation of the heart that is the object of spiritual reform” (p. 69). He grounds this assertion through the words of participants who cited the ability to weep in these sessions as evidence that “their heart had been opened” and physical proof of having undergone spiritual transformation (p. 70). Rudnyckyj is therefore able to trace how this particular affective practice was central to the project of producing a reformed economic subject within the Krakatau Steel company, where “a disciplined but entrepreneurial worker who will work hard and avoid corruption because he or she is aware that every action is observed by Allah” (p. 70). While he is careful to state that not all employees were so affected, weeping (or the lack thereof) remained the litmus test from which employees understood themselves as a successful (or unsuccessful) subject of spiritual reform.

These examples provide a pathway to understand how the articulation of affect creates subjectivities through emotional expression. In their focus on how these practices are experienced and reflected on in the everyday life of individuals, Richard's and Rudnyckyj's (2009) work encourages examination not just of the practices themselves but also an exploration of the experiences, and reflections on, these

practices. In relation to examining hospitalized palliative care, their framework can be used to trace how emotional expressions of the affective experiences of dying shape specific subjectivities for specific outcomes. By explicitly connecting affective expressions to Foucault's work on governmentality, Richard and Rudnyckyj provide a way to articulate how the emotional labour practices of end-of-life care are processes through which everyone involved in the dying process conducts themselves and others, simultaneously producing those who enact it and those on who it acts. Setting the provision and uptake of hospitalized palliative care within this framing then enables me to examine practices of care as technologies that simultaneously shape the ability to govern biological processes and make productive the conduct of critically ill populations *and* generate self-governed understandings and orientations to the dying process. In this understanding, while clinicians may be privileged cultural brokers for the shaping of patient and family conduct, their practices of care also shape their own potential for capacity and resulting orientations to self and other, and generates the terrain for being acted on. While Richard and Rudnyckyj do not reference the concept of emotional labour, they include the lived practices that shape affective expression as well as the outcomes of these practices. This framing then encourages theorizing the relationship between structures and sentiments *in situ* of specific moments of palliative care. Further, in their attention to muscular bonding and ritual weeping, they address how the labour to shape expressions of affect, as well as the resulting moments of affective solidification, does not necessarily require language. This is a particularly salient point for my work as I understand that the emotional labour practices giving shape to emotional states are not always comprehended and communicated verbally.

For the purposes of my work, there is nevertheless one key challenge in applying Richard and Rudnyckyj's (2009) terminology. They state that "affect describes the reflexive actions generated between individuals" (p. 61), and, at the same time, they also identify affect as the medium within which subjects circulate (p. 59). If affect describes both the environment and the specific actions within the environment, it becomes difficult to differentiate between the affective environment of the hospital and the actions that occur in this environment. While emotional labour practices necessarily shape the hospital environment, I believe there is a need to analytically distinguish between them to better understand the processes by which this occurs.

An Affective Economy of Hospitalized Palliative Care

Defining an Affective Economy

Before delineating my own iteration of an affective economy I provide a summation as to how the ideas and accompanying terms presented in this chapter specifically inform my framework. First, my understanding of an affective economy emerges from Foucault's (1972, 1983, 1988) interest in discursive formations, governmentality, and technologies. Second, I also use Hochschild's (1979, 1983) understanding of emotional labour, feeling rules, and framing rules. Together, these ideas allow me to identify emotional labour as the key governmental practice within an affective economy that is generated through, and reflected in, specific socio-historic relations of power/knowledge for the purpose of guiding conduct. These relations are understood as emerging through specific social norms—feeling rules and rule reminders—that circulate and are negotiated through emotional labour practices. Borrowing from the discussion on affect, I suggest how temporary moments of affective solidification can be examined as emotions. An analytics of affect is used to understand how emotional labour conditions the capacity to act and be acted on, where the resulting emotions emerging from this work may increase or decrease the capacity to act within a specific discursive formation. Emotions are then understandable as the productive outcome of the intersection of technologies of power and technologies of the self, and they operate as an index of power specific to the affective economy of their generation. My iteration of affective economy also references the work of Ahmed (2004) and Richard and Rudnycky (2009). I draw on Ahmed's understanding as to how emotions seemingly take on a life of their own through relations of circulation and exchange. Her emphasis on these relations as a system of production, an economy, highlights that, while we may claim emotions as personal, they are better understood as constituted through ongoing relations that continuously reproduce individuals and collectivities that either increase or decrease their capacity to act. This awareness requires that attention is given to relations than just individual feeling states. I also follow in Richard and Rudnycky's footsteps in suggesting that an affective economy generates and conducts both subjects and subjectivities. Additionally, I am indebted to their work to understand the circulation, negotiation, and outcome of these practices as constructing a specific population to be

regulated, where the practices constitute the object of its interest. I reference their interest in including the lived *outcomes* (i.e., the personally claimed emotional experiences) of this circulation and negotiation. I also use their understanding that affective expression is not always reducible to language, where the creation, negotiation, and situated uptake of particular emotional states may be communicated through the body as much as through words. Finally, I borrow from all three authors' understanding that this work to shape affective expression, and the (desired) resulting emotional states, may hide the histories of their production, thereby naturalizing and reproducing relations of knowledge/power.

Collectively, this leads to my definition of an affective economy as a specific discursive formation understood and explained through its emotional labour practices. An affective economy framework encapsulates the relations from which these practices emerge, the practices themselves, and the negotiated outcomes of these practices. Through this focus, I understand specific emotions as created, circulated, and expressed within specific socio-historic relations of power/knowledge through specific forms of human practice (emotional labour). These practices mutually constitute both relational subjectivities (the capacity to act) and relational subjects (the capacity to be acted upon). These practices condition conduct by shaping the possibilities of capacity through specific framing and feeling rules that temporarily solidify affective experiences into emotion, resulting in emergent physical states coterminous with certain modes of thinking. Through this relational work of shaping affective expression, the emotional resources of both individuals and collectivities are organized. This work is done in the service of making emotions productive: to enable individual meaning, to enhance social cohesion, and to generate knowledge for purposes of governing populations. Through this organization, an affective economy constitutes both its population and its behaviour of interest.

Defining an Affective Economy of Hospitalized Palliative Care

I define an affective economy of hospitalized palliative care as a discursive formation understood and explained through its emotional labour practices. For the purposes of this research, I focus on clinicians' practices of therapeutic relationship building, addressing total pain, and offering of the dying role as a specific set of

knowledge/power relations that emerge through the organization of the dying process within hospitalized palliative care. I situate these relational practices as circulating and privileging clinicians' understandings of the emergent physical states of the terminally ill patient, which is coterminous with their cultural authority to define the appropriate emotional orientations to these understandings. These practices attempt to order the affective experiences of dying (the diminished capacity to strive) through invoking framing and feeling rules that generate, solidify, and naturalize emotional orientations that maximize the social productivity of the dying process. I understand this productivity as occurring through emotional orientations that create individual meaning, provide collective social order in face of loss and mortality, and increase the ability to govern the biological processes of dying for the population as a whole. Both the practices and outcomes of this labour are governmental, where the historically contingent framing and feeling rules within the provision of hospitalized palliative care enable specific emotions that shape our capacity to enact, experience, and understand the dying process in specific ways. While this economy has privileged cultural brokers and practices that frame "appropriate" emotional orientations to the dying process, these orientations are negotiated, validated, and/or contested through the rights and obligations generated through the emotional labour participation of all involved parties. This economy is also constituted through a multiplicity of medical and non-medical discourses about the good death, and therefore continues to evolve both within and against these discourses. Taken together, these ideas construct an affective economy of hospitalized palliative care as necessarily fluid and ambivalent, defined as much by its negotiations and disjunctures as by mutuality, cooperation, and participation. Having set out my theoretical framework, I now turn to an ethnographic description of my fieldwork from which, in part, this framework was generated.

Chapter Three: An Ethnography of Hospital-Based Palliative Care

[Palliative care is] like delivering babies—you meet these people at this really intense time of their lives and you get involved really quickly. Quickly and intimately.
(Palliative clinician)

My research emerges from fieldwork within two Western Canadian hospitals between October 2008 and December 2009. Both hospitals are acute care focused and service a largely urban population. Each hospital has more than 500 beds, and both include dedicated palliative units and palliative consult teams that work throughout the hospitals. During my fieldwork, I was usually at one or both hospitals three to five days a week, approximately four to seven hours a day. As I became familiar with the clinicians and their daily routines, I began to ask about possible patient or family member participants for my research. This settled into a routine where I would look on the patient information board each morning for new admissions. Reasons for not approaching a patient included: cognitive issues, symptom burden, extreme psychosocial distress, impending discharge, imminently dying, and/or not speaking English. If any of these issues were present, I asked clinicians about family members and their potential interest in participating (unless the patient was pending discharge or imminently dying). Working together, the clinicians and I would establish who was appropriate to approach, with the clinician introducing me when they had a moment of “free” time. This form of introduction became less frequent as I gained confidence in the rhythms of daily care, and, after the initial discussion of who was appropriate, I would often introduce myself without a clinician as intermediary. For consult patients (those who were not located on a dedicated palliative unit but receiving care from a palliative consultant), I met with a consult clinician each morning (usually a senior nurse) and read the list of patients being seen that day. Patterns and criteria of recruitment of patients and/or family members was similar to the unit, with the difference that consult clinicians more often introduced

the project and provided the information brochure to ascertain interest before I introduced myself.

General Description of Units

Each palliative unit has approximately the same number of beds, with both private and semi-private rooms. One unit (hereafter referred to as “Unit A”) works on a primary team model, where patients admitted to the unit have a primary physician, a primary nurse, and a primary team member. Although the patient may be cared for by a diversity of clinicians, this team is responsible for coordinating all aspects of care. The rotating palliative physicians staffing this unit are consultants to the patient’s primary physician, usually a general practitioner or hospitalist with experience in palliative care (or, on rare occasions, the palliative physician assumes the role). The other unit (hereafter referred to as “Unit B”) works from a more traditional model where a rotating roster of palliative physicians are responsible for the care of the patients once they are admitted to the unit. Each unit usually has four to six registered nurses on day shift (or approximately a 3:1 clinician to patient ratio); on night shift it is common to have two registered nurses with nursing support from licensed practical nurses. Along with the physicians and nurses, each unit has a clinical nurse leader and a part-time social worker. Each has volunteers who visit with patients and/or family members. Neither unit has full-time pastoral support, although a pastor is usually present during weekly rounds and is available if requested.

Both units are located on the top floor of their respective hospital. Each unit is quiet and spacious, with spectacular views of the city. Each has a central space for a nursing station, with a unit clerk present during working hours. Both have a large patient and family lounge, with a television and a book and movie library. Each has a small “memorial” area, a non-denominational wall shrine where names of the recently deceased are posted. There are no set visiting hours and it is common for family members or friends to stay late or overnight in the patient’s room, particularly if the patient is close to death. While there is always some level of activity, particularly in the morning during nursing shift change and when other clinicians arrive to begin the flurry of their workday, there is a marked contrast between these units and the other units of

the hospital. Staff strive to create a relaxed atmosphere and they work to familiarize themselves with the patient's rhythms: their daily moods, what they enjoy or dislike, their families and friends, and other personal aspects while they undertake the seemingly endless tasks that make up daily physical care. This individualization, relative calm, spaciousness, and slower pace are some of the first things that patients and family members remark on, and these spatial, auditory, and temporal markers are important indicators that signify the palliative unit as fundamentally different than other hospital units.

A particularly memorable example of these differences in care was a homeless man who, although in many ways physically well "enough" to be transferred to hospice, had mental health issues such that the staff realized he could not be transferred to hospice and would be with them until he died. While the patient was not able to eat much, and never really was able to keep food down, he had an inordinate fondness of hot dogs, and on several occasions various clinicians would procure one for him from a vendor near the hospital. He would almost immediately throw them up, but his evident happiness with being able to eat hot dogs and their ability to honour his requests pleased the staff, even as they had to go in and clean up afterwards. In another example, staff made allowances for a patient's young adult children who increasingly used their mother's room as a place to hang out and sleep, in order to avoid returning to their small apartment occupied by an abusive father.

Admission Criteria for the Palliative Care Unit(s) and Palliative Consult

Admission criteria for both units are based on the same policy guidelines. The criteria require that the patient has a life-limiting prognosis of less than 12 months; is diagnosed as palliative; needs acute management for uncontrolled symptoms of a physical, psychosocial, and/or spiritual nature; has either verbally agreed to or formally signed a "No CPR" order; and/or is wanting an acute care death (consistent with the principles of end of life palliative care). While patients can be admitted either from the community or from other units of the hospital, at both sites priority is ostensibly given to patients in the community. The justification for prioritizing community admissions is that hospital patients have existing competent care, and can have the additive care of a palliative consult clinician. However, although community transfers were common, during

my observation period the majority of admissions to the palliative care unit were internal transfers. These transfers were predominantly for complex pain and symptom management, usually combined with concerns regarding goals of care and discharge planning. While it was rare for a patient to be admitted solely due to psychosocial issues, this did occur, usually due to these issues delaying or blocking discharge.

While the palliative care consult teams are organized somewhat differently between the two hospitals, the reasons for calling a consult are the same: for pain and symptom management of advanced life-limiting illness, including discussions regarding goals of care and discharge planning. Most consults I observed were requested for more than one purpose. Complex pain and symptom management were the predominant reasons (similar to unit admissions), but these were generally intertwined with goals of care planning and discharge concerns. When the primary reason for consult was for physical or pharmacological reasons, the palliative physicians typically made the initial visit. When the patient had stabilized and/or the reasons for consult were predominantly psychosocial or practical, the palliative nurses were the ones primarily responsible for care. Consult clinicians may visit a patient and/or family member once but more often several visits are required. It was not uncommon in complex cases for the consult clinician to visit a patient and/or family member daily until discharge or death. Consult patients do not have to be in agreement with a comfort approach to care or have a do-not-resuscitate order. These patients may or may not be “officially” designated as palliative; what marks them as requiring these services is the perceived need by their medical team for the specific set of practices that constitute palliative expertise. During the time of my observations, the majority of patients and/or family members subject to the consult referral had little or no previous experience with palliative care or its services. While I witnessed consultants strenuously advocating for early referrals, almost all requests occurred in the patient’s last months of life and were often within weeks or days of dying.

General Overview of Palliative Patient Populations and Clinicians

Within the community an “official” designation of palliative occurs when the patient is registered for BC Palliative Care Benefits (BCPCB). BCPCB is available to British Columbia residents who have “reached the end stage of a life-threatening

disease or illness and who wish to receive palliative care at home” (Government of British Columbia, 2011). The program covers prescriptions, medical supplies, and equipment commonly used at the end of life. Coverage requires that a physician prognosticate (using the Palliative Performance Scale¹²) the patient having a life expectancy of no more than six months. Patients must also “consent to the focus of care being palliative rather than treatment aimed at cure” (Government of British Columbia, 2011). If these patients are admitted to the hospital, they are most commonly referred to by clinicians as palliative. There is no formal designation of a palliative patient emerging from hospital protocols as designation is commonly understood through the use of palliative consultant services, transfer to the palliative unit, and/or less commonly chart notes using descriptive terms such as “palliative,” “end of life,” or “terminal” to describe the patient’s medical status.

During my observation, there were approximately 180 patients admitted to the palliative care units between the two hospitals.¹³ 72% of these patients died during their first admission (an additional 7% were readmitted a second time), with the rest being discharged to home, hospice, another hospital, or long-term care. The average length of stay was similar between hospitals (15 days versus 16 days); the longest stay on Unit B was 45 days, where Unit A had several lengthy admissions (three months or longer). The average age of patients at each unit also was quite similar (68 years versus 69 years). There were four main differences between the hospitals in patient profiles and practice: Unit B had a significantly higher percentage of male patients compared to Unit A (62.5% versus 47%), almost twice the number of non-cancer admissions, and a higher rate of discharge and of readmission.

¹² The Palliative Performance Scale is a clinical tool for measurement of a patient’s performance status.

¹³ I do not have an estimate for the number of patients seen by palliative consult clinicians. In both hospitals, although referrals were designed to be organized through a phone and computer system, many initial visits were initiated from verbal requests. Additionally, if a patient had been seen by palliative services and then discharged and re-admitted, the patient would automatically show up on the consultant’s daily list, even if the clinicians were not officially requested for another consult.

I interviewed and/or observed fewer clinicians on Unit B than Unit A (17 versus 24). The senior clinical staff on Unit B had a higher turnover rate than their counterparts at Unit A. As a general rule, the palliative physicians and nurses on Unit A are older and more experienced than the palliative clinicians on Unit B. On Unit A, clinicians are somewhat more conventional in limiting aggressive treatments, although there were many times patients underwent acute, potentially life-extending interventions even in the last days of life. In contrast, Unit B is staffed with younger physicians and nurses who generally support a more interventionist approach, including tentative discussions of removing the admission requirement of a do-not-resuscitate order. In practice, there were times when these differences were seen by clinicians as challenging to defining ethically appropriate care, where clinicians from one unit expressed differences in opinion regarding treatments offered to patients at the other. Accordingly, questions of new practices and new patient populations were a source of on-going discussion, where the senior clinicians from each hospital intensely debated between themselves at regional meetings issues of admission, definitions of palliative care, appropriate forms of treatment, and visions for the future of palliative care. These concerns were also debated among the lower-level clinicians, although usually amongst their own colleagues. While careful to acknowledge the skills and compassion of each other, clinicians from the two hospitals each felt that their model worked best and provided the preeminent form of patient care.

General Characteristics of Research Participants

A total of 28 patients and 8 family members agreed to be part of my research. Twenty of the patients were male (average age 61 years) and eight were female (average age 54 years).¹⁴ Six of the family members were female and two were male,

¹⁴ Why more male than female patients chose to participate in this study is unclear. Several clinicians speculated that their male patients often had less of a support network and desired conversation and company. Other clinicians wondered if men were more willing to participate in research as a way to assert a sense of heteronormative masculinity, even as they understood they were critically ill, they felt the continued need to “act as if” they were not. Interestingly, one clinician wondered if women were less willing to participate because “they were done with feeling they had to be nice.” I was not able to determine from any professional or academic literature—or based on personal speculation—why participation rates between males and females differed.

with an average age of 76 years.¹⁵ Twenty-four patient-participants had diverse cancer diagnoses, two had COPD (chronic obstructive pulmonary disorder), and two had end-stage heart failure. Patients of family members I interviewed had an average age of 76 years and a more varied disease profile. Although it was still predominantly cancer related, one patient had ALS (Amyotrophic Lateral Sclerosis), one had Parkinson's disease, and the other late-stage dementia. While there were a variety of ethno-cultural backgrounds of patient and family member participants, including South Asian and Chinese, only one family member-participant and two patient-participants had English as a second language.

I also observed and/or interviewed more than 40 palliative clinicians, allied health staff, and administrators. Of the clinicians, 85% were female, reflecting the gender differential in palliative care provision. Consequently, I refer to all clinicians in my work as she/her, regardless of the "actual" gender of the clinician. There was a range of palliative care experience, from less than one year to more than 20 years, with an average close to five years. The vast majority had several years of non-palliative experience in other specialties and units, and their negative experiences of life-prolonging care within these specialties were often cited as a key reason for moving to palliative care.

I make few claims that my research is representative of the palliative patient populations during my time at these hospitals. While I explore the history of the "good death" within an Anglo Western secular context, which necessarily includes how its "markers" (e.g. open awareness, emotional orientations of acceptance, activities of closure) become naturalized as common sense, my work does not include how this understanding is negotiated and lived within potentially differing philosophies and practices that emerge from diverse intersections of gender, ethnicity, class, ability, and sexual orientations. In the conclusion of this dissertation, I discuss how some of these concerns may be addressed within an affective economy framing by future researchers.

¹⁵ The relationships included child, spouse, parent, and inlaw.

I believe it is also important to state that I do not assume my acts of witnessing and corresponding interpretation necessarily reflect the experiences of those I observed. While I was free to come and go, patients and family members had no other choice but to continue to sit with the process of dying—an existential difference highlighted by Long, Hunter, and van der Geest (2008) as little discussed in ethnographic reflections on illness and suffering. Further, given that I could not observe any interactions without first obtaining written consent, those who self-selected to participate may not represent general characteristics, experiences, or perspectives of those receiving palliative care at these hospitals. My system of “recruitment” was not exhaustive—although I made strenuous attempts to connect with all patients deemed appropriate, some were missed because I was away for several days or because I was already following many patients. There were other times when I just could not face approaching another person that day. While I did not talk with or observe the dying of everyone on the unit or who was being consulted, the patients and family members that did chose to participate came from a range of socio-cultural backgrounds and ages. They had different diagnoses and prognosis, and they went through a range of terminal care pathways. They participated in my research for a variety of reasons: in the belief that it would improve the care of others, a desire to spend time with someone who was interested in hearing about their experiences, and as a way to distract from the mutual fear and boredom that all hospitals can engender. From this diversity, I was able to witness a range of hospitalized dying. In this spirit, while I have little interest in making objective claims to representation and generalizability, I do offer this diversity as a marker that the experiences recounted here emerge from a heterogeneous population.

There was also an awareness of the inevitable impact of the “gatekeeping” function performed by clinicians, which potentially further narrowed the available scope of participants. However, I never had a sense that any clinician directed me away from a patient or family member due to ethical complexities, decision-making dilemmas, or conflicting perspectives as usually it was the opposite. At both hospitals, I was often asked by clinicians if I had spoken with particular patients (or family members) because their physical and/or emotional care was particularly complex or in some way interesting and unique from the general population. Clinicians knew that my work focused on their emotional labour and their interest to include these cases in my research was framed as

a desire to ensure my work documented some of the complexities they faced. They may have also pointed out these cases in particular to seem impartial to a possible critique of their work. Consequently, in this study, similar to other qualitative research in palliative care, the impact of clinician's gatekeeping on the representativeness of those invited to participate remains unknown (Addington-Hall, 2002).

Observation

In my observations, I divided my time between the units and the consult teams, dependent on where the participants were located. If I was on the unit, I would spend the majority of my time in or near the nursing station, observing and interacting with clinicians as they engaged in their daily work. If I was following a particular patient or family member on the unit, I would accompany the clinician into the patient's room, to family or medical meetings, observe informal hallway conversations, review their written chart notes, and talk with them about the patient. As the units were small and self-contained, I often spent time informally with the patient or family member chatting in the hallway and/or the lounge. There were times that patients or family members saw me walk by their room and would flag me down for a chat if they wanted to socialize or tell me a piece of news. If I was following a particular patient or family member recruited through the consult team, I would observe the clinician interacting with the patient or family, interactions between them and non-palliative clinicians, attend meetings regarding care, and review chart notes. There was less informal interaction between these patients or family members and myself as I was often only on the units when the palliative clinicians were also present or when conducting interviews and/or reviewing chart notes.

At a conservative estimation this process provided me with over 1,000 hours of observation and almost an equal number in pages of fieldnotes. In writing notes, my usual habit was to observe for short periods of time (15 minutes to an hour), followed by short periods of recording those experiences in my notebook, including what I remembered of the conversations, as well as my own thoughts and feelings. In medical meetings or other contexts where note-taking did not disrupt the flow of conversation, I took, to the best of my ability, verbatim short-hand notes of conversations. These notes

would be followed later in the day by my own thoughts on the meeting. In the evenings I transcribed my notes into my computer.

Interviews

I interviewed patients, family members, and various clinicians, support staff, and administrators. Interviews with patients or family members¹⁶ lasted anywhere from 45 minutes to two hours, with most lasting approximately an hour. Many of the interviews with patients were held over two sessions due to exhaustion, levels of medication, symptom burden, appointments for tests, or other clinical interruptions. Questions focused on illness history, coping with physical symptoms, emotional responses to illness, relationships with clinicians, decision-making, gaps in care, and care goals. Interviews were often emotional, and most times participants cried or expressed distress in other ways. However, they also laughed, sighed, rolled their eyes, smiled, and expressed anger and a range of other emotions. I debriefed with participants after each interview to ensure that participation had not left them feeling emotionally overwhelmed. As part of this process I offered psychosocial referrals, although none of the participants expressed interest or later pursued this option. All but two interviews are taped (as those patients preferred that I take only notes).

Interviews with clinicians lasted from 25 minutes to more than an hour, with the average lasting approximately 45 minutes. Questions focused on definitions of palliative care, main challenges in providing care, ways of meeting those challenges, therapeutic relationship building, common emotions in palliative care (both of self and other), support services required for delivering ethical care, the perceived evolution of care, and desired changes for the future of palliative care. For those clinicians I observed regularly, I also included questions regarding their experiences of having a researcher accompany them during their work. Their perspectives are discussed later in this chapter.

¹⁶ There were three occasions where patients wanted to participate, but also wanted their spouse to be present. After talking with my dissertation committee, I conducted these interviews jointly using two separate consent forms.

Charting

Charting took up a considerable portion of each clinician's day and was considered fundamental to having adequate knowledge about patients. In many cases, chart notes are the primary way that clinicians speak to each other about a patient and their care plans, particularly consult patients. Clinicians looked at the patient's notes before entering their rooms, and would write their own (sometimes lengthy) notes before moving on to the next patient. Not infrequently, they would return later the same day to the chart to see if others had provided more information, acted on information they had written or that was already in the chart. In these binders, questions, concerns, agreements, requests, updates, and debates regarding diagnosis and prognosis, tests, treatments, goals of care, concerns about discharge and the psychological disposition of patient and family members filled dozens if not hundreds of pages. I examined these texts to see how care providers constructed clinical narratives about their patients. I focused on the chronology of disease, symptom management, care planning, psychosocial issues, and decision-making points regarding treatment, including discharge planning. I also noted where clinicians agreed or disagreed with each other, and the specific language that was used to describe patients' emotional states. I paid particular attention to notes that described encounters for which I had been present as textual representations of the now "official" version of that interaction.

While I include a diversity of clinicians', patients', and family members' voices in this work, by necessity and interest I focus on some participants and observations over others. As my work centres on processes of emotional labour and negotiation, I made a conscious choice to extrapolate the instances where this labour occurred or was discussed in ways that highlighted the complexities involved. This emphasis meant that while I observed and/or interviewed more than 40 clinicians, approximately half (19) are directly referenced in this work. These clinicians, especially the ones in the extended case studies I will present (Kirsten, Sally, June, Kelly, Gina, and Penny¹⁷), primarily occupied "senior" positions and had worked in the field for more than a decade. Clinicians from both units are relatively equally represented in my interview excerpts and

¹⁷ All names of clinicians have been changed.

in the extended examples collated from my field notes. Of the 36 patients and family members who participated in this research, there are seven that I include here, and four of those in detail: David, Ruby, Toby, and Jake.¹⁸ I chose to focus on each of these patients as they represent a range of the emotional labour negotiations and processes that constitute hospitalized dying. Similar to the “average” palliative patient I observed, David, Ruby, Toby, and Jake required varying amounts of clinicians’ emotional labour to negotiate the transition through the terminal care pathway. Similar to other patients, their processes of negotiation were shaped by their differential ability to claim narrative authority, fluctuating prognostic indicators, offered treatments, and/or location of care. This combination of diversity and commonalities in the negotiations to facilitate their good death enabled me to explore how the practices of hospitalized palliative care are constituted *in situ* of the mundane complexities of every day care. Finally, their instances of care afforded me examples that are not easily identifiable to any one care provider, patient, and/or family member.

Ethics in Hospitalized Palliative Care Research

Hospitals occupy a seemingly contradictory space in relation to the privacy, respect, and autonomy of patients. Clinicians and other “human” faces of institutional policies strive to ensure that the vulnerable population of patients and their families that they care for are protected during times of crises and distress. Competent care includes not only care for their bodies, but also creating affective environments of respect and privacy. Yet these hospitals are also spaces for the creation of knowledge, requiring observation and information gathering by visiting clinicians, students from diverse medical fields, and researchers. How hospitals navigate the potential ethical quagmire between the requirements for advancement of knowledge with desires for privacy and respect is often an uneasy dance between multiple partners and interests.

¹⁸ All names of patients and family members have been changed.

Studying Up

The following section addresses my experiences of doing ethnography in a hospital setting, and discusses how my research design, implementation, and writing were fundamentally shaped by the ethics of biomedicine. This discussion highlights that institutional culture is not something that we as researchers study from the “outside” but that we are immediately and continuously affected by the same environment as our participants. While there is a plethora of literature on the ethics of conducting research with palliative patients, a thorough discussion as to how institutional culture(s) shape the methodology of palliative care research is lacking (Addington-Hall, 2002). Some researchers (Hoeyer, Dahlager, & Lynoe, 2005) have highlighted how this lack is evidenced in many hospital studies and ethnographies, where authors rarely include details of the challenges they faced in gaining institutional access, the risks of engaging in critique of practices observed, or the responses of clinicians to being observed. For example, neither Kaufman (2005) nor Glaser and Strauss (1965, 1968) in their otherwise comprehensive works address the impact of ethical review board policies on their research, how they negotiated access to hospital clinicians, how clinicians perceived being research subjects, or how they viewed the researcher’s “findings.” Additionally, there is no literature that I could locate that discusses the ethics specific to researching palliative clinicians.

Scholars interested in studying up within generalized medical settings have identified several challenges for researchers in gaining acceptance for hospital-based qualitative studies. These challenges can include: institutional review boards, property rights in regards to information collected, discomfort or hostility by hospital staff, lack of an “official” role, ethical and/or political quandaries, and conflicting identity/loyalties (or what others have termed “boundary blurring”) (Davis, 2001; Dickson-Swift, Kippen, & Liamputtong, 2006; Forsythe, 1999; Hoeyer et al., 2005; Pope, 2005; Wind, 2008). While I experienced most of these to some degree in my research, the main ethical challenge I initially struggled with emerged from negotiating the ethics of informed consent and property rights to data with the institutional review board that regulated both hospitals. A secondary ethical challenge arose once I had been in the field for some time, which was centered on the relationships I developed with both patients and clinicians that were generated within complex, and at times exceptionally intense, affective environments.

Gaining Entry into the Medical World – The Ethics of Informed Consent and Ownership of Data

Ethics of Researching Palliative Patients

The most pressing ethical considerations in researching terminally ill patients are autonomy and competency within the potential context of extreme vulnerability, pain, anxiety, and *non compos mentis* at the end of life. Additionally, critically ill hospital patients are a captive population and they may participate in research from a desire to please health care professionals and/or from a concern that refusal to participate may jeopardize the quality of their health care. There are also issues of privacy; the end of life is often an intensely personal time for patients and their families and extraneous strangers asking personal and sensitive questions can potentially be upsetting and invasive. Given these concerns, a few clinicians and researchers assert that any research with palliative populations is at best questionable, and at worst, unethical (de Raeve, 1994; Janssens & Gordijn 2000). The prevailing perspective, however, is that research with terminally ill people does not present insurmountable challenges when compared to other forms of research with vulnerable populations, and it is potentially beneficial to patients, family members, clinicians, and to the systems of care these individuals are located within (Cassarette & Karlawish, 2000; Dean & McClement, 2002; Hutchinson, Wilson, Skodol, & Wilson, 1994). From a patient and family perspective, multiple studies have found that they wish to participate in both clinical and qualitative palliative care research as they express a hope that sharing their experiences will make a difference in society, and that the suffering of others in similar situations can be reduced, eliminated, or given new meaning (Dorbatz, 2003; Aoun & Kristjanson, 2005; Kuhl, 2006; Nuland, 1995). Of course, as it is for all participants who engage in research that entails more than a single encounter, informed consent with populations of critically ill patients and their families cannot be assumed to be static. All patients wish to have the autonomy and opportunity to choose or refuse to participate in research, and application of ethical principles needs to occur on a case-by-case basis (Bruera, 1994; Gysels, Evans & Higginson, 2012; Lee & Kristjanson, 2003; Stevens, Wilde, Paz, & Ahemdai, 2003). As highlighted by the National Institute of Nursing Research, palliative patients and their family members are diverse with respect to their decision-making

capacity, which depends on numerous factors, and so blanket prescriptions about safeguards, however laudable, are not useful (Cassarett, Karlawish & Hirschman, 2003).

Informed Consent Process

Given this tension between patients' and family members' desire to share their experiences, and awareness that the end of life can be an intensely personal and often traumatic time, my ethical goal was to offer all those potentially involved in the study (clinicians, patients, and family members) repeated opportunities to define the limits of their participation without censure. With frequent fluctuation and rapid deterioration in cognition and physical ability, unpredictable levels of pain and exhaustion, along with potentially radically shifting emotional states, my primary concern regarding informed consent with patients and family members was that a single "moment" of consent during a period where they felt relatively well would not necessarily indicate their ability or desire to provide consent during future periods. As I wanted to conduct observations, interviews, and undertake chart reviews, I felt that each component required a separate consent process. After discussing my proposed plan of research with clinicians and with my academic committee, it was agreed by all parties that what would work best was a three-part consent process. As per standard observational protocol for minimal risk research in medical settings, I would secure verbal consent during the first observation, followed by signed consent before the subsequent interview and review of chart notes, if and when potential participants expressed further interest. I would also continue to secure verbal consent at each subsequent observation. Verbal consent processes had been successfully used by other researchers within the health authorities from which I was seeking approval, even in cases of high-risk research, which mine was not.¹⁹ Further, dynamic consenting processes such as this have been suggested by other palliative researchers as the most ethical form of ensuring consent in this population,

¹⁹ At this time of my research ethics application, there were two projects taking place in these hospitals where the board had approved verbal consent as appropriate for observation, even though the research was with marginalized populations and had been designated high risk. Perhaps the board felt that this was appropriate as the principal investigator on these projects was a high-level, internationally renowned clinician. However, this potential justification is weakened through the knowledge that he was not involved in any of the direct interviewing and observation.

where sensitivity is required regarding context, timing, and other concerns (Addington-Hall, 2002; Munhall, 1988; Raudonis, 1992; Seymour & Ingleton, 1999).

To observe daily clinical life, I also proposed that I would be present on the palliative units and attend daily rounds and staff meetings. While general observations would be made of both palliative and non-palliative clinicians both on and off the palliative units, no personal data that might identify any clinician would be recorded. If any clinician felt uncomfortable with generalized observation, they could speak to me and I would ensure that none of their actions or interactions would be recorded. I would also seek out individual written consent from each palliative clinician to observe their interactions with patients, family members, and other clinicians, as well as a separate consent form for the interviewing process (which I also used for interviewing non-palliative clinicians and administrators). To inform non-palliative clinicians, I put up information posters in all of the units the palliative consultants worked in, spoke with and secured approval from the unit operation leaders, and secured the clinicians' verbal consent if I observed them directly.

Ethics Review Board

As gatekeepers, institutional review boards are powerful actors in shaping what kinds of research can be conducted, and therefore what kinds of knowledge can be constructed and validated. From a bureaucratic perspective, the multiple levels of ethical clearance required by my research were daunting. I required clearance from my university ethics board, from the health authority regulating the hospitals within which I wanted to do research, and from each unit manager where I would be observing clinician interactions.²⁰ I had little difficulty securing ethical clearance from my university, and the directors of the two palliative programs also provided written formal approval (and enthusiasm) for the project, as did the non-palliative unit managers. Despite being armed with these inter- and intra-institutional documents, official clearance from the hospital ethics review board was a frustrating and labyrinthine process. While the board did not express concern regarding the informed consent process for clinicians, and

²⁰ This included 10 units between the two hospitals—the two dedicated palliative units, and eight other general medicine or acute care units where palliative clinicians provided consults.

though my research had been designated minimal risk to participants, they were adamant that all patients and/or family members needed to engage in a single signed consent process (after 24 hours of reviewing study information) before any observation could take place. Following the Tri-Council policy, along with national and international research examples with palliative populations, I argued that my consent process would balance the ethics of verbal consent for initial observations with an in-depth, nuanced, and situational-relational approach to consent if and when a research relationship developed. To bolster my position, the clinicians that I would be working with signed a letter of support for the ethical and practical aspects of consent I had proposed. These included: (1) verbal consent being invoked on a daily basis by a diversity of observers, including medical students doing research; (2) patients being most comfortable with this form of consent for observation in medical settings; (3) the clinicians' own beliefs that it was an ethical practice generally and was made more so by the protocol I had set in place; (4) verbal consent allowed for research to occur without substantially interrupting the flow of care, thereby facilitating research while not adding to patient or clinician burden; and therefore (5) requiring written consent for initial observations violated the culture of the teaching hospital.

The board's position remained unchangeable even after multiple conversations. Following many months of negotiation, I realized that if I wanted access I would have to modify my initial proposal. This meant that I could not initially meet participants during the clinical encounter. The clinicians, while sympathetic, were clear they were unable to systematically facilitate such a consent process during their work-related interactions with patients and family members. Participants now either had to seek me out (through an information brochure located at the front desk of each unit) or I would require introductions from clinicians during the rare periods of time they were not "busy" with a patient or other work. While I have no doubt that the board acted out of a desire to protect the best interest of patients and family members, many do this work "off the sides of their desk" with sparse access to resources regarding appropriate methods for research that are not clinical trials. Their position, therefore, may have been shaped by what many researchers assert is a lack of familiarity of the methods needed to construct ethical qualitative research with palliative populations (Fine, 2003; Koenig, Back, & Crawley, 2003; Lee & Kirstjanson, 2003; Pope, 2005).

Informed Consent in the Field

During my research I modified the consent form verbally, having participants, if they wished, write in and initial on the form what aspects they would like to participate in. Patients could choose any one aspect of consent (i.e., observation, interview, chart review), several, or all. This was also true for family members. All participants were willing to engage in all aspects of the research with the exception of one family member who, while open to being observed and participating in the interview, expressed reservations regarding the chart review. I also continued to seek informal verbal consent each time I observed a patient or family member. No patient or family member asked me to leave during any observation, and the opposite happened more than once, where the patient or family member asked me to be present, saying that they wanted me to better understand what they were going through. Clinicians could choose to participate in an interview, but not to be observed, or vice versa. One clinician asked that she only be interviewed and not observed. I also once had a clinician request that I leave halfway through a meeting about restructuring fee-for-service payments. While the other clinicians in the meeting expressed surprise at this request and asked that I stay, I did not want to cause dissent and left.

Ownership of Data

An accompanying issue that created dissonance was who would own my data once it was collected. Given that I had no professional or academic affiliation with these hospitals, the ethics board required that I have a senior clinician and/or academic affiliate as a principal investigator in addition to my (non-affiliated) academic committee. Further, given that I was working at two sites, I was required to have a principal investigator at each site. This created a challenge to ownership of my research as a principal investigator traditionally holds primary responsibility for data collection, analysis, and dissemination of a project. Thankfully, the program directors of the palliative units at each site willingly stepped into these positions, even with the knowledge that I would not share any raw notes or information, nor relinquish ownership of any data to them or their institutions on the completion of my project. This conflicted with the position of the board that the hospitals, and these clinicians, would own the data. I also felt strongly that these host sites, particularly the clinicians themselves, may

be able to use certain aspects of my research. My solution was to write a memorandum of understanding that stated I would provide a document with analysis of particular aspects of my research to each of the palliative units (dependant on their interests). This intent has been realized through multiple presentations at each unit, as well as at conferences well attended by clinicians from these hospitals. I also stated that any publication of research that did not include information gathered from patients and/or family members would acknowledge the hospitals, if they so choose. In the event of a disagreement with interpretation between myself and the clinicians, I included conflict resolution possibilities such as including dissenting opinion(s) and providing resource links within my work to other perspectives. To date, I have not yet had substantive disagreement emerge from any of my presentations.

Research Relationships in Hospitalized Palliative Care: Experiences in the field

I have outlined my challenges of informed consent with institutional review boards, discussed how I conducted my fieldwork, and provided descriptions of the units, the clinicians, the patients, and family members that I observed. Yet these general descriptions and statistics share little about what it was like to spend a year researching palliative practitioners and those they cared for. As Lee and Renzetti (1993) have asserted, conducting research on sensitive topics can benefit from reflection, as a way to “confront seriously and thoroughly the problems that these topics pose” (p. 10). Consequently, my response to this call for reflexive inclusion in research dovetails with other researchers’ call “for more published accounts of investigators’ experiences in dealing with the effects...of conducting studies on sensitive and emotionally laden topics” (Kinard, 1996, p. 69; see also Hubbard, Backett-Milburn, & Kemmer, 2001).

I knew from the outset my research would be emotionally charged. Hospitals are intense affective environments, and working with those who have an advanced illness is rarely unproblematic. During my fieldwork I had to continuously negotiate my own engagement, which presented both significant challenges and benefits. There were times I was frustrated at my inability to provide tangible physical or emotional relief to the distress I was witnessing, and I was envious of the clinicians who had the skill and

knowledge to do so. There were moments I questioned the value of my work during such a sensitive time in a person's life. There were times I felt angry, or deeply unhappy, about care decisions made by both patients and clinicians. I occasionally felt guilty that patients shared so willingly and I seemingly did so little in return; that I and my loved ones were in good health, and that at the end of the day, I could walk away from the hospital knowing that I was only a researcher. There were also the grindingly mundane experiences of watching family members being petty and cruel to one another. Finally, to observe, and accompany others, going through the processes that my family and I went through brought to mind my own experiences, and these encounters intertwined with my own personal feelings of grief.²¹

At the same time, as I accompanied the clinicians in their work, day after day, grief became only one part of the emotional spectrum of my research. I was grateful for the opportunity that patients, family members, and clinicians provided me to learn about their world, their experiences and perspectives. There were innumerable moments I witnessed patients and family members expressing their love and appreciation for one another and for the time they had remaining. Personal connections were made, small victories were celebrated, and setbacks mourned. There was also a great deal of laughter and days where I was deeply moved at being able to be present with these people. Sometimes, all too rarely, there was just day-to-day life, where nothing remarkable happened, either good or bad. My experiences of intertwined concern and curiosity are reflected in Kaufman's (2005) recounting of her own responses in observing end of life in acute care contexts:

My struggle to articulate my emotions reveals that my "feelings" and "thoughts" cannot so easily be separated...I was simultaneously sad and curious, anxious for families, apprehensive about diagnoses, appalled at what patients went through, and at times very uncomfortable about interfering (sometimes simply by being present, sometimes by asking questions) in others' work and lives. My emotions regarding patient and

²¹ Additionally, eight months before entering my fieldwork, I underwent a serious operation that culminated in a lengthy hospitalization, diagnostic confusion, treatment uncertainties, a further surgery, and a blood transfusion. These events occurred in one of the hospitals within which I conducted fieldwork, and there were times where the memories of my own experiences, entangled with my research observations, physically overwhelmed me and I would experience stomach pains, anxiety attacks, and nausea.

family suffering were inseparable from my emotions about being a careful researcher, constantly on guard about the impact of my intrusion on staff routines and into patient and family privacy. (pp. 16-17)

Being present as a researcher in this environment meant navigating my own inevitable emotional fluctuations that occurred within it. Similar to Kaufman, though, it also required an awareness of not only how I was connected but also of how I distanced myself from those I was observing and with whom I was interacting. As an “outsider” institutionally, professionally, and personally, I was in a liminal position to both clinicians and to patients and family members. This lack of defined role has been identified by others as a tension for researchers in medical contexts, such as Wind (2008), who stated she never felt she did “proper” fieldwork within a rheumatism clinic because she was never an “active” part of events (p. 81). From this position she calls for hospital ethnographers to change the traditional term “participant” observation to “negotiated interactive” observation (p. 79). Davis (2001) also addressed this liminality in her ethnography on nurses’ use of computer technology, stating that, “I did not have a legitimate role to play...I felt that the level of my participation in hospital life was never clearly defined, even by myself” (p. 41). In her solution to combat these feelings, she details how she either volunteered or staff would ask her to perform small tasks (p. 44). While other researchers do not advocate changing terminology or participating in the work of those observed, they highlight how they do not fit into existing categories of clinician, patient, family member, or volunteer (van der Geest & Finkler, 2004). In my own research, I felt this ambiguity most keenly in two scenarios: when patients were approaching death and in creating affective ties with clinicians. In the section below, I detail how the development of research relationships during my fieldwork blurred my boundaries between being an independent researcher, participant, observer, friend, and colleague.

Boundary Blurring with Patients and Family Members

In order to conduct “successful” interviews, I had to quickly develop rapport, both to create a safe environment to discuss personal thoughts and concerns and in recognition of the potential rapid deterioration of patients. While patients and family members understood that I was not a clinician, I was often associated with these

professionals by default as I shadowed them throughout their day. Patients and family members were also aware that I acted outside the norms of a medical professional, particularly if they had a lengthy admission. Some of these participants I saw every day during what was possibly the most vulnerable, difficult, and emotionally challenging part of their lives. As Dickson-Swift, Kippen, and Liamputtong (2006) question, “How, then, do researchers maintain responsible boundaries in research while incorporating some boundary crossing with participants to develop the empathy and rapport needed to undertake the research?” (p. 862).

With patients and family members I had to continuously negotiate boundaries between observer and participant as I attended family meetings, had both formal and informal conversations, listened to what had happened in their lives, what they were hoping for, what they were worried about, what they had lost, looked at photographs, held their hands, laughed at their jokes, hugged them, and, with family members, expressed my condolences after a death. Many interviews included tears, and it would have been dishonest for me not to show the emotions I myself felt from hearing their stories. Other times conversations centred on mundane and daily issues with little or no emotive content, evidencing a desire primarily for company. Patients and family members were willing to participate in my research, but in return many wanted a human face to the research—they wanted to know that they, and their families, mattered to me. This did not mean that they wanted to be friends. Rather, what I am attempting to evoke is the mutual desire between myself and these individuals for recognition that their lives had significance outside of being a research “subject.” This mattering developed and was expressed through discussions of their past (including letters and photographs), having personal questions asked of me, being teased (and on one occasion flirted with), and conversations about family, finances, sports, and other aspects of daily life, which included, at times, their thoughts on death and dying. Like the clinicians, I wanted to both connect with and make a positive difference to these individuals who were often part of my daily life. This desire is evidenced in an excerpt taken from my fieldnotes that recollects a conversation with Frank, a patient I had been talking with for several weeks.

September 2009: At this point in the conversation, two friends quietly knock on Frank’s door for a visit; as I leave I ask if there’s anything he needs and he jokes that he’d love a

double scotch. I laugh and tell him I could probably arrange that; he perks up and says "Really?" I tell him I can't promise it but that I'll ask his doctor. As I turn to leave one of his friends says "He really likes his beer." I find his clinician in the nursing station and tell her that Frank asked about the possibility of having a beer. She laughs, rolls her eyes and says "Well if he wants to throw his fluid levels out of whack go ahead, he can have one beer a day". The clinical nurse leader gives me some money out of their petty cash fund, and I walk a few blocks to the liquor store. As I walk I am overcome with a feeling of happiness that I can actually do something practical for Frank, something that he wants and enjoys, in some small tangible way. I realize this feeling must be similar to what the clinicians tell me about the rush they get from helping patients—it's like an extreme emotional sport. I buy Budweiser, on his request. The store doesn't sell individuals cans so after much deliberation I buy a six-pack. I wonder if he will live long enough to finish it.

Unlike Kaufman (2005), I became quite attached to several patients during the course of my research because they were warm, insightful, funny, reminded me of myself and family, or because their care was particularly complex and challenging. Personalized caring was a part of my research relationship; I cared how participants were coping, what they were feeling, how they were cared for, and how they were going to die. I, like the clinicians, had a desire to see them "die well." I do not see this only as a problem of "boundary blurring" but also a basic human characteristic—we care about other people, particularly when they are experiencing distress and crisis. This is also a form of ethical "witnessing" in the face of suffering. Similar to other ethnographers who have developed research relationships with vulnerable populations, I believe that offering a stance of neutrality in the face of (at times) deep suffering and palpable pain is morally questionable (Lawlor & Mattingly, 2001; Scheper-Hughes, 1992).

Given such investment, these connections also created ethical challenges for me, particularly as patients neared the very end of their lives. My process of continued verbal consent became increasingly problematic during the last stages of dying where patients often had difficulty in speaking, lucidity, and/or remaining conscious in the last days and hours of their lives. When obtaining verbal consent was no longer possible, I had to ask myself each time I observed a clinician-patient interaction if I felt it was

ethically appropriate to be in the room, even with written consent. There were times where I observed interactions that, in retrospect, I am not sure I would do again; there are other times that I look back on when I chose not to be present and now feel that I should have been, based on the relationship that developed. This was particularly true of one patient who I (and other clinicians) had grown very close to and been following for several months, as is recounted in the following extract taken from my fieldnotes.

May 2009: Carol [the consult clinician] has informed me that Jim will most likely die over the weekend and that if I want to say goodbye that “this is the time” as “he is going to change very quickly.” Part of me wants to go in, but I tell Carol that I’m not sure Jim can provide consent as he can no longer speak. Carol then enters his room, ostensibly to check on his status, but in reality to say goodbye. I do not follow her, and she emerges 15 minutes later, a bit teary. She tells me he looks “really bad and is becoming increasingly confused,” but that he knew that she was saying goodbye and he wrote “I love you,” and burst into tears and everybody was hugging. As I heave a big sigh, she tells me that it’s OK to cry, because sometimes people need permission to do that.

I did not see Jim again before he died, although I had previously visited him several times a week during his lengthy admission. In the days after his death I told myself that this stance was one of respect in that I did not believe that he would be able to provide cogent consent for my presence, and/or that the family may be uncomfortable with my presence during the last hours of his life. In retrospect I believe my actions stemmed primarily from the inability to say goodbye to someone I had grown close. I hid behind my role as a researcher so I did not have to express my feelings as an individual, and I continue to carry regret for my actions in this instance.

In this sense the status of informed consent between researchers and participants at the end of life can become a particularly troubling one when: (1) research relationships unfold over a significant period of time, (2) they develop within intense affective environments, and (3) evolve to where the participant may no longer be able to indicate consent. In my research, patients and family members gave consent for all observation at the beginning of their participation, and I supplemented this process with repeated informal verbal consent processes. However, I continue to question their (and

others') ability to *anticipate* what a researcher observing the last hours of life "looks like," and when they may no longer have the capacity to communicate clearly a change of mind. These tensions were especially challenging for me with patients who initially expressed a strong and/or sustained belief that they would be discharged. Further, I did not use the words "palliative," "terminal," "death," or "dying" in any of the consent materials or project information due to the potentially negative effects these words would have on the distress levels of the patient and/or family members. My uncertainty and ambivalence regarding "correct" terminology is not unique; as Addington-Hall (2002) notes somewhat dryly, language use in informed consent and palliative care research is a "quandary...not easily solved" (p. 11).

How to support researchers engaged in sensitive topics also continues to be a challenging topic for research supervisors, academic committees, and research ethics boards. I do not have a tidy summation regarding the ethical implications of building research relationships with those who are facing death. At best, all I can do is point to existing research that identifies the necessity of continuously thinking through the process of consent with vulnerable populations on a case-by-case basis (Bruera, 1994; Cassarett, 2002; Lee & Kristjanson, 2003; Stevens et al., 2003), while including discussion as to how my experiences of being present in these contexts were shaped by my own desires and challenges. Having worked professionally in areas of sensitive research other than palliative care, I do not believe there is any one set of strategies that can be applied. Dickson-Swift et al. (2006) suggest that protocols be designed or at least discussed for: disclosure, rapport, clarity between research and therapy, exit strategies, and the management of boundaries, including developing friendships (p. 867; see also Rosenblatt, 2001; Hubbard et al., 2010). To this list I would add the development of self-care strategies.

I have struggled with my willingness to include the "messy" aspects of my research for fear of being perceived as "doing" ethnography incorrectly. Following Davis (2001), I believe it is important to recognize my own emotional labour as well as those I researched, particularly given the centrality of the concept within my dissertation. In including my personal experiences, my hope is that this recognition of the intertwining between the "personal" and the "professional" may have value for others who are considering research in similar environments with vulnerable populations.

Boundary Blurring with Clinicians

I also do not have a neat summation of the entanglement effects from the boundary blurring that occurred between myself and the clinicians with whom I worked. Although I do not have any form of medical certification, my academic credentials, previous years as a researcher, interest in palliative care, and growing knowledge of clinicians' day-to-day experiences in providing care gave me a quasi-legitimate status as a caring professional. In addition, it helped that I had the enthusiastic approval of the head clinicians and that I had personal experience with death and dying. My physical appearance also buttressed a sense of belonging in that I am a middle-aged female who dresses conservatively, similar to the age, gender, and class-status of many palliative clinicians who, for the most part, also do not wear white coats. Additionally, given the amount of time I spent on the unit in the nurses' station, wandering the halls, hanging out in common areas, talking with patients and family members, conversing with other clinicians, taking copious notes, sitting in the lunch room, reviewing chart notes and attending daily meetings and rounds, I quickly became a relative "constant" in their professional spaces.

My notebook became an important and visible marker to clinicians to reference my research project as a whole. It was a source of familiar teasing; often clinicians would remark that I "wasn't ready" for a meeting or to shadow them if I didn't have my notebook. Other times they took the notebook very seriously, pointing to it during particularly challenging moments and saying "make sure you write *that* down." There were three occasions, early in my research, where clinicians after using black humour would laughingly remark, "Oh god, you're writing that down?" or "Now we're going to look horrible." I only had two occasions, also early in my research, when a clinician formally asked me not to record an interaction; both times were due to humorous remarks where they expressed concern that it may be read by "outsiders" as inappropriate. On more than one occasion, clinicians asked if I had any information about a patient or family member that I could share with them so they could have better insight. In one case, where I felt strongly that it would help the patient's course of care, I asked the patient if he was willing to have me share the information. He expressed surprise that the clinicians did not already have the information and felt that it was important that they knew. Other than that one case, I did not share any information with

clinicians, or ask any other patient or family member if they were willing to share information emerging from our conversations.

While most clinicians initially remained cognisant of my independent researcher status, and occasionally verbalized a tolerant bemusement in my ongoing interest in them, I rarely experienced a sense of discomfort on their part to letting me into their “world.”²² Further, after a relatively short period of time I felt the majority of clinicians expressed few reservations in sharing many of their personal thoughts on their activities as I followed them in their daily work. This is evidenced in the following two short excerpts from my fieldnotes:

February 2009: I just had a conversation with Toby [a clinician], whose cat had just died. She tells me [and several other clinicians who are in the room] that she put her cat down and she ruminates on how well it all went and wonders why we don't do this with people, especially “Since we're extending life so people are presenting with more symptoms.” She states that “If we're extending life then in some cases we're also extending suffering.” She questions if people should have the right to ask for “needles” and states “Why do we treat our pets with more dignity?” After she leaves the room, one clinician says “Well terminal orders are the same thing”; another clinician gives a kind of half smile and says “Don't say that.”

February 2009: Kirsten [a consult clinician I am shadowing] sighs as she writes chart notes about a consult patient receiving aggressive treatment who now wants to pursue a risky course of surgery. She looks up at me, and rubbing her forehead says “You know there are some days I don't even know what palliative care is anymore.” She looks back down at her chart notes and continues writing.

During my fieldwork I became close to many of the clinicians. I often ate lunch with them, discussed light personal matters of family, friends, relationships, and weekend plans, and at times engaged in “workplace” gossip. I attended workshops and conferences with them and in one case copresented a paper at an international conference with a

²² When this did happen it was primarily within the artificial context of interviewing, where I had two clinicians revert to what Pope (2005) terms, “public accounts...effectively giving rehearsed presentations” (p. 1183) regarding their experiences of providing palliative care.

clinician. During this time I also exchanged deeper confidences, including my hopes or frustrations with patients and their treatments. Our relationships developed through spending months with each other and mutually experiencing intense situations.

Near the end of my fieldwork, I perceived significant boundary blurring was also occurring on the part of clinicians. After so much time together, it was not uncommon for some clinicians to ask my thoughts regarding the challenges of a particular patient or situation. I also perceived that other clinicians were beginning to interact with me more as a nursing or social work practicum student rather than as an external academic researcher. Collectively, these experiences became a marker of knowing when it was time to exit the field. I then asked clinicians I spent the most time with about their experience of the research relationship and accompanying social ties, and include some of their responses below.

Kelly: Having you around has been very interesting, especially once I understood more about how you are using your data. We got really used to you being here, and talking with you; you stayed longer than the residents, and so often I just wouldn't notice that much. But once you started talking about what you saw, that really opened my eyes. I couldn't believe some of the things you said [in a presentation]...It's really spot on, and nobody is talking about some of the challenges in doing this work on the ground. It made me quite emotional.

Carol: It was a bit odd at first, having someone follow you around everywhere. I wasn't sure what you were up to, but I liked that you were interested in what we do, and you were very respectful...After a while I came to expect to see you all the time, and when you left it was kind of sad. I enjoyed having you here; in particular because it made some of us have to think through what we are doing because you asked so many questions.

Penny: I think having you here has made me more aware of the pressure I feel, and more aware of how I work. Of course I've always done it, I'm just more aware of the work now. I'm more aware of the impact, of the pressure. You've opened my eyes to some of the things that I just did [before] without having a deeper understanding...because we talk about it...[For example] The other day after that difficult family meeting I still hadn't had a chance to talk to you, and I wanted to know what you think.

These quotes provide strength to Pope's (2005) assertion that carrying out ethnographic research within medical settings can provide a catalyst for reflections and opportunities for mutual dialogue between clinicians, others interested in health care, and the researcher (p. 1185).

Although friendship is too strong a term for the majority of relationships I developed with clinicians, they were affective ties (Rawlins, 1992). My admiration of their emotional and physical stamina, compassion, humour, sense of moral obligation in providing care, and their openness, interest and curiosity that facilitated my entry into their worlds was extraordinary. Yet my understanding of their work developed, in part, through their challenges in providing care. While many of the issues I address are direct reflections of their own awareness and frustrations in this regard, I do not want my research to be perceived as a betrayal of their trust or feelings of goodwill. These concerns are similar to what Lofland (1995) terms an "ethical hangover" for researchers, a "feeling of persistent guilt or unease over what is viewed as a betrayal of the people under study" (p. 28). While he is referencing the relatively unequal relationship between indigenous peoples and Anglo anthropologists, these concerns have also been relevant to my research context. As a consequence, I am careful in my use of language, and forward the assertion that even in the most challenging cases the care provided emerged from deep compassion and an enduring ethical concern that helping people die with a minimum of suffering is the right thing to do.

Ethnography and Narrative

The Importance of Narrative

Clifford Geertz (1994) famously conceptualized culture as "webs of significance" spun by humans. One of the most significant ways we create these webs is through narrative. The centrality of narrative as a meaning-making activity is evidenced from its root in the Latin verb *gnare*, meaning "to know." For the purposes of this work, I define narrative as *expressive acts (which require emotional labour) of an individual or group that work to connect experiences of affect to existing structures of meaning (discursive formations)*. Through this connection, the capacity of narrator and audience is increased

or decreased by shaping emergent physical states and modes of thought. These expressive actions are relational work and they require a real or imagined audience, are generated within available social meanings, and emerge from specific relations of power and knowledge. Narratives are a manifestation of discursive formations; in the structuring of expression, they produce “truth” conditions and thereby (re)produce, naturalize, and/or challenge what can be knowable. Attention to narrative within ethnographic studies of medicine is then an exploration of how meaning-making emerges through narratives where individual experiences of being-in-the-world are rendered knowable and given meaning through their relationship to larger social frames of true or false (Kaplan, 2010; Kaufman & Morgan, 2005; Lock, 1993; Scheper-Hughes, 1992).

It is through acts of narrative that understandings of the self emerge, and the importance of language cannot be overstated in the processes of socialization. Yet the ordering of experience occurs through somatic as well as linguistic signifiers, where subjectivity is not exclusively an outcome of language. Felt emotion is itself a narrative act—expressions of experience communicated to self and to others through framing and feeling rules that order both emotions and the acts of expressing them. Emotions, then, are not only generated by our reactions to, or interactions with, narrative, but can also be understood as narrative. By this I mean that *emotional states are narrative states*, whereby categorical experiences of shame, pleasure, or guilt (among a host of other emotions) are as infused with meaning, known, and communicated as much in the invocation of corporeal signifiers (such as nausea, laughing, and crying) as they are by linguistic signifiers. This returns us to Massumi’s (2002) assertion that “[p]erceived experience, articulated as emotion, can be understood as the narration of affect” (p. 5).

Narrative as Ethnographic Procedure

In my research, the centrality of narrative informed both my procedure and my analysis. I challenged myself to pay attention to both the content and context of narrative building in order to illustrate the diversity of ways in which knowledge about the dying process was generated, naturalized, and/or contested. This focus is highlighted below in a fieldnote entry recorded approximately half-way through my observations.

June 2009: “Processing” is a very popular word clinicians use to describe patients and/or family members who are “transitioning” (also a popular word) in their thinking, realizing things are not going to go well. Patients don’t seem to really want to talk about being sick; they want to tell stories about their lives, who they are/were without the illness. A lot of all of this “processing” then seems to be about creating stories and who has the power to create which stories that become the “truth” of the situation. I am thinking about this in relation to today, where Sally [clinician] was talking with Thomas [patient], trying to guide the conversation about increasing his sedation to reduce his anxiety as he comes closer to death, and how he was resistant. Her language seemed vague and non-specific, but it also seemed very guiding in use of terms like “in my experience,” “in the future,” “as things progress,” and saying “some people prefer to be more sedated for their symptoms.” He wouldn’t respond to those prompts, instead focusing on the possibility of stabilization, returning home and spending time with his boyfriend and dogs. It was clear that this was frustrating Sally, but she was also respectful and backed off, saying they’d “wait and see,” and then changing the subject. The doctors want to create stories about the present and future, which have more weight because of their expertise, but they are not always even close to accurate, and patients and family members often seem to try and come up with alternative stories that reference their past states. Each try to humanize the situation through stories, but in their own way; doctors by referencing clinical experience and “quality of life,” and patients and family members about who they used to be and what they are hoping for—stabilization, length of life, returning home, and spending time with family and friends like they used to. Communicating and making stories of uncertainties seems a way for the unknowable to be made sense of for everybody, but not everybody always agrees.

I include this developing analytic reflection to highlight that my interest was not only who said what to whom, but also to examine how these moments of conversation can be understood as negotiations of power and knowledge to frame how the dying process is constructed by all involved parties.

I also paid attention to “back room” moments between clinicians to better understand how narratives of the dying process are informed by a broad range of potentially competing interests.

April 2009: In rounds, June [clinician] talks about a patient who has been recently readmitted and is on antibiotics, receiving blood transfusions, and several other treatments. She wonders aloud “Are we prolonging [patient’s] life or prolonging her dying?” She states that there needs to be a family meeting to “have to have the great debate.” Sally [another clinician] asks if [patient] will stay on the unit until she dies, and June states “Yes, and we’re going to have to answer to [the health authority] and it’s going to screw our statistics...she’ll be here for weeks to months.” She continues that she’s noticed that there is “more and more angst among family and patients that don’t want to leave the unit and the hospital.” Sally sighs and agrees, stating that she can understand why, because they feel safe here. A third clinician joins in laughing and says “They shouldn’t feel safe here,” while a fourth clinician jokes that it’s due to “over staffing.” The fourth clinician continues that it’s not a big issue at the moment as the patient won’t be on “the radar” during hospital-wide meetings about length of stay for another 11 days. June asks if they have to tell administration that the patient was so recently re-admitted and the fourth clinician states that “It doesn’t matter as long as [the patient] was out of the hospital for more than 24 hours.”

By including these notes, I aim to highlight the ways in which my daily observations of clinicians talking was necessarily embedded within a diversity of considerations, including questioning care goals, contested awareness contexts, tensions regarding most appropriate location of care, and concerns for administrative backlash regarding length of stay.

Narrative Analysis within an Affective Economy of Hospitalized Palliative Care

My narrative analysis of the dying process emerged from my interest in theorizing the intersections among discourse, emotional labour, and affect within the hospital setting as an affective economy. In earlier versions of my thought, I began constructing an initial framework as to how the emotional labour of palliative clinicians could be understood as a specific regime of practices for the (largely disciplinary) governance of conduct that socialized patients to die well. In this understanding, clinicians were the authoritative purveyors of the framing and feeling rules that patients and their families

passively enacted. This then led to the assumption that the emotional labour of constructing a good death was primarily undertaken by clinicians and directed solely towards patients and their families. Although I understood that negotiation and even resistance to these rules was possible, I assumed that these instances would be relatively rare. This perspective is implicitly championed by many of the scholars reviewed in the previous chapter who suggest that clinicians hold a relatively unchallenged position of privilege (Field, 1996; McNamara, 2004; Perakyla, 1991; Timmermans, 2005). While my research does not contest this assertion in total, tracing the subjective effects of negotiation *in situ* also highlights that mediation between the individual and collective is never a neat and tidy process, and it is traceable as much by its negotiations and disjunctures as by its coherence and conformity.

Once I was in the field, I quickly realized that hospitalized palliative care practices were not as clear cut as I had initially assumed. What seemed relatively straightforward in my head was often an entirely different experience in the field: messy, fragmented, and often ambiguous in both process and outcome. I found the actual work that gave shape to hospitalized palliative care was in many cases much less purposeful and much more muddled than I anticipated based on the ongoing public conversations and literature regarding the good (if institutionalized) death. If, as I had initially proposed, hospital based palliative clinicians were the privileged brokers of the good death, why was it often so complex in practice? As my research and analysis evolved, I came to understand that providing specialist end-of-life care within an institutionalized context that has diverse patient populations is often an uncertain practice, even in “ideal” situations where the patient is clearly at end of life and expresses open awareness. Many of the patients I directly and indirectly observed were still receiving forms of treatment that could be conceptualized as life-extending. In turn, palliative clinicians were often unclear as to when to withdraw these treatments, even those with waning efficiency, based on concerns that the patient may suffer due to less than optimal symptom management. Yet continuing the interventions raised concerns about medical futility, significant side effects, requirements of continued hospitalization, a prolonged dying process, and/or worked to construct false hopes of stabilization. In the most extreme cases, these practice ambiguities created “zones of indistinction” (Kaufman, 2005) where patients were neither actively dying nor could they be discharged from the

hospital. In these instances, clinicians faced ongoing challenges in establishing goals of care, the anticipated time of death remained uncertain, and there was often a lack of agreement about appropriate location of care. Such situations led to clinicians repeatedly phrasing purpose of admission and care as “tweaking” or “tuning up,” constructing patients as “a work in progress” that required them to “wait and see,” and often asking one another if they were “extending the dying process” or “causing suffering.”

Combined with uncertain prognostic indicators and ongoing treatment possibilities, clinicians’ ability to organize the dying process was further challenged by complex family dynamics, interaction with non-palliative specialists, diverse cultural norms, evolving professional boundaries, and bureaucratic mandates. Therefore, while many of the patients I observed had relatively unproblematic deaths that could be conventionally labelled as “good,” many others required complex, shifting, and ambivalent negotiations of emotional labour by all parties. I began to understand that clinicians hold their privileged position within a context they do not fully control, and they are often required to engage in constant and substantive negotiation with patients and family members, as well as other clinicians, and, at times, administrators. Although I observed strong differentials in the authority granted to clinicians to frame understandings of care based on their clinical knowledge and expertise, they also identified as empathic care providers who are uniquely positioned to listen to, and act, based on the desires of the patient and their social networks. Even though patients and family members turned towards clinicians to explain what was happening regarding disease process and care options, they also often asserted their own, not always complementary, understandings.

Connecting my interest in discourse, emotional labour, and affect to these emergent, situated interactions that I observed served as a way to tack back and forth between macro- and micro-understandings as to how narratives give shape to the dying process, and to understand how the provision and reception of end-of-life care is “lived.” In this understanding, narrative acts are a central element, emerging through emotional labour, by which an affective economy operates—how it is reproduced, negotiated, legitimized, and contested. I propose that the key emotional labour technique within an

affective economy of hospitalized palliative care is the capacity to claim and naturalize a (usually implicit) “rights-based” narrative authority. For the purposes of this work, I define narrative authority as the ability, achieved through narrative acts, to legitimate (among a set of possibilities) framing rules that organize a specific understanding of the dying process that is shared among a group of people. I term this a “rights-based” process as authority emerges from entitlement claims (feeling rules) about appropriate behaviour and emotional orientations that appeal to larger discourses of true and false (framing rules). These claims both call forth and contest the two discourses of truth that constitute hospitalized palliative care. The first is that palliative care is a specialty designed to meet the unique needs of those at the end of life while *at the same time* appropriate for those who are not at the end of life. The second discourse champions empathic claims to patient and family member autonomy *and* clinicians’ medico-cultural authority to define direction and outcome of care.

I focus on two sets of feeling rules that emerge from these discourses. The first is what I term “clinical” feeling rules, which I define as narrative acts that reference the legitimacy of biomedicine to define the parameters of the real and true. The goal of clinical feeling rules is to have the audience “take on” the speaker’s perspective based on the “objective” rationales of biomedicine (see for example Kaufman, 2005). These feeling rules are based on collective clinical knowledge and attendant specialist expertise of end of life, and are, therefore, to use Foucault’s language, totalizing. Clinical feeling rules reference the authority of biomedicine, embodied within clinicians, to define the truth about a patient’s emergent physical state as one of terminal decline (or not), leading to their cultural authority to define the appropriate emotional orientations to these understandings, as well as the most appropriate direction and outcome of care. However, by referencing the applicability of palliative care for those who are not necessarily at end of life, combined with claims to biomedicine’s focus on beneficence, curative and/or aggressive treatments, patients and family members can also use clinical feeling rules to contest palliative clinicians’ claims to narrative authority. The second set of feeling rules I term “empathic” as they are narrative acts that reference individual experience to define the parameters of the real and the true. The goal of empathic feeling rules is to have the audience feel and “take on” the speaker’s perspective by evoking “personalized” responses (see for example Buchbinder & Timmermans, 2014).

These feeling rules emerge from situated personal experience and desires, and are, therefore, again to reference Foucault, individualizing. While clinical ethics advocate patient and family member autonomy, claims to autonomy *in situ* of care provision are often constructed, negotiated, and claimed through individualized empathic appeals. Patients and family members use empathic feeling rules to reference their inalienable right (their autonomy) to define the truth of the emergent physical state of self,²³ the appropriate emotional orientations to these understandings, and therefore the corresponding direction and outcome of care. As palliative clinicians champion individuated understandings of those at end of life, they also use empathic feeling rules to complement clinical perspectives of autonomy by referencing the unique experiences, histories, and desires of each patient to shape direction and outcome of care. This vaunting of autonomy across both clinical and empathic framing rules, however, make it possible to be claimed as *the* definitive framing and feeling rule by patients and family members when negotiating and/or contesting clinicians' knowledge claims.

Through the (differential) capacity to invoke these at times competing discourses within increasingly diverse contexts, everyone involved in the therapeutic relationship is enabled to *negotiate* the authoritative basis of the framing and feeling rules that naturalize emotional orientations to the experiences of hospitalized dying, including the direction and outcome of care. Ideally, the emotional labour of all involved parties generates coproduced and mutually agreed meanings that facilitate all six outcomes of care, and results in a generative dying process for the mutual benefit of all. As previously highlighted, however, hospitalized palliative care is a discursive formation within which subjects may simultaneously and/or differentially use both clinical and empathic feeling rules. For example, many of the patients and family members I observed used clinical feeling rules in their claims to narrative authority to define the parameters of the real and true, as they referenced interventionist solutions to symptom management, curative medicine, and chronic disease models in their right to autonomous decision making regarding goals of care. In turn, these claims also rested on the discourse of palliative care as appropriate for those still seeking (or hoping for) life-extending treatments. They also combined these claims with empathic narratives framed by references to the

²³ Or, in the case of a family member, the "intimate other."

personal, including past experience, the need for continued hope, and cultural or religious identification. While clinicians relied on clinical feeling rules to shape the purpose and outcomes of care, they also used empathic narratives to frame their practices for themselves, other clinicians, and with patients and family members. For example, I often observed clinicians' ongoing labour to have patients and family members accept discontinuation of treatment(s) and/or transfer in location of care by constructing truth claims based on their medical experience and specific expertise in end-of-life care. At the same time, they also framed this desired outcome as an individualized process that required an understanding of the patient and/or family member's unique personality and history.

Ideally, these claims merge within the processes of negotiation, and result in a "common sense" understanding of the patient's emergent physical state as one of terminal decline that is based on clinical expertise. From this perspective, clinicians' authority to generate, circulate, and legitimate the dominant framing rules and attendant feeling rules emerges due to their privileged position within existing relations of knowledge and power. Yet, as I have proposed, the legitimacy of these narratives about the good death emerge within practices of coauthorship, and requires patients' and family members' willingness to engage in this legitimation. Adding further complexity, I found that when and how these rules were invoked by all parties was subject to change depending on time, place, and audience. These negotiations resulted in a range of care outcomes, including what I came to term the "seamless good death," the "negotiated good enough death," and the "contested peaceful death."

Negotiating the Dying Process within Hospitalized Palliative Care

The Seamless Good Death

Optimally, palliative clinicians' emotional labour is a seamless process, whereby they are able to simultaneously meet all the requirements that constitute a good death. In these instances, all six ideal outcomes of care are achieved. Prognostic indicators are accurate, any issues of total pain are successfully addressed, and patients' physical

symptoms stabilize or deteriorate relatively quickly to ensure they can be efficiently transitioned along the terminal care pathway. Equal attention is given to the patient's clinical pathology and their (and family members') expressions of distress. Clinicians expend modicum amounts of emotional labour in developing therapeutic relationships and care practices are largely uncontested. Clinicians' are able to personalize their connection to patients and family members through generating individualized knowledge about their particular experiences of distress, as they simultaneously render these emotional and physical experiences resolvable through totalizing practices of care. Clinicians' positions as privileged cultural brokers are not significantly challenged as patients and family members are willing to express their emotions within the dominant framing and feeling rules offered by clinicians, and therefore everyone is involved in mutual coauthorship that naturalize meanings about the dying process. Patients and family members express open awareness of impending death and are willing to take on the dying role in its entirety, which results in a minimum of social disruption. In these instances clinicians are able to identify as both compassionate and efficient. Finally, in the seamless good death, clinicians' emotional labour generates knowledge about the dying process that naturalizes the need for further specialist intervention in future deaths.

The Negotiated Good Enough Death

As I have suggested, however, an affective economy of hospitalized palliative care is a meaning-making system which contains a multiplicity of narratives, practices, and desires that are not necessarily coterminous. When the diverse requirements of a good death cannot be met for all parties, the best that clinician's emotional labour can achieve may be a negotiated good enough death. In these instances, all six ideal outcomes of care may not be achieved. Given the uncertainties and ambivalences that commonly mark the hospitalized dying process, day-to-day palliative care provision frequently includes ambiguous prognostic indicators, fluctuating ability to manage symptoms, and a range of other challenges to efficiently transitioning patients. Defining appropriate care practices and outcomes may remain a moving target until shortly before death and be subject to ongoing negotiation by patients and family members, other palliative and non-palliative clinicians, and/or hospital administrators. The development of therapeutic relations may be superseded by focus on physical symptom management,

constraints of task-based care, and/or transition concerns. Alternatively, patients and family members may be reluctant to engage in therapeutic relationship building and/or express their individual experiences of distress as ordered emotions. They may question clinicians' privileged cultural status as purveyors of appropriate feeling and framing rules and resist coauthorship. They may invoke claims to narrative authority through appeals to autonomy and their own interpretation of clinical framing rules, including prognostic uncertainty, clinical trials, and/or previous medical crises they survived. They may also, and at times simultaneously, reference an empathic framing by referencing compassion, cultural identity, and/or hedging against the unknown. Some may express open awareness but articulate different forms to different audiences in different contexts, and/or only accept the rights (and not the responsibilities) that inhere in the role.

Acceptance of the dying role may be further challenged due to clinicians' uncertainty as to if and when they should offer it, based on the patient's uncertain prognosis, continued medical investigations, and interventions. Resolution of total pain may not be completely achieved, or alternatively, clinicians may focus on pharmacological interventions, and/or conceptualize suffering as outside their professional mandate. In these instances, clinicians' emotional labour may be only partially invoked and/or successful in individualizing the experiences of distress. This then challenges clinicians' capacity to render the experiences of dying resolvable through totalizing practices of care and thereby minimize social disruption. Some clinicians may begin to question both the process and outcome of their care practices, and their emotional labour may not generate new knowledge about the dying process or justify the need for increased specialist intervention. In turn, care practices may become partially visible as repressive relations of power to both clinicians and those they care for. In this ambivalent and shifting environment, clinicians are challenged by their inability to do anything other than "wait and see," while continuing to attempt different medical treatments and/or emotional labour techniques in order to facilitate transitions along the terminal care pathway. Even so, resolution of these challenges may be initiated by the patient's physical deterioration rather than proactively through clinicians' emotional labour articulated in therapeutic relationship building, addressing total pain, and offering of the dying role.

In these instances, clinicians' practices of care may become centered on achieving a good enough death. In a good enough death, clinicians frame acceptable outcomes of care within two precepts. The first emerges from the practices of palliative medicine where clinicians' primary responsibility is to (in so far as possible) enable patients to be symptom free. The second is grounded in the philosophies of palliative care where clinicians are also responsible (in so far as possible) to facilitate patients' control over how they die (McNamara, 2004; Kellehear, 1999; Russell & Sandler, 1998; Walters, 2004). As noted by others, this simplification of the fluid and ambivalent contexts within which the dying process is negotiated can favour clinicians who "return to routine medical practices and a hierarchy of care which prioritizes the physical management of symptoms" (McNamara, 2004, p. 929). In extreme cases, where prognostication remains radically uncertain, issues of total pain cannot be resolved, and therapeutic relations and goals of care are marked by open and irresolvable conflict, the attempt to achieve a good enough death may transmute into a "peaceful" death, where focus centres on successful management of physical symptoms associated with the final moments of the dying process.

The Contested Peaceful Death

In the physically peaceful death, all six ideal outcomes of care are challenged. These instances have many of the same characteristics as the negotiated good enough death. While some patients cannot be transitioned efficiently in a good enough death and/or require a "wait and see" perspective, there are usually some (albeit eventual and partial) building of therapeutic relations, resolution of total pain, and acceptance of the dying role. What marks the peaceful death as different from the good enough death is clinicians' inability to successfully engage in any of these practices, regardless of the patient's physical deterioration, leading to a complete *blockage* of the terminal care pathway. In these instances, while clinicians may expend exceptional amounts of emotional labour in negotiating the dying process, therapeutic relations are primarily marked by open and entrenched conflict. Patients and/or family members continue to refuse clinicians' status as privileged purveyors of the appropriate feeling and framing rules to understand their experiences. In the physically peaceful death, patients and family members rarely express any forms of open awareness. For those that do, their primary purpose is to advocate for the rights that accrue to the dying role without

acknowledging the accompanying responsibilities. They remain resistant to the partial and eventual coauthorship that marks the good enough death. Coauthorship may also fail due to entrenched family dynamics, cognitive impairment, mental health issues, and/or intractable pain. Sustained counterclaims to narrative authority then require clinicians to invoke increasingly explicit rule reminders as they simultaneously strategize how to best stabilize fluctuating physical symptoms. This means that clinicians' cannot coauthor meaningful end-of-life narratives that naturalize the direction and outcome of care in order to efficiently transition patients through the terminal care pathway.

Patients and family members' refusal to frame experiences as ordered emotions through the feeling rules provided truncates clinicians' ability to individualize experiences of dying or resolve them through totalizing practice of care. Furthermore, patients and family members often construct clinicians' practices as *increasing* their distress. Consequently, issues of total pain are either unresolved or are multiplied. Practices and outcomes of care may then lead to open and irresolvable conflict between patients, family members, palliative and non-palliative clinicians, and/or hospital administrators, where each becomes entrenched in their particular claims to narrative authority. This breakdown of negotiations fundamentally challenges clinicians' ability to minimize the social disruption of the dying process. Clinicians may then repeatedly question both the process and outcome of their care practices, and, in these instances, their practices do not generate new knowledge about the dying process or justify the need for increased specialist intervention.

When relations are continuously contested, clinicians' emotional labour practices become hierarchical, rendering them visible primarily as relations of repressive power for determining the care pathway. The best that can then occur is a peaceful death, where meaning is not generated within therapeutic relations that cultivate the patient's "quality of life" during the processes of dying but through appropriate physical symptom management occurring in the last moments of a patient's life. In this understanding, death is constructed as peaceful through signifiers marking the dying process as *lacking physical discomfort in the last moments leading to death*. Consequently, a peaceful death occurs when clinicians' cannot utilize their emotional labour to generate any of the six ideal outcomes of care. In my observation of these instances, the hours leading to

death were most often peaceful, and family members were grateful, even if the rest of the dying process was conflict-laden. By focusing on the last moments before death than on the dying process overall, palliative clinicians narrow their scope from the dying process as an integrated temporal process to a discrete physical, and heavily medicated, event.

The definitions and contents of each of the above categories are a bricolage taken from academic literature, palliative research, and my own study. While the term “good death” is used in academic literature and some medical research on death and dying, it was rarely used by clinicians. In my observations, roughly a third of the 180 patients I witnessed as part of general admission to the palliative care units fell into what I have constructed as the “seamless good death” category. Approximately half of those transitioned to hospice. The remainder died relatively quickly, usually within two weeks, with most of them spending the whole or the majority of their admission on the palliative unit. My use of the term “good enough” death borrows from the work of McNamara (2004)²⁴ and was not commonly used by clinicians. In my observations, approximately half of the patients admitted to the palliative units fell into what I have constructed as the “negotiated good enough death.” The majority of these patients did not transition to hospice, and it was not uncommon to see their names on the “Elongated Length of Stay” lists that were drawn up as a regular part of administrative procedures. The “peaceful death” was a term I found in a significant amount of palliative literature, usually invoked to describe what I have constructed as a “good death” (American Association of Colleges of Nursing, 2015; Callahan, 2000; Kirchhoff, 2002; Lattanzi-Licht & Mahoney, 1998; Mazzarino-Willett, 2009). This term was also well used by clinicians, albeit primarily as a general descriptor of the final moments for most of their patients regardless of care challenges. In my observation of patients admitted to the palliative unit, what I have defined as a “peaceful contested death” was the least common end to the dying process, or approximately 10-15% of admissions. Few of these patients successfully transitioned to hospice and almost all had lengthy admissions.

²⁴ McNamara (2004) uses the term to assert that there is an increasing failure by end-of-life care providers to facilitate a good death due to increasing medicalization and bureaucratization although they remain “proactive” in alleviating physical pain.

None of these categories should be considered unitary or stable. Individuals bring a range of person- and culture-specific beliefs and behaviours that inform how they engage in meaning-making activities, including the dying process. This framing of possible outcomes is created with the understanding that the relations constituting them are flexible, context-dependent, and subject to continuous reinterpretation. Participants in an effective economy of hospitalized palliative care may move between seamless acceptance, radical contestation, and negotiated understandings of a good death or they may choose a specific understanding throughout the course of the dying process. Therefore, although a theoretical model can distinguish between the three for analytical purposes, in practice they are not separable categories within which relations of meaning-making behaviour of the dying process can be unproblematically located. The intent of these categories is to conceptualize the differential outcomes of clinicians' emotional labour practices *collectively* within an affective economy framework regardless of whether or not a good death is achieved. In so doing, I am able to suggest how hospitalized palliative care is a complex cultural system of relations that simultaneously enables and constrains possible forms of meaning-making, identity, and governance of conduct in this stage of life. Consequently, while my research echoes the findings of other studies regarding the privileged position of clinicians to forward "cultural scripts" based on their specialist knowledge and cultural status, in paying attention to specific moments of negotiation and outcomes, my analysis may complement existing understandings as to *how* these cultural scripts are enacted as negotiated, accepted, and/or resisted. In this spirit I now turn to a discussion of therapeutic relationship building.

Chapter Four: Therapeutic Relations

Hospice palliative care aims to help patients/families manage the challenges and opportunities they face during their changing illness and bereavement experiences. To fulfill that goal, caregivers must be skilled at maximizing openness and adaptability in the attitudes, knowledge, skills and behaviours of everyone involved in the therapeutic relationship. They must also have specific skills to assist patients and families through the transitions they experience during illness and bereavement. (Canadian Hospice Palliative Care Association, 2002, p. 21)

In Western culture, awareness of dying is rendered through a psychological discourse of fear and loss. Consequently, acknowledgement of impending death is understood primarily as a “traumatic crisis” for the dying individual and her social networks. This crisis has intrapersonal, interpersonal, and transpersonal components, including separation from previous social roles and the loss of personal meaning (Becker, 1973; Cassel, 1982; Mikulincer & Florian, 2000; May, 1995; Strauss et al., 1982). In order to address the multifactorial suffering emerging from open awareness, therapeutic relationships in hospitalized palliative care specify the subjective experiences of the dying individual and her social network as the object of work. In attending to these experiences, everyone involved in the therapeutic relationship labours to co-author “new” emotional orientations to understand, and make meaningful, the dying process. Through these relationships, clinicians come to know the best way to care for each and every individual while simultaneously generating knowledge of, and practices of care for, their patient population as a whole.

This chapter explores how therapeutic relationships emerge from clinicians’ emotional labour techniques, are enacted through narrative, and work to order emotional orientations to the dying process. In reference to existing research, my own observations, and interviews with clinicians, I delineate specific emotional labour

practices that constitute therapeutic relationships. I also utilize Foucault's thoughts on contemporary confessional society to explore how therapeutic relationships generate their object of work. Building on his thought and the other scholarship introduced in the previous chapters, I then suggest how specific aspects of therapeutic relationships both create and reflect relations of knowledge and power. These relations work to orient "appropriate" conduct of the patient and/or their family members through specific narrative acts that forward implicit framing rules and attendant feeling rules (and, at times, explicit rule reminders) that ideally lead to open awareness and an ordered dying process. I also contextualize this emotional labour *in situ* of the lived tensions and ambivalences that can challenge successful relationship building. This chapter, then, is concerned with describing what constitutes therapeutic relationships in hospitalized palliative care, and laying out how these relationships were lived within the complex settings in which I did my research.

Describing Therapeutic Relationships from Existing Literature

There is no one generally accepted definition of what constitutes therapeutic relationships in palliative care. Common elements that emerge from the professional literature construct these relations as continuous emotional coproductions between clinicians, patients and family members that generate individuating knowledge about the subjective experience of the patient and their social networks (Luker et al., 2000; Mok & Chiu, 2004; Pavlish & Ceronky, 2009; Tan, Zimmerman, & Rodin, 2005). Through this knowledge, reciprocal relationships of care are created, and they become the medium through which shared understandings of the illness experience emerge, providing the foundation to "explore and address biopsychosocial" issues related to dying (Tan et al., 2005, p. 143; see also Richardson, 2002). This attention to the "psychosocial and emotional components of the care relationship" requires "an intimate and personal relationship" between clinicians, patients, and the patients' social networks (Wasserman, 2008, p. 623; see also Skilbeck & Payne, 2003). The benefits of these relationships are multidirectional. For patients and family members, therapeutic relationships are understood to improve quality of life, including adjusting to illness and death acceptance

(Mok & Chiu, 2004; Rodin, 2013), enhanced psychological health and well-being (Richardson, 2002), fostering feelings of value and dignity (Canning et al., 2007; Chochinov, 2002;), and enabling activities of “personal” closure (Wasserman, 2008). Therapeutic relationships are also understood to benefit quality of care by facilitating shared decision-making, ensuring appropriate direction of care, and improving care outcomes (Canning et al., 2007; Tan et al., 2005). Finally, therapeutic relationships are cited as a practice that generates both personal satisfaction and professional identity for clinicians (Fallowfield, Jenkins, & Beveridge, 2002; Li, 2004).²⁵

Therapeutic relations both construct, and emerge from, an understanding that clinicians are working for the patient’s overall well-being. While trust in clinical competency is a fundamental requirement of the therapeutic relationship, the *relationship* itself is both mechanism and context within which conversations and decisions about clinical care take place. Consequently, in the literature on palliative care practice, therapeutic relationship building has repeatedly been identified as the central domain of practice to which all other domains are inextricably linked (Canning et al., 2007; Mok & Chiu, 2004; Richardson, 2002; Rodin, 2013; Sampson, Finlay, Byrne, Snow, & Nelson, 2014; Skilbeck & Payne, 2003). Given the perceived benefits of these relations, many practitioners advocate for further research and development to increase the efficacy of these relationships (Bergdahl, Benzein, Ternestedt, & Andershed, 2011; Breitbart et al., 2004; Chochinov, 2006; Sampson et al., 2014; Tan et al., 2005). Some specialists frame this need as a way keep focus on practices that demark the uniqueness of palliative care as it expands in scope (Wasserman, 2008). Others adopt a more business-like model for their advocacy, citing “improved treatment outcomes” that minimize resource use (Morrison, Penrod, & Cassel, 2008; Smith & Cassel, 2009). Regardless of perspective, therapeutic relationships function as a fundamental signifier central to both the identity and delivery of hospitalized palliative care. As noted by one prominent and vocal clinician:

²⁵ Within this literature there are a few palliative clinicians who acknowledge these relationships have instrumental utility and/or champion their development as a way to occupy an empathic emotional role that one may or may not “genuinely” feel in order to generate pro-social norms (Back & Robert, 2005; Morrison & Meyer, 2004). However, these authors do not connect this utility to anything other than benefiting clinician-patient communication.

Skilful symptom management, advance care planning and adherence to patients' stated preferences constitute competent, ethical medical practice. Conversely, failure to provide skilful symptom management and to practice ethical decision making represents medical negligence. The correction of existing problems is desirable, but referring to such remediation as "palliative care" effectively lowers established practice standards. (Byock, 1998, p. 169)

Within this shared understanding of the centrality of therapeutic relationships, there is both an implicit and explicit expectation that clinicians engage in specific practices in order to "know" the patient and family. These practices "acknowledge personal attributes, unique differences, and the essential or even subtle qualities each [patient] embodies," articulated through clinicians' "attitude, behaviour, compassion and dialogue" (Chochinov, 2002, p. 2258). These practices require clinicians' active emotional labour to generate an individualized understanding of a patient and/or her family. While the benefits of therapeutic relationships in palliative care are well addressed in the professional literature, the language identifying *specific mechanisms* that constitute these relations is often vague (Skilbeck & Payne, 2003). Definitions primarily invoke generalized and idealized practices, such as those forwarded by Abama (2005) who constructs therapeutic relationships as emerging through "the words the [clinician] and patient compose together...yield[ing] ethical knowledge that is co-authored, contingent and contextual. This requires deep listening, a 'being there'...[with] joint and collaborative development of ways to handle a situation" (p. 339). This necessary symbiosis between clinicians' emotional labour, their narrative acts, and practices of care is also generically invoked by others within the speciality who highlight the centrality of communication practices such as "talking and listening" combined with the requirements of emotional openness to "be present" and "spend time" with the patient in order to develop therapeutic relationships (Georges, Grypdock, & Dierckx De Casterle, 2002; Skilbeck & Payne, 2002; Romanoff & Thompson, 2006; Tan et al., 2005).

Some may argue that the practices underpinning successful therapeutic relationships are well documented, such as evidenced in the "Essential and Basic Steps During a Therapeutic Encounter" matrix provided by the Canadian Hospice Palliative Care Association (2013). Although this document does provide an overview of what

outcomes should occur from these relations (such as assessment, information sharing, decision-making, care planning, care delivery, and confirmation), the language for *enacting* these processes are signified by general terms (such as establish, assess, collect, review, and share). Although seemingly detailed, these types of understandings leave unquestioned the specific emotional labour practices that clinicians use to establish and sustain therapeutic relationships. This example gives strength to Skilbeck and Payne's (2003) assertion that, while there is a "taken for granted assumption" among clinicians regarding the meaning of the term, there is also a lack of clarity about which activities constitute and foster these relationships (p. 251).

From a broader social sciences perspective, researchers have studied a range of clinicians' interactions to identify specific emotional labour practices that facilitate an informal and "friendly" affective *environment*. Strauss, Fagerhaugh, Suczek, and Wiener (1982) are perhaps best known for their discussion of clinicians' "sentimental work" with terminally ill patients, of which they state is "present as an ingredient in *any* type of work where the object being worked on is alive, sentient, and reacting...[and done] either to get work done efficiently or because of humanistic considerations" (p. 254). While these authors do not invoke the term "therapeutic," they delineate seven types²⁶ of sentimental work as integral to clinicians' ability to manage "trajectory work" (defined as all clinical work over the course of illness), and in creating a ward's sentimental order. They assert that:

A great deal of non-sentimental work could not be carried out easily, efficiently, or at all if the requisite sentimental tasks are not done. Conversely, when the sentimental work is not done, or is done badly in somebody's judgement, then not only medical work may be affected but so may interactions, moods, composesures and identities. (p. 274)

Others have examined the ways in which palliative clinicians use physical cues, humour, compliments and "small talk" for building trust, comfort, and the expression of feeling (Bottorff, Gogag, & Engelberg-Lotzkar, 1995; Copp, 1998; Dean & Gregory, 2004; Hockey, 1986; James, 1989; Li, 2004). These forms of communication generate

²⁶ These include: (1) interactional work and moral rules, (2) trust work, (3) composure work, (4) biographical work, (5) identity work, (6) awareness context work, and (7) rectification work.

the emotional context from which therapeutic relationships emerge, while naturalizing the direction and outcome of care by “creating an atmosphere of acceptance” (Bottorff et al., 1995), “maintaining collegial relations” (Dean & Gregory, 2004), and the impression of “nice professionals and organizations” (Li, 2004).

Regardless of perspective, these scholars collectively highlight that building therapeutic relationships at end of life requires clinicians’ emotional labour to construct an ostensibly non-judgemental environment that restores the autonomy and integrity of the dying person through practices of individuation. These practices include (but are not limited to) learning and valuing: the dying person’s unique history, their family dynamics and social networks, their individual “coping styles,” and their personal hopes and fears. At times, practices of individuation also include clinicians’ willingness to acknowledge and witness personal suffering. Ideally, these practices result in a therapeutic relationship that fosters feelings of trust, open awareness, and activities of closure for patients and family members, as well as engenders a sense of personal and professional satisfaction for clinicians, and generates the affective environment through which mutually coauthored framing rules regarding appropriate care directions and outcomes are naturalized.

Clinicians’ Descriptions of Therapeutic Relationships

When questioned directly, most of the clinicians with whom I worked referenced similar activities to describe how they build therapeutic relationships.²⁷ In particular, they highlighted the importance of “knowing” the individual histories and experiences of patients and their families. This knowledge primarily emerged, at least initially, through informal and personalized conversations that did not reference the current illness. For example, in my interviews with clinicians, they often addressed the importance of making personal connections through small talk.

²⁷ I did not directly ask clinicians to define their understanding of a therapeutic relationship but focused on the activities that facilitate the building of them.

Gina: [You try] to get a connection through the way you go into the [patient's] room and talk to the patient, the family and [you] talk about if they have kids, what they used to do, what their hobbies are, that's the way you build relationships.

Tamara: I think pictures are a great conversation starter when there are family photographs in the room, and if there aren't any, I often ask specifically for them to bring some in...I always say "Here I am meeting [patient] for such a tiny fraction of her life, I want to see what she looked like before she was sick." They're really touched that someone is interested and then it turns into sometimes, you know, a good life review for some people. So that's one thing I find is a really good launching pad.

Along with this conversational friendliness and personal interest, clinicians also referenced the importance of non-verbal communication, such as Gina's remark about "the way you go into the [patient's] room." This emotional labour requirement in modeling a pleasing and warm affect was cited as integral to developing what clinicians termed "trusting" and "open" relationships.

Tamara: When I go into a room I always smile, I'm always happy, which doesn't mean I'm happy all the time (laugh) but it really helps them. They have more trust.

Cindy: Just trying to be there emotionally for people is such a huge part of what we do...sometimes you give someone a hug and they respond so strongly, as if that's what they need exactly. They just open up.

Donna: The most important thing that a patient and a family need, or the thing they appreciate the most, is how you can relate to them, what your affect is like with them. That's where their satisfaction comes from, even though it's a terrible situation, it's not dependent on dealing with the minutia but to be there for them, regardless of what you can't do, they just want somebody to see them...and be somebody they can trust.

Clinicians also discussed the requirement for respect and empathy, particularly their ability to make patients and family feel secure through bearing witness and being present in the face of suffering.

Cindy: I think people want you to bear witness; I think people want you to be present. I think part of the feeling of safety is that you tell people "You know what? You're not alone"...and I often tell people "You're safe." And I

often tell family members, because you can often see them trying not to cry in your presence and I always say “This is probably the safest place in the hospital to cry” and then they break down.

Francine: I think patients and families are searching for caregivers who can reflect back thoughts and emotions, or at least acknowledge things, not be dismissive.

This need for individuated empathy and respect was referenced as a requirement even when clinicians perceived a conflict between their own and others’ understanding of appropriate framing rules regarding behaviour and/or directions of care.

Jane: We have to respect what they’re going through. It’s sometimes hard to be there [with a patient or family member]; you know they’re not always pleasant (laughs). They’re going through denial, they’re angry...sometimes they don’t treat [the staff] well. Or the family is going through a very difficult time and they show their guilt feelings or wanting to do more, for their sake or for the patient’s sake and it’s hard to be the mediator between what they want and what is medically appropriate...But meanwhile you have to be there for them and support them.

For these clinicians, therapeutic relationships are constructed through a diversity of techniques, including the ability to be emotionally present while witnessing suffering, modeling specific forms of public affect, and using verbal and non-verbal communication to make a personal—and, at times, physical—connection. Through these connections, clinicians, patients, and family members ideally coauthor trusting and emotionally “open” relationships. As evidenced in the last quote, however, even when relations are conflicted, clinicians understood difficult emotions as preferable to a lack, or “repression” of emotions. Without patients and family members’ willingness to be emotionally open, clinicians’ felt fundamentally challenged in their capacity to build *successful* therapeutic relationships.

Gina: I think it’s naturally easier to have a therapeutic relationship with someone who is open and can share easily. It’s challenging when it’s with someone who’s quite withdrawn...it’s hard to support them...it feels like hard work when there’s not good communication between me and the patient...It doesn’t mean that it is, but it feels that way...it’s harder to go into a room and you have to, not brace yourself, but take a deep breath and align yourself and go in. It’s much harder to do; much harder.

Kirsten: It's so easy to hide behind your tasks...The energy that it takes to be genuine and authentic in every interaction is a lot, so you have the tasks to protect yourself, particularly when [patients and family members] are not willing to acknowledge what's happening.

A lack of "willingness" on the part of patients and family members to be emotionally "open" may then increase both the amount and visibility of the emotional labour required to provide care. Many clinicians talked at length about the challenges that accrue in situations where patients or family members are uncommunicative and/or resistant to open awareness. They also highlighted how their ability to generate meaning and positive relationships within difficult emotional circumstances was an integral source of professional and personal satisfaction.

Ruth: I enjoy the psychosocial interaction. Feeling like you made a connection. Feeling like when someone says "Thank you," that's very rewarding...Anybody can hang an IV or prescribe but when you've been able to convey your caring and help them make meaning at a very stressful and intimate time in someone's life, which dying is, and whenever the patient or the family really thanks you, you think "Yeah, I did something good" (laughs). I find it very rewarding.

Carol: It is challenging me in ways that are good for my own personal and spiritual development. As well I think it [palliative care] uses me in the best, in all my ways more than as a family doctor...[Asking] "How can I fully be with another human being through whatever processes that they have? How can I create a safety net for them so that they can make this transition in the best possible way for them?"

Cindy: It's so important, and I feel a sense of duty, but that's not the whole of it at all. The fulfillment that I get, that it's so important to do it. That our society is so death denying that it's important to face it and promote it and say "it's not that bad." It just feels like an important thing to do, and very fulfilling in a spiritual way. I'm not religious at all, but...

Michelle: It's an honour to be able to be with people, families, and folks who are dying at a very difficult time. Sometimes [they are] scared, sometimes in crisis...to journey with people when they enter that time. To help them, to draw on whatever resources they have, to do those things that will bring meaning or value or hope to them.

As exemplified in the last quote, a critical aspect of this satisfaction is the ability to ameliorate suffering through relations that provide meaning to the experience of dying. This understanding references the foundational work of both Saunders (1978, 1996) and Kübler-Ross (1969) that detailed the importance of listening to the individual experience of each patient, and the corresponding practices to help transform these experiences, as central features to the provision of care.

Yet the act of listening also orders these experiences in certain ways. How palliative clinicians use emotional labour practices to give narrative order to the experiences of dying is highlighted in Michelle's thoughts as to how she talks with her patients.

I try to validate their pain and perhaps confusion or anger, and that way hopefully produce some kind of working therapeutic relationship...If you look at the amount of time we spend having those kinds of conversations, I think that is the huge piece that kind of helps families move to that next piece in terms of "OK, here's where we're at"...When [patients and families] talk about end of life stuff, we're very astute...very aware...so you try and kind of pick up what's behind the scenes in terms of, "what's the fear here, what are the hopes and expectations"...When someone starts talking about death...hopefully I can drop everything else and kind of explore that a little bit, and I always ask people if they are afraid...so we can talk about how we can make plans so that won't happen...the relationship building is very key to other decision making later on because they feel they've got someone they can trust with that.

Value here is assigned, not only to the process of listening, but also in working to ensure movement through potentially negative emotional states that are "behind the scenes." Subsequently, the potentially traumatic effects emerging from the inability to strive are rendered as meaningful, and therefore ordered, emotions for all involved. This ordering ideally leads to resolution of distress that benefits the individual patient, her social networks, her care providers, and the institutions they are all located within.

While some of the clinicians I worked with articulated an awareness that they are required at times to engage in emotional labour practices that they may or may not "genuinely" feel, few ever spoke about these techniques as *consciously* deployed tactics for the instrumental utility of trajectory work. The purpose and outcome of therapeutic relationships were constructed by clinicians as primarily benefitting the patient and her

family, marking their particular professional identity, and facilitating personal satisfaction in their work. Yet, as I have suggested, these practices do more than signal ethical care by understanding each patient as a unique and expressive individual—they also shape the content, direction, and outcome of these expressions. In order to explore further how this occurs, I now turn to an examination of therapeutic relationships using a Foucauldian lens to consider how clinicians' emotional labour practices that constitute these relations can be understood as governmental. This examination frames these practices as an intersection between technologies of power and technologies of the self, constituting the incitement to talk. This section then necessarily builds on scholarship introduced in Chapter Two that addresses how narrative acts between clinicians and patients construct individuated knowledge of the experience of dying, and how these acts work to naturalize the direction and outcome of care.

Confessional Society and Therapeutic Relationships

In contemporary Western society, a key way in which we are able to recognize and act on our subjectivity is through the expression of affective states, the process of “talking things through” regarding our emotions, experiences, and thoughts. Through expression of the way something makes us “feel,” therapeutic narratives have come to infiltrate most aspects of social life (Lupton, 1996; Moller, 1996; Walter, 1994). This incitement to talk is what Foucault (1990) calls a “confessional society” where practices of therapy and self-help have increased the importance of emotional narratives to identity formation, where talking things over has become the primary means for ordering uncertainty, vulnerability, anxiety, and dependency. These narrative acts create meaning of individual experience by rendering them through particular framing rules provided by contemporary discursive formations. The only requirement under this confessional mode is that individuals constitute their subjectivity within these framing rules. As technologies, these practices are enacted in the name of both personal and social well-being through “management of the individual and the social body as a vital national resource, and the management of the ‘problems of living’, made up of techniques of advice and guidance, medics, clinics, guides and counsellors” (Rose, 1996, p. 37). The organization and legitimization of self within a confessional society is therefore a pedagogical practice

where this naturalized impetus to talk things through also self-organizes awareness of “normal” and “deviant” states. Consequently, narrative, even in the most mundane of circumstances, seeks “the fundamental relation to the true, not simply in oneself...but in the self-examination that yields...the basic certainties of consciousness” (Foucault, 1980, p. 60).

The time when Saunders’ work was important to Canadian hospitals was one in which “the new discourse on dying encouraged the dying qua subject to speak” (Armstrong, 1987, p. 656). Unlike Aries (1974, 1981), who argued that new practices of care were emerging as a response to the institutional silencing of death, or Walter (1994) who explains the new openness to dying as part of a larger “expressive revolution,” Armstrong (1987) argues these changes emerged from a totalizing incentive “of a productive power which at certain points produces silences and at others incitements to discourse” (p. 651). This incitement is evidenced in the epigraph that opened this chapter. In focusing on individuals and their “true” feelings, therapeutic relationships construct emotions as a legitimate site of clinical concern, shaping how patients and their social networks self-govern themselves as they live through the dying process. In an affective economy of hospitalized palliative care, therapeutic relationships are conceptualized as the primary site within which this incitement is manifested and by which certain interpretations (meanings) of the experiences of dying emerge and are naturalized through clinicians’ emotional labour. How this simultaneous incitement and naturalization emerge within the therapeutic relationship is explored further in the following quotes taken from clinicians describing the ways in which they talk about death and dying with their care population.

Donna: I usually just ask [the patient] about what’s going on, and what’s led you to this point. I look for openings in the conversation where I get the sense there’s knowledge about what’s happening and I try to essentially get them to open up about things I know they know about. It’s like I try, the game is, if I was to structure it that way, is to get the patient to tell me what I want to know from them without me having to ask. And the reason I’m doing it, it’s not a game, it’s more like...if I can get their perspective about what they know about themselves it opens a channel for going to the next step. Rather than asking someone “How much do you want to know about what’s happening,” it’s more “Where can we go from here?” Then you feel it out. If you get a few hints that there is some tension or anxiety, especially if you’re talking to two people, you just

develop a sense of things, of where to push the buttons and where not to. I'm not always right, but for the most part it's been working.

Belinda: I try and frame it as trying to understand their experiences, so I open the conversation with a general statement because it casts a wide net which allows them to respond how they choose. If they are avoiding something then I can re-cast my net with another question...I don't look at peoples' responses so much but more what's underneath, why they are saying it, and what they are "really" saying.

Donna and Belinda both reference a belief in an underlying and authentic emotional self which can be ascertained by therapeutically listening to the individual's experience. At the same time, they referenced a requirement for specific emotional labour practices and narrative techniques to order patients' and family members' expressions of awareness in particular ways. Ideally, these understandings emerge "spontaneously," as evidenced in Donna's desire to have a patient "open up about things I know they know" without having to explicitly ask. While open awareness is desirable in and of itself within the therapeutic relationship, it is also necessary in order for clinicians to successfully "open a channel for going to the next step" (i.e., discussing transitions through the terminal care pathway). However, again referencing Donna, accessing this "knowledge" of impending death may require her emotional labour expertise to know how, when, and where "to push the buttons" in order for the patient and/or family member to confess this knowledge, or what Belinda terms her ability to look at "what's underneath [and] why they are saying it." Belinda uses the terms "framing" and "re-casting" to articulate the ways in which she generates knowledge about the patient's inner self, particularly within the context of avoiding open awareness. Similar to Donna, she highlights how the "real" subjective experience of the patient may be hidden, needing further conversational techniques for the essential truth to be "caught" and brought to light. Therapy, therefore, occurs not only through listening, but also due to clinicians' emotional labour of conversational techniques to access and render visible an *already assumed truth* of the patients' and family members' experiences and understandings of the dying process. As May (1992) articulates, this understanding is based on "the notion that [the patient's] clinical disassembly has had the effect of mystifying her 'real' or 'authentic' character" (p. 591), and therapeutic relationships are required to "re-member" the patient by bringing the whole person into view. Ideally, these

relations facilitate both personal meaning *and* trajectory work as “the patient, after a series of [therapeutic] encounters that lead her to accept the inevitability of death, recognizes this inevitable outcome and thus renders herself unproblematic” (p. 596). Consequently, therapeutic relations as a way to “invite [clinicians] to be mindful, curious, and open to surprises” (Wasserman, 2008, p. 623) are simultaneously a set of practices that facilitate ideal trajectories through the terminal care pathway by propagating certain forms of awareness and conduct.

I have explored how clinicians’ valorization of the therapeutic relationship is based on a compassionate desire to ameliorate suffering associated with the traumatic crisis of open awareness through recognizing the uniqueness of an individual’s experiences at the end of life. I have also suggested how therapeutic relations in palliative care work to socialize the patient and family into a preconstituted and totalizing understanding of the dying process that facilitates the remaining ideal outcomes of care. In my third month of fieldwork I observed a particularly clear example as to how this symbiosis occurs *in situ* of daily lived care provision, which is recounted below.

December 2008: A newly admitted patient’s daughter is extremely upset with news that her unconscious mother will probably not regain consciousness, and is close to death. The daughter keeps requesting life-extending therapies, openly states that she is “angry” at the current physician for “not doing enough,” and is often at the nursing station strenuously requesting consultation with other specialists. Two days after admission, I see a nurse²⁸ leaving the patient’s room. Catching my eye she tells me that she’s on her way to track down the doctor because the daughter is “still really struggling.” The doctor agrees to see the daughter and goes into the room under the pretence of “listening to the patient’s lungs.” The nurse turns to me and sighs, saying “we [the nurses] were in the firing line long enough; it’s time to send them [the doctors] in for support.”

The doctor emerges a few minutes later and the nurse asks if the daughter has “settled down,” to which the doctor replies “No, she’s getting worse.” She returns to the room

²⁸ In this example I differentiate between the clinicians’ professions in order to discuss in the following section how institutional hierarchies may shape relations of power within contested therapeutic relations.

with some medication and the nurse again turns to me. “Unfortunately when we send the doctors in [to try and resolve distress] it can be like we’re sending in the enforcers. Once a family member said to me that it was like bringing in the big guns and [the problem is that] we still have to have a therapeutic relationship with that patient and family. [Yet] we may not be able to do it any other way.” Two days after this interaction, I have a chance to talk with the doctor and ask how the daughter is doing. She laughs and says, “We had a long talk, so no more inappropriate behaviour, and she understands medically why we are not going to [give desired treatments]. She’s becoming institutionalized—I swear we do that so well.”

Shortly after this exchange I have a chance to interview the daughter. When I ask about her relationship with the clinicians she replies that, “The people on the ward are taking care of her [mother] but they are also taking care of me, so that’s made it easier for me to settle...They just treat me like a next door neighbour. It’s kind of an informal comfortable atmosphere that they create and foster. For me it’s been a positive experience. And whenever it wasn’t, like with the lashing out and anger and that kind of thing, there’s always been someone, a nurse or doctor saying ‘Just wait a minute. You have to remember that this is normal’ [and those conversations] sort of corrected me back on the track of reasonableness. [Before] I hadn’t been able to say that I wanted my mother to go [die], to have no more suffering and because I felt bad for having those thoughts I was getting angry (she begins to cry). I was angry at home, I was angry at work, I was angry with my husband. I confessed this [anger] to one of the doctors and she told me ‘Don’t feel guilty-you want her to go for all the right reasons’, which gave me permission to verbalize it, and I don’t feel like anyone is judging me for that. So I haven’t really had much of a chance to get bent out of shape about something because there’s always been someone guiding me back on track. Everybody has been so supportive and nurturing. It’s like they understand what’s going on; it’s not a process for them, [it’s] a very high level of understanding and compassion.”

From a framework of an affective economy of hospitalized palliative care, the therapeutic relations developed here successfully facilitated the six ideal outcomes of care. First, through these relations, the daughter comes to acknowledge her mother’s dying trajectory. This occurs when her initially disordered emotional expressions

("lashing out and anger and that kind of thing") are successfully reinterpreted through clinicians' feeling rules as expressions of misplaced guilt in wanting her mother to die.²⁹ This emotional labour enables the daughter to move herself into an open awareness context by "confessing" an awareness of both her mother's dying, and the desire for her mother's death. This shared understanding of the daughter's emotions then also generates the second goal of care—a mutually coauthored narrative where her emotions are naturalized and rendered addressable through clinicians' rule reminders such as "this is normal" and "you want her to go for all the right reasons." Through their emotional labour that constitutes these therapeutic relations, the staff are able to relatively quickly reinstate the sentimental order of the unit, articulated by the daughter as "guiding me back on track" within "a friendly, informal environment." This labour then facilitated the third goal of care—a resolution of the social disruption she was causing to the unit, as well as experiencing in her day-to-day life. In conjunction with the clinician's medical expertise, this "naturalized" emotional understanding then also removed the daughter's desire for continuing treatment which potentially blocked efficient trajectory work along the terminal care pathway, which is the fourth ideal goal of care. Clinicians thereby enabled the fifth goal of care in having established an identity as both compassionate and efficient. They were also able to successfully meet the sixth goal of care that was ensuring the further need of their specialist services. In this instance, therapeutic relations functioned to create an impression of "nice" professionals within a "marketable" institution (Li, 2004) that requires expert levels of understanding and compassion. As a whole, this example explores how clinicians, through therapeutic relationship building, function as compassionate "moral entrepreneurs" (Field, 1996) in "brokering" the dying process through offering a specific cultural script that oriented the daughter's emotional expression, mediated her moral anguish, and ordered the uncertainties inherent in the dying process (Timmermans, 2005).

This example also highlights how therapeutic relations also ordered the daughter's conduct in ways that rendered these practices (at least partially) visible as

²⁹ While the daughter articulates feeling "bad" about wanting her mother to die, she does not initially render it coterminous with feelings of guilt. Other possible interpretations of feeling "bad" could also include anticipatory loss and/or frustration at the inability to control her mother's suffering (than *only* as guilt).

relations of power. Both clinicians expressed a clear understanding that their interactions may contain both repressive and totalizing aspects as evidenced by the nurse's use of the term "enforcers" and the physician's thoughts on how well they "institutionalize" those in their care. Further, the nurse's recall of a previous conversation with a family member referenced the at times mutual awareness of the institutional hierarchy embodied in physicians' authority, and how this awareness can trouble therapeutic relationship building. This insight is combined with the nurse's understanding that repressive tactics may be unavoidable when their authority is continuously contested, acknowledging that "we may not be able to do it any other way." While this understanding of the power differentials inherent in the therapeutic relationship was also referenced by other clinicians I observed and spoke with, few were willing to be as explicit as one particularly outspoken clinician who stated,

As practitioners we have a lot of control, and there is conflict in that relationship that I don't think everyone really appreciates. Nobody really wants to talk about the reality that we have all of the control, 100% of the time, on a certain level.

This vignette highlights how therapeutic relationships can generate deeply felt emotional understandings of the dying process through confessional practices. It is also a clear example as to how, through specific narrative techniques within these relations, clinicians, patients, and family members are continuously engaged in negotiations of meaning-making that ideally cocreates a specific orientation that facilitates clinicians' ability to manifest all six ideal outcomes of care. As the next section explores, however, in spite of all their efforts, clinicians may not be able to successfully facilitate all, or any, of these outcomes through therapeutic relationship building.

Tensions in Therapeutic Relationship Building

While the clinicians I observed were experts at establishing therapeutic relationships, they were not always able to do so successfully. When asked what the challenges were to building these relationships, clinicians cited a range of issues they articulated as "pressures," "difficulties," and "tensions." I collectively reference these issues as tensions to highlight how these issues emerge not from antithetical practices

but as an effect of the stretching³⁰ that occurs through clinicians' attempts to extend the scope of palliative care while simultaneously continuing to reference its originary philosophy and practices of care. Clinicians referenced three particular tensions to successful relationship building: (1) the evolution and mainstreaming of palliative care, (2) institutional valuing of these relationships primarily to effect rapid transitions, and (3) increased patient and family member involvement in clinical care decisions.

Evolution and Mainstreaming of Hospitalized Palliative Care

All palliative clinicians I spoke with and/or observed cited changes to their medical practices and patient populations as both a compassionate necessity and as a source of pride in a maturing specialty. However, this expansion was also understood as a form of mainstreaming within the hospital-as-institution that challenged their ability to establish individualized therapeutic relationships as well as the purpose and outcome of these relationships. Many clinicians articulated this dual awareness in their discussions of mainstreaming as an effect of their successful self-promotion while also acknowledging their services as increasingly embedded within a normative biomedical or "systems" model of care that prioritizes acute symptom management over individualized relationship building, even at the end of life. This perspective is evidenced in the following quotes.

June: Palliative care has changed so much...now it is much more mainstream and as a result it's evolving so quickly because people are putting more energy into it...[But it is] a lot more pressure. A lot more pressure for us. Whereas the population we used to have, basically we weren't doing surgeries and we weren't doing tube feeds; it was much different. We used to focus on relationships...Now it's different...everybody knows who we are. We've become a system.

Carol: In the current palliative model, in my 10 years in palliative care, the acuity has gone up and the length of stay has gone down. It used to be that we had the luxury of developing significant long term relationships with people as they began their process of living with a terminal illness through their dying. We don't get that luxury anymore.

³⁰ I use this word to reference the etymology of "tension" meaning "to stretch or strain".

Diane: A lot of times people's stay is short; people die quite quickly...[Before] it was more like hospice is now...patients, they stayed longer, they stayed to die. But nowadays there are more hospices and we really try to move the patient out, so a lot of time their stay is short, it's really short, and we don't have time to make relationships sometimes. It can be a point of tension.

June, Carol, and Diane all contextualize their understanding through a contrasting "before and after" framework. They do so to highlight changes to both their practices and their patient populations, and in particular to reference how these changes create a different affective environment where therapeutic relationship building is now conceived of as a "luxury" within a "system" focused on acute symptom management and rapid transition through to death or discharge. These quotes address how some clinicians understand the impetus for their care practices as becoming centered on the institutional needs of organizational efficiency that are solely focused on governing the *biological* processes of dying.

Effecting Rapid Transitions

Clinicians spoke at length about their expertise being valued, at times, primarily to effect rapid patient and family member transitions through the terminal care pathway. This instrumentality, and the frustration surrounding it, is evidenced in the following conversation between two palliative consultants, who (at the end of a particularly challenging day) discuss how their expertise is desired to solve "blockages" along the care pathway once it becomes clear a patient is dying.

Rhonda: It's the ones where the family wants to keep the person alive to the last nanosecond possible on all kinds of life support and the patient is suffering, and we get called in to solve it. Carol: Or when you go [to a unit] late in the evening to do the new consult and the file is 5 inches thick and the person has been in and out of the ICU and nobody is really talking about anything because they've been on this trajectory of active, active interventions and suddenly they call palliative care and we're supposed to make sense of it all. Rhonda: [Sarcastically impersonating a non-palliative clinician] Can you please tell the patient that they're dying? [Reverting back to normal voice] Uh, no (laughs).

For the clinicians I observed, and reflecting others' research findings, the desire for palliative involvement and/or transfer within the hospital often emerged from the

inability or unwillingness of non-palliative clinicians to talk with their critically ill patients about changing, or withdrawing, life-extending care (Han & Arnold, 2005; Weissman, 2009). This means that in their expanding scope of practice, palliative clinicians are increasingly engaging with patient populations who have little awareness that their treatment pathway has changed and/or wish to continue aggressive life-extending treatments. Clinicians' expressed this awareness as a professional tension, where their institutional value in facilitating changes to patients' and family members' understanding is an "outcome" they cannot always (nor necessarily want to) deliver. This understanding was particularly evident for clinicians in their work as consultants, where they frequently would express, to me and to other clinicians, concern that their services were being requested for affecting rapid transition through the terminal care pathway as much as for their technical expertise in physical symptom management at end of life. In turn, this instrumentality was cited as negatively affecting understandings of their work as a superior and/or unique form of care for this patient population, and challenged their professional and personal identities. In some extreme cases, this awareness triggered a self-reflexive understanding that their emotional labour practices were fundamentally grounded in repressive relations of power that do not necessarily benefit either their patients or themselves. Yet as frustrating as this instrumental rationality was, particularly for clinicians acting as consultants, the practitioners I observed also understood it as fundamental to the success and expansion of their specialty. My observations then reflect existing research exploring palliative clinicians' interface with other specialities, where they reported taking extra care to ensure that their perspectives and philosophies complimented general biomedical and interventionist-driven goals (Costello, 2001; Hibbert et al., 2003; Rousseau, 2009).

Increased Patient and Family Member Involvement

Therapeutic relationships in palliative care require individuated flexibility to achieve a good death. This individuation is constructed through a discourse that champions coauthorship in care as the clinician validates the patient and/or family members' involvement in direction and outcome of care. Through this coauthorship the patient's autonomy is enshrined, and is expressed as the ability to control the dying process in ways that they choose.

Michelle: I think I've learned that therapeutic relationships are going to be different for different people and that there are different standards. And sometimes I have to let go of my goals, [and recognize] that this is as good as it's going to get and it's the way the person has lived their whole life.

Gina: When I first started...there was a sense that if someone came on to the unit that they had to go through the Kübler-Ross stages of dying. We were successful for caring for people in that therapeutic model, but slowly the champions of that perspective have either changed that perspective or retired. And we've discovered that...rather than force people "You gotta do this before you die to have a good death" that [instead we say] "You tell us what a good death is for you and we'll see how we can help you do that."

Both Michelle and Gina reference the importance of framing their care practices through the lens of patient and family member autonomy, articulated here as "different standards" and not "forcing" people into a certain understanding of the dying process. In these instances, it is the patient's and family member's unique and diverse experiences that are vaunted as the proper source of the dominant framing and feeling rules by which understandings of the "good death" are coproduced. Here, unequal relations of power are understood as generative, and patients and family members are constructed as the natural source for the authoritative framing rules through which to shape the dying process. As evidenced by Gina's quote, however, this understanding of autonomy is one in which the incitement to talk about the dying process in certain *totalizing* ways ("...they had to go through the Kübler-Ross stages of dying") continues through the "discovery" of a new discourse of *individualized* confession ("You tell us what a good death is"). In turn, this individualizing incitement is understood as necessary for clinicians to be therapeutic "helpers" in the good death.

Nevertheless, particularly with new patient populations, this vaunting of autonomy in the therapeutic relationship can cause significant practice challenges. Patients and family members may use the framing rule of autonomy in attempts to claim *sole* narrative authority regarding the direction and outcome of care, which may include a refusal to express open awareness. The unwillingness to acknowledge impending end of life may translate into demands for continuation of life-extending and/or futile treatments, and cause blockages in transitioning through the terminal care pathway.

Alternately, open awareness may be expressed but may be used to further buttress the “right” for aggressive interventions. Furthermore, patients and family members may not agree between themselves as to the best course of care. This can lead to situations where there are multiple and conflicting claims to defining the appropriate framing rules to understand the direction and purpose of care. This struggle for narrative authority by invoking the discourse of autonomy may then fundamentally challenge the ability of clinicians to meet the six ideal outcomes of care. In these instances, clinicians may be required to invoke increasingly explicit rule reminders that render visible the therapeutic relationship as a relation of power in which they have the “legitimate” clinical and cultural authority to define the care pathway. The tension that can ensue between these two grounding sources of authority to define a good death was a common topic for clinicians, and I include a lengthy excerpt from one senior clinician to exemplify their perspective.

Carol: It's interesting; I know everybody wants maximal medical care. Everybody wants everything done, of course they do. Why wouldn't they want it, unless they're really, really suffering? Of course they will. What we have to do is be very careful as clinicians not to offer things that are not appropriate...So a lot of it [providing palliative care] is being very aware what is appropriate for that patient at that time. And I think what is frustrating a little bit is people are aware much more of what they can have and are requesting things and we're kind of going along with it. Like the chemotherapy; why are we giving all these [treatments], so many of these people chemo that we didn't give years ago? A lot of it is that the oncologists say, “Why not? It's not really harming them.” Well, it's taking away from the real work patients should be doing. We've had 9 years of medical school and background training and 20 years of experience; we shouldn't be making these poor patients and families make the decision when they don't have all the background. So, instead of saying to patients and family members, “Do you want to be tube fed?” We should be saying, “Tube feeding is not indicated in this situation,” rather than offering it in an inappropriate manner just because we can. And that's what's happening more and more, because clinicians are sensing that patients and family want to take more responsibility because they don't trust the system, they know a little bit more, and they want to be involved.

As Timmermans (2005) so adroitly points out, the cultural authority of clinicians to define the parameters of real and true emerges through their medical authority, or what Carol here refers to as her “9 years of medical school and background training and 20 years of experience.” Specific framing rules, feeling rules, and rule reminders emerging from the practices of palliative care therefore necessarily champion

individuality and autonomy *as well as* medical expertise and institutional constraints. Consequently, the freedoms generated within therapeutic relationships for patients and family members to express a private “inner self” and/or difficult emotions are also simultaneously rendered through clinicians’ medical expertise and the need for bureaucratic efficiency. It is therefore not surprising that evoking these narratives can at times cause tension as the first (autonomy) is one of *individualization* and the second is one of *totalization* (medical expertise). Instead of rendering these narratives only through their conflicting aspects, the next two chapters will explore how these seemingly paradoxical interpretations of palliative practice, through an affective economy framing, can be understood as simultaneously enabling and constraining particular forms of subjectivity at end of life.

Therapeutic Relationships within an Affective Economy of Hospitalized Palliative Care

In this chapter, I have examined therapeutic relationships as a critical emotional labour practice undertaken by clinicians for constructing subjectivity within a confessional society seeking to order the dying process. Using examples taken from clinician interviews and my own observations, I gave flesh to these assertions in discussing how these narrative acts could be understood as momentarily visible manifestations of the relations of power and knowledge that generate the object of their work. First, I referenced Foucault’s work on confessional society to suggest how therapeutic relationships create individuating knowledge of the experiences of distress stemming from the inability to strive (of self or other). Second, I suggested how therapeutic relationships generate the “truth” status of these experiences by using feeling rules, expressed through narrative acts, as exemplified in my short vignette between palliative clinicians and a family member. Third, I suggested how these relations offer techniques of resolution for distress that can be understood as simultaneously totalizing and individualizing.

I have traced how and why therapeutic relationship building is a central practice to facilitating the six ideal outcomes of care. I also explored key tensions that can arise in developing these relationships within the context of hospitalized palliative care,

particularly the expansion of practice with new patient populations, interfacing with mainstream medical specialities, and increased patient and family member involvement. Some proponents of hospitalized palliative care may argue that these tensions are tangential as increasing focus on acute symptom management, stabilization, and discharge frees their specialty from prioritizing therapeutic relationships to guide patients and their social networks through to a good death. As noted in Chapter Three, however, between the two hospitals, more than 70% of palliative unit patients died on their first admission. Additionally, the clinicians I interacted with expressed a clear understanding that the continuing expansion and visibility of their speciality is in part due to their expertise in building therapeutic relationships to effect efficient transitions through the terminal care pathway. Finally, they also expressed a fundamental interconnection between the ability to build therapeutic relations and their professional and personal identities. Therefore, concerns as to how to best order the dying process for the mutual benefit of individuals, care providers, the institution of care, and the wider society in which all are located remains an integral requirement of hospitalized palliative care provision. Therapeutic relationships in hospitalized palliative care, then, continue to be a cornerstone for the complex apparatus of health and therapeutics brought to bear at end of life within institutional settings.

This returns me to the benefit of understanding these emotional labour practices within an affective economic framework. Through this framework, I understand the tensions to successful therapeutic relationships as emerging from two sets of contradictory (although not necessarily unstable) discourses that define contemporary hospitalized palliative care. The first discourse vaunts palliative care as a specialty designed to meet the unique needs of those at the end of life while *at the same time* appropriate for those who are not at the end of life. The second discourse champions empathic claims to patient and family member autonomy *and* clinicians' medico-cultural authority to define direction and outcome of care. Through the (differential) capacity to invoke these at times competing discourses within increasingly diverse contexts, everyone involved in the therapeutic relationship is enabled to *negotiate* the authoritative basis of the framing and feeling rules that naturalize emotional orientations to the experiences of hospitalized dying (including the direction and outcome of care). Ideally, the emotional labour of all involved parties generates coproduced and mutually agreed

meanings that facilitate all six outcomes of care and results in a generative dying process for the mutual benefit of all. Rather than seeing therapeutic relationships solely as a process of negotiation *within* competing discourses, an affective economic framework of hospitalized palliative care also understands therapeutic relationships as an affective space in which these discourses are *generated*. In this perspective, therapeutic relationships both create and reflect the ambivalent and fluctuating affective environment of hospitalized palliative care. In order to explore this assertion further, in the next chapter, I turn to an examination of the concept of, and attendant therapeutic practices to resolve, total pain.

Chapter Five: Total Pain

A cry to be rid of pain is not worthy of man...Man by his very nature finds that he has to question the pain he endures and seek meaning in it. (Cicely Saunders, quoted in Clark, 1999, p. 733)

The subjective experience of pain produces two powerful opposing effects; the constructive capacity to infuse things with meaning and the deconstructive potential to obliterate meaning. (Waskul & Van der Reit, 2002, p. 503)

This chapter focuses on a core enactment of the therapeutic relationship: addressing total pain.³¹ With particular reference to David Clark's (1999, 2002, 2007) work on total pain and disciplinary power, I suggest how the concept of total pain can be understood within an affective economy framework as a discursive practice that has the capacity to simultaneously enable and constrain particular forms of subjectivity at end of life. I propose that this discourse, and the attendant therapeutic practices of resolution, operate as relations of power and knowledge through rendering the often chaotic subjective experiences of distress at the end of life as ordered *suffering*. I further suggest that the designation of total pain may also function as a specialist descriptor of relational challenges and signify sites of contested negotiations within clinicians' emotional labour practices that work to organize the dying process. To provide support for these assertions, I explore three moments where the concept is explicitly invoked by clinicians to assign meaning to a patient's experiences of distress. I do so to better understand: (1) how and when clinicians construct patient distress as total pain; (2) what emotional labour practices clinicians use to address total pain; and (3) how these practices attempt to facilitate the six ideal outcomes of care. In using these examples I am able to propose how exploring total pain *in situ* of the hospital setting and within an

³¹ The bundle of care practices for addressing total pain is also known in the palliative cannon as "total care," "active total care," and "holistic care."

affective economy framework complements and extends existing understandings of total pain through inquiry as to how, when, where, and why the concept is invoked, as well as attending to the negotiated outcomes of these practices. Similar to the previous chapter, I also explore key tensions that shape clinicians' interest and ability to enact these emotional labour practices, which influences how total pain is constructed and negotiated within the hospital setting. I conceptualize these tensions as constitutive (rather than as extrinsic) to hospitalized palliative care, as they simultaneously enable and constrain clinicians' ability to seamlessly guide the dying process and thereby meet the six ideal outcomes of care.

Origins of Total Pain

By the 1950s pain had become an area of medical specialization as other aspects of illness and disease were organized, observed, and spoken about in new ways. Previously conceptualized from a purely positivist view (where pain was the result of physiological signals sent to the brain when a part of the body was injured), researchers now began to understand pain as a complex situation (rather than a discrete event) that could be read for knowledge about the individual as well as their pathology (Braude, 2012; Clark, 1999; Shute, 2013). Pain was no longer reducible to a purely physical experience, and addressing pain now required an awareness of the patient's interpretation of the experience, including their personality, past experiences, and social relations. Clinical understandings of pain then necessarily became located within the embodied individual patient, where "pain is what the experiencing person says it is, existing whenever he says it does" (McCaffery, quoted in Shute, 2013, p. 40).

This change in perspective was both informed by, and reflected within, the emergence of palliative care. Although clinical interest in pain management became an increasingly "legitimate" concern in post-WWII medicine, expertise in addressing late-stage cancer pain remained relatively underdeveloped. Seymour, Clark, and Winslow (2005) trace how newly specialized knowledge about pain specific to end of life began to emerge from: (1) an interest in translating "clinical wisdom into clinical practice" in caring and sitting with those who were dying, (2) the increasing importance of "evidence and scientific credibility," and (3) the burgeoning interest in "phenomenological and social

understandings of the body” (p. 3). Collectively, they identify these changes as emerging from accumulating clinical evidence and the influence of “conceptual revolutions” in pain research, including the nascent field of end of life care. However, what Seymour et al. (2005) do not discuss is how the *lack* of knowledge about end of life pain was also generated by newly *emerging* knowledge about the needs of patients at the end of life. As I observed in my historical overview of the development of palliative care, the successful establishment of this specialty required that practitioners not only identify a unique care population with unique needs, but also required that they establish unique medical practices to meet this population’s care needs. *Acceptance of palliative care as a medical specialty both enabled and required end-of-life pain to be understood as separate from other forms of pain.*

Although now in common use among diverse medical practitioners, Saunders was responsible for coining the term in the early 1960s. Clark, a sociologist and historian of Saunders’ work, has traced how the concept originated through her multidisciplinary training in nursing, social work, and medicine, combined with her strong religious faith, and become synonymous with specialist end-of-life care. Clark (1999) recounts that, like Kübler-Ross, Saunders developed certain ways of talking with and listening to patients, thereby enabling them to become active subjects. She would tape record her conversations with patients, as:

[i]t is a very great help, both to get permanent records of them talking about their pain and its relief, but also about their attitudes towards their illness; what they know about it, and what they find particularly hard, and it is very revealing. (quoted in Clark, 1999, p. 729)

Saunders understood pain as having an affective dimension, “indivisible from both the body and the wider personality” (Clark, 1999, p. 733). By focusing on “lived experience,” Saunders irrevocably constructed physical pain as both a cause, and reflection, of subjective suffering. As her work progressed, she began using the term “total pain” to explicitly conjoin the physical, mental, social, and spiritual components of pain with the concept of suffering (Saunders, 1978). In turn, the success of the burgeoning specialty naturalized this form of pain as needing specialist therapeutic

practices to resolve the multifaceted pain unique to end of life as one in which clinicians could help order and make sense of these experiences.

Saunders was interested in *understanding* a patient's experience of distress as suffering as well as in *transforming* these experiences. This required clinicians "to analyse, to assess and to anticipate" through two forms of intervention (Saunders, quoted in Clark, 1999, p. 733). The first intervention was articulated through a conventional medical dimension, focused on the prevention than on the alleviation of pain, which was accompanied by an expert understanding and advocacy of analgesics (specifically opioids such as morphine) that would best work on specific types of terminal pain. The second dimension linked clinicians' ability to manage pain through their capacity to listen and elicit patients' experiences of illness, including their emotional distress. This was a multifaceted pain which could not be relieved solely by pharmacological expertise as it demanded particular emotional labour skills where "[l]istening has to develop into real hearing" (Saunders, quoted in Clark, 1999, p. 731). The concept of total pain can then be understood as emerging from, and promoting, practices of care that are concerned not only with physical symptom management but with patients' subjective experiences, including autonomy, meaning-making, narrative, and biography.

Saunders (2006) advocated for specific practices to facilitate the patient's identity and value in the face of radical dissolution in order to ensure that end-of-life pain does not become intractable suffering (Kellehear, 2009; Lucas, 2012). These practices conjoined specialist physical pain management skills with emotional labour practices of therapeutic relationship building, including: listening, talk therapy, family meetings, legacy work, and hope work (Cohen & Mount, 2000; Foley, 2006; Mehta & Chan, 2008). Collectively, the practices of resolving total pain became known as "total care," requiring multiple levels of attention, inquiry, and application of specialist knowledge. Through this specialist emotional labour, patients' and family members' subjective experiences became a valid source of evidence for, and site of, clinical practice (Saunders, 1996).

As a manifestation of the therapeutic relationship, the specialist practices of recognizing and addressing total pain are constitutive to the identity and uniqueness of

palliative care, and the majority of professional descriptors use “total care” and “palliative care” as synonyms.³² Practitioners also invoke the concepts of total pain and total care to mark their specialty as clinically and ethically superior to conventional forms of medical care for the terminally ill, and as rendering their work morally and professionally fulfilling (Byock et al., 2001; Meghani, 2004; Mehta & Chan, 20008; Mount, 1985; Saunders, 1978, 1996). Like other descriptors utilized in palliative care, however, there is at times a curious circularity in attempts to define what practices of addressing total pain actually consist of, as each term used to define a practice winds up referencing another. Clinicians acknowledge that this elision challenges their ability to both define and address their patients’ total pain (Billings, 1998; Mehta & Chan, 2008; Schute, 2013). Additionally, while researchers interested in end-of-life pain reference a large body of literature³³ that extends pain *beyond* the purely medical and the clinical, the concept of total pain has little critical scholarship to frame how it has become an *object* of medical inquiry.³⁴

In order to address this gap in the literature, the rest of this chapter is concerned with exploring total pain within an affective economy framework. I explore how total pain in hospitalized palliative care can be understood as a discursive practice that constitutes two objects of work: (1) patients’ (and family members’) subjective expressions of

³² For example, the World Health Organization (2014) defines palliative care as: “The active and total care of patients... [where] control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount” (para. 1).

³³ Particularly well known examples include Bendelow and Williams’ *Transcending Dualisms: Towards a Sociology of Pain* (1995), Eric Cassel’s *The Nature of Suffering and the Goals of Medicine* (1982), and Good, Brodwin, Good, and Kleinman’s *Pain as Human Experience: An Anthropological Perspective* (1991).

³⁴ While other scholars interested in the social organization of dying have examined a diversity of end-of-life clinical practices as relations of knowledge and power (DaSilva & Cruze, 2010; Glaser & Strauss, 1965; Kaufman, 2005; Lawton, 1998; May, 1995), Clark (1999) is the only one who *specifically* references the concept of total pain.

embodied distress³⁵ at the end of life, and (2) the conduct of these individuals who are understood as suffering. I examine the concept of total pain, and the attendant practices of total care, as relations of knowledge and power that both reflect and construct a larger affective economy of hospitalized palliative care. I suggest how these relations are governmental, and work “at a distance” to organize both clinicians’ practices of care and the patient’s (and her social network’s) experiences of dying. In this understanding, the discourse of total pain operates as a back-room “cultural script” (Timmermans, 2004) through which clinicians’ invoke, circulate, and privilege certain understandings of care that ideally enables embodied distress to be transformed into personal meaning, facilitates trajectory work, and generates specialist knowledge and practices to best care for this population. This discussion is then necessarily located within my larger concern as to how clinicians’ emotional labour techniques work to facilitate the six ideal outcomes of care, including: (1) open awareness (including acceptance of the dying role), (2) coauthorship of meaningful end of life narratives, (3) ensuring a minimum of social disruption, (4) naturalizing direction and outcome of care for efficient trajectory work, (5) clinicians’ simultaneous identity as both compassionate and efficient, and (6) the generation of specialist knowledge of the dying process and need for future interventions. My thoughts are also fundamentally structured through Clark’s (1999) seminal work on total pain and disciplinary power as will be discussed in the following section.

Reading Total Pain as a Nomenclature of Facilitation or Inscription

Clark (1999) contrasts the concept of total pain as a liberating “nomenclature of facilitation” against a disciplinary “nomenclature of inscription” (p. 727). I propose, however, the concept may be best understood as having the capacity to simultaneously

³⁵ I define embodied distress as any expression where a person uses their body (including speech) to communicate a significant and unwelcome decrease in the capacity to strive. This includes but is not limited to: physical expressions of anxiety (such as hyperventilation, increased heart rate, and trembling), crying, insomnia, turning away from the person speaking, refusal to talk, verbal “outbursts,” and compulsive and/or repetitive behaviours (such as picking at an object or self).

facilitate *both* outcomes. This discussion provides the ground from which to understand total pain as a discursive practice within an affective economy of hospitalized palliative care that necessarily has the generative capacity for summoning³⁶ both “nomenclatures” symbiotically, where one necessarily brings forth (with varying degrees of visibility) the other. I do so to draw attention to how the discourse of total pain and the accompanying practices of resolution both generate and reflect a complex and ambivalent affective environment that requires fluid and evolving negotiations between all of those involved in the provision and uptake of care.

Clark (1999) proposes total pain as a “nomenclature of facilitation” as it is the primary orienting discourse for clinicians working with end-of-life patients, requires clinicians to explore and understand the embodied position of their patients, and therefore address the “phenomenological connectedness between individual experiences of pain, distress and suffering” (p. 734). In this understanding, clinicians valorize care practices that facilitate the patients’ capacity to be human and enable their belonging in the world even at the very end of life. This understanding of total pain is evident in my earlier analysis where I traced how the concept helped to create individual, social, and specialist meaning from a process previously seen as devoid of anything other than the autonomic physiological responses of a decaying and socially devalued body. This discussion included how Saunders’ (quoted in Clark, 1999) openness to the use of morphine, advocating for the importance of listening to patient, and understanding of physical pain as only one dimension of suffering both created and reflected indivisibility between the mind and body, as well as between the empathic and clinical, in therapies appropriate for end of life populations. I noted how this perspective humanizes and individualizes institutionalized end-of-life care, where clinical focus transcends the purely corporeal to include therapies needed to compassionately engage in the work of “help[ing] the patient to reconstruct his world and his relations with others” (Saunders, quoted in Seymour, Clark, & Winslow, 2005, p. 9). In this understanding, then, total pain renders visible and concomitantly legitimizes the distress that many individuals near the end of life may experience through disgust or disassociation with

³⁶ I use the term “summoning” purposely here as the origins of the word nomenclature come from the Latin *nomenclatura*, which encompasses both *nomen* (name) and *clatura* (calling; summoning).

their deteriorating bodies, existential questioning of the meaning and purpose of their lives, and/or in grappling with deeply felt regrets. As secular Western culture conceptualizes the processes of dying as something (at worst) taboo or (at best) liminal, the emotional labour practices designed to address these forms of distress can help to “re-suture” the dying individual and her relations back into the social fabric by rendering their needs and desires as equally valuable to those who are in good (or recoverable) health. The discourse of total pain provides both a clinical signifier and a social status for the patient’s experience as *suffering*, therefore legitimatizing forms of distress that previously have been ignored, pathologized, and/or seen as moral “weakness.” Perhaps most importantly, total pain understands the body as *lived*, where pain is a multifaceted event that fundamentally shapes our capacity to be in the world. Through practices of total care that facilitate the dying person’s ability to engage in embodied action for the production of meaning, the discourse of total pain can increase the capacity of the dying person and her social networks. Consequently, suffering can be resolved and healing can occur even when there is no longer hope of a cure.

Clark (1999) then troubles this reading in suggesting that the discourse of total pain can also be read as an extension of the medical gaze as a new mode of surveillance. He (briefly) explores total pain as having the potential to be a “nomenclature of inscription,” a repressive disciplinary power “rooted in knowledge and technologies of care” (p. 734). As an extension of medical domination, this form of care of the dying requires new clinical possibilities of doing everything, even at the very end of life. In this understanding, total pain requires that patient narratives be read for deeper significance, where clinicians are required to transform suffering through “a wider and deeper searching for signs of trouble, in the social network, in the psyche, even in the soul itself” (p. 725). Referencing Foucault, Clark (1999) acknowledges that total pain can be read as a historically grounded disciplinary power within medicine where the “behaving body” requires inscription for moulding certain forms of conduct, and forces the bearer of these conducts to take responsibility for them. “Paradoxically and contrary to its own claims,” he argues, “this is a strategy of power, one which in subjecting human suffering to a new nosology, at the same time objectifies it and prescribes strategies for its relief” (p. 734).

Given this framing, I am deeply indebted to Clark's work in relation to my own thoughts about total pain. His scholarship enables an understanding as to how the discourse of total pain does not reside within a single patient, perspective, or practice but is constituted and circulated between possible signifiers (nomenclatures) of facilitation or inscription (Ahmed, 2004). This allows him to consider the concept of total pain as *potentially* having both capacities, where the experiences of dying are constructed through the autonomous expressions of individuals *and* inscribed through relations of power. Yet while Clark (1999) advocates this in theory, he does not engage with this polysemous reading in practice, and, at times, even contradicts himself by stating that these understandings are oppositional as "paradoxical and conflicting" (pp. 727, 734). This perspective is further reflected in the organization of his discussion as he limits himself to outlining one possible reading versus the other without exploring how they may be mutually constituted. It is also reflected in his conclusion that total pain is best understood as a nomenclature of facilitation, and that this perspective most accurately reflects Saunders' intentions. Clark's work then implies that total pain ultimately has to be understood as a repressive nomenclature of inscription *or* as an empowering nomenclature of facilitation. With this in mind, I now turn to an affective economy framework to extend Clark's thoughts as I believe it provides a theoretical avenue to understand how the discourse of total pain necessarily has the capacity to *simultaneously* enable and constrain particular forms of subjectivity at end of life.

Total Pain in an Affective Economy of Hospitalized Palliative Care

Clark (1999) constructs the two differential understandings of total pain as "paradoxical and conflicting." Understood within a framework of an affective economy of hospitalized palliative care, however, I suggest that total pain operates as a "sliding signifier" (Ahmed, 2004) that works to enable both outcomes simultaneously. By this I mean that the discourse of total pain is manifested through a specific set of techniques for penetrating the entirety of a patient and effecting their normalization in relation to specific ideas about what constitutes appropriate emotional orientations to the end of life. At the same time, the discourse of total pain enables dying patients and their social

networks the capacity to articulate, and have validated, complex expressions of loss that affect every aspect of their embodied “being-in-the-world.” Here, the concept and attendant practices of resolution are understood as work that attempts to maximize the social productivity of the dying process by transforming overwhelming and disordered embodied distress into both individualized meaning *and* generalizable clinical knowledge as to appropriate conduct and “best practices” for this unique population.

Clinical practices of addressing total pain bring meaning and order to the often inchoate expressions of distress emerging from the decreased capacity to strive at the end of life by constructing these expressions as *suffering*. In this assertion I differentiate between distress, which I define as individualized expressions which communicate awareness of a threat to the capacity to strive, and suffering, which I define as the outcome of narrative framing of these expressions. As discussed in Chapter Three, narrative occurs when individuals, or groups of individuals, work to connect experiences to existing structures of meaning (in this case the discourse of total pain). In hospitalized palliative care settings, total pain produces the “truth” conditions of these experiences of distress, and therefore (re)produces, naturalizes, and/or challenges what can be knowable about the experiences of diminished capacity at the end of life in these contexts. In understanding these expressions of distress as suffering, clinical practices of addressing total pain bring meaning and order through compassion and nurturance articulated within the application of specialist skills, including listening, talk therapy, family meetings, legacy work, and hope work. Through these emotional labour practices, the patient and family members’ (at times) disordered distress ideally transforms into ordered emotional expressions of grief, sadness, and other aspects of suffering which can be addressed. This is done for the best interest of the individual patient and her social networks in concerns for personal catharsis and resolution. At the same time, clinicians’ practices of total care function to naturalize and extend the reach of the biomedical gaze in the creation of new forms of knowledge about the subjective experience of dying, shape understandings of the self so that individuals fit within an appropriate “normalized” way of living (even at the end of life), and regulate the conduct of future patient populations. Therefore, when practices of total care are successful, the discourse of total pain achieves individual and social meaning, signifies the need for specialist holistic care, justifies the extension of palliative-specific expertise, and

facilitates institutional goals. In this way, total pain is constructed as a productive intersection between technologies of power and technologies of the self, simultaneously allowing and requiring the “truth” of the patient to emerge. Consequently, within an affective economy framework, the concept of total pain enables a set of care practices through which the totality of the dying patient is brought into the world in a way that has the simultaneous potentiality to be a nomenclature for facilitation and a nomenclature of inscription.

Given such a basis, this framing allows me to examine the concept of total pain as a discourse that not only reflects, but also continuously emerges through, contemporary practices of palliative care. By this I mean that an affective economic framing enables me to render visible the “hidden” traces of total pain’s history of production, including how it is constructed, used, and negotiated in current practice (Ahmed, 2004; Buchbinder & Timmermans, 2014; Richard & Rudnyckyj, 2009). This position requires exploration as to where I observed the concept of total pain and attendant practices of resolution being used by clinicians *in situ*. I now turn to three diverse examples where clinicians’ specifically invoked the term to frame understanding of patients’ expressions of distress, to describe the totality of a patient’s suffering, and to direct practices of resolution.³⁷ In my observations, the term total pain was evoked by clinicians only as a private “back room” designation, used solely in conversations with other clinicians, and/or in chart notes. The term total care was rarely used by clinicians and always in a public “front room” context as they described palliative care to patients and family members or, on occasion, in teachings to clinicians unfamiliar with palliative care. Given these constraints, I focus on two aspects of total pain within these accounts: (1) how and when the concept was used by clinicians, and (2) how and when clinicians’ emotional labour was then directed through practices of total care that attempted its resolution. Through these examples I suggest how total pain and its practices of

³⁷ These examples function as a detailed “summary” as to how care unfolded in each situation, rather than an in-depth ethnographic exploration. Given the small community of palliative care practitioners, further detail substantially increases the possibility of identifying the participants discussed here. While neither clinicians nor patients expressed any concern with being identified, there remained the possibility that identification of the *institutions* the participants were located within could open me to litigation. This was a particular concern in my examples of negotiated good enough and contested peaceful deaths.

resolution can be understood as a discourse that both constructs and reflects a fluctuating and ambivalent affective environment of hospitalized palliative care that is shaped by the fluid and complex negotiations between all of those involved in the provision and uptake of care.

Total Pain in the Seamless Good Death, the Negotiated Good Enough Death, and the Contested Peaceful Death

Total Pain in the Seamless Good Death – David

March 2009: David, an elderly man, is admitted to the palliative unit with uncontrolled physical pain. All of the clinicians agree that he is in the very last stages of life, although they hope to stabilize his symptoms and discharge him to hospice for end of life care. Over the next few days the chart notes indicate that clinicians are able to “get on top” of his pain; however he continues to express distress due to his inability to sleep and repeatedly requests increased amount of sedation for “panic attacks.” Given the relative stability of his physical symptoms, June [his clinician] begins to discuss a possible hospice discharge with him. However, David states that while he previously agreed to the transfer once he stabilized, he no longer wants to go because he’s not “sick enough.” For two days the clinician attempts to discuss the discharge with David’s wife when she is outside of his room, but she becomes physically and emotionally agitated when June talks about the “extent of your husband’s illness.” The following day in weekly rounds June states that David “is a good example of the total pain patient,” and that he and his wife are “still in denial.” The team agrees that June will make another, more concerted, effort to talk with David as he is clearly “suffering.”

In conversation with the patient the following day, June tells him that “you are too sick to return home or to be transferred to residential care” but that he “no longer needs the expertise of the palliative unit,” and therefore hospice is the most appropriate location of care for him “at this stage of [his] illness,” as they had previously agreed. David sighs and after a long pause acknowledges that he is “probably” dying, but that he wants to go home. He states that he is “worried about the practical issues” of leaving his wife behind as he has “always paid the bills, done the driving, and fixed things around the house.”

June suggests a family meeting, telling David that “your wife needs to hear from you that you are not afraid for yourself, you’re just afraid for her once you’re gone.”

The meeting occurs two days later and includes David, his wife, June, and two other senior staff members. When June turns the conversation to David’s location of care, his wife initially tries to change the topic, but June redirects her by stating, “your husband has some important things to say that he wants you to hear.” David begins to tear up, but tells his wife of his fears. She too begins to cry, stating that since they are both Catholic and believes they will be “reunited in the next life,” that these practical issues are her main fears as well. Through the conversation it is agreed that the social worker will contact the patient’s eldest son and a neighbour and collectively they will start dealing with practical household details the patient can no longer take care of. David and his wife then both express a willingness to discuss a transfer to hospice. June closes the meeting by stating the benefit of the meeting is that David and his wife can now focus on “spending time together in his remaining days.”

After this meeting the chart notes indicate the David is able to sleep and is no longer requesting sedation. When he is transferred three days later both David and his wife both express gratitude to the all the staff for “helping us work through a difficult time.” Afterwards, June remarks that while she is a bit sad to see them go because “they were such a sweet couple” that she knows “we did something good there.”

In this example, David’s physical pain is controlled soon after admission. His clinician invokes the concept of total pain relatively early in David’s admission to reference a trifecta of psychological and practical concerns: (1) the patient’s embodied expressions of emotional distress (insomnia and panic attacks); (2) the patient’s and wife’s mutual refusal to express open awareness (“denial”); and (3) to designate a potential blockage along the terminal care pathway (“I’m not sick enough to go to hospice”). This descriptor inscribes David as requiring therapeutic practices of total care that go beyond corporeal concerns of acute symptom management. In this account, the clinician’s practices successfully resolve the concerns that triggered the diagnosis of total pain. While David is initially resistant to the clinician’s framing of both the stage of his illness and most appropriate location of care, his resistance dissipates relatively

quickly once June asserts her authority through the use of explicit clinical feeling rules and rule reminders. David's acceptance is cemented when he "confesses" both his open awareness and the "source" of his distress. His confession enables the co-creation of a therapeutic space, where conversation provides an ordering of his previously disordered embodied distress into the specific emotion of worry regarding his wife's practical needs. In turn, this individualizing knowledge enables June to render it as resolvable through generalized practices of total care (in this instance the organization of a "family meeting"). In this space the clinician again claims narrative authority, this time using empathic feeling rules, expressed as David's desire to "say some important things" to his wife. In positioning herself as an advocate for David's position, June's authority is naturalized as emerging from *David*, not from herself. His wife accepts this framing by "confessing" the source of her own distress, which enables further practices of resolution (organizing the help of the son and neighbour). The meeting then extends the therapeutic space initially created through the conversation that generated David's acknowledgement of open awareness, and there is a mutually coauthored understanding of the "truth" of David's dying process amongst all parties, including the appropriate location of care. These practices of total care resolve the patient's suffering as he is able to sleep and no longer reports anxiety attacks. At the point of discharge there is mutual esteem, signified by the positive emotions expressed by everyone.

Understood within an affective economy framework, the discourse of total pain recounted here functions simultaneously (and relatively invisibly) as a nomenclature of facilitation *and* of inscription. In this account, the clinicians' use of framing rules and practices of total care are productive relations of power and knowledge that are able to successfully facilitate all six ideal outcomes of care. June's invoking of the term identifies David (and his wife) as a site of contested practice and relational challenges, and therefore as in need of therapeutic intervention. Through her emotional labour, however, David's clinician is able to resolve these challenges and expedite the patient's open awareness and acceptance of the responsibilities that inhere in dying role and resolve their suffering. This work enables the patient and his wife to feel better even though there is no hope for a cure, cocreates a narrative of their last days together as "meaningful," ensures efficient trajectory work, minimizes the disruption of the unit's sentimental order, reestablishes symbiotic niceness, and enables the clinician's

professional identity as both compassionate and efficient. In this example, the concept of total pain both emerges from, and is resolved by, specialist care practices that simultaneously benefit the individual patient, their social relations, the staff, and the institution of care. Subsequently, even though David did not die on the unit, clinicians were able to facilitate a seamless good death.

Invoking the concept of total pain, however, does not automatically resolve the distress of patients. While I observed many instances where clinicians' practices of total care were successful, I also observed many patients that required clinicians' sustained emotional labour to negotiate the resolution of total pain. In these instances, clinicians' capacity to facilitate all six ideal outcomes of care was fundamentally challenged, and the designation of total pain marked sites of complex, shifting, and, at times, deeply contested understandings of the dying process.

Total Pain in the Negotiated Good Enough Death – Ruby

September, 2009: A palliative consult is requested for a “goals of care” conversation with a younger female patient who has relatively recently been diagnosed with an aggressive relapse of disease. The patient, Ruby, has interacted with palliative services on a previous admission, but her attending clinician reminds Kelly [the consultant] that both the patient and her husband are “very sensitive to the word ‘palliative’.” On entering the room the consultant, who has not met Ruby before, states that she is there to “help with pain” and identifies the purpose of her visit as “discussing a possible ‘tune up’ with the goal of going home.” Ruby states that her goal is to stabilize her symptoms and to be discharged home, regardless of the physical distress the treatments may cause. She and her husband then spend some time discussing possible treatment pathways once her symptoms have stabilized. Kelly does not reference these possibilities, and instead focuses on Ruby’s current pain management needs. Once the meeting is over, both the attending clinician and Kelly privately agree that given the extent of the patient’s disease progression, associated symptoms, and “suffering,” that Ruby “would be better served on the palliative unit.”

A family meeting is called several days later to discuss a possible transfer, but neither Ruby nor her husband expresses any willingness to be transferred. Afterwards Kelly’s

chart notes state that the patient and her husband felt “pressured” by the conversation as they feel they are getting the care they need in their current location. The note also states that the patient is “experiencing total pain,” and highlights that “this may cause potential challenges for clinicians in determining the appropriate care pathway.” Over the next two weeks, the chart notes trace the continuation of both intensive life-extending therapies and further conversations with multiple clinicians (both palliative and non-palliative) that “a palliative transfer is in the best interest of the patient.” During this time Ruby’s symptoms fluctuate and remain poorly controlled. Finally, although she says she’s “very torn about the decision,” Ruby and her husband accept a transfer “for symptom management needs” as long as current treatments continue (a framing which is also echoed in the chart notes).

On admission to the palliative unit, due to the instability of Ruby’s symptoms, several staff express uncertainty if they are providing symptom management for purposes of stabilization and discharge (as stated in the chart notes) or end-of-life care (based on their observation of her deterioration). Over the next several days, while palliative clinicians are able to better control her physical pain, staff report how they frequently find her crying in her room. When asked what is upsetting her she replies that she “doesn’t want to talk about it” and that “they wouldn’t understand.” Although the chart notes state that “the patient and her family are slowly coming to understand the role and benefits of palliative care,” Ruby and her husband continue to aggressively advocate for the continuation of intensive testing in order to pursue further interventions. They cite her relatively young age, the fact that she is a mother, her “right” to all possible treatment given her previous remission, and that others have survived this disease. While her clinician Kirsten (no longer Kelly) frames Ruby’s current admission as focused on stabilizing her symptoms, and that they are all working towards this after which they can “revisit” other possible treatments, she also tells Ruby that “I understand that you need to hope for the best but you also need to prepare for the worst.”

In weekly rounds, Kirsten remarks on the “challenging nature of her total pain.” It is agreed that staff will make a concerted effort to spend more time with her, although as the next few days pass they express continuing frustration in their inability to do so due to the requirement of task-based activities with other high needs patients. During this

time Ruby's physical decline visibly accelerates yet both she and the staff continue to make tentative preparations for an upcoming surgery for symptom management. At this point several clinicians ask, "What is her quality of life?" and "Are we prolonging her life or are we prolonging her dying?" Ruby is no longer able to mobilize or feed herself, and she begins to openly discuss her sense of loss and sadness about the things "I wanted to do but now will never be able to." Through these conversations Kirsten suggests she create a "legacy project" for her children, and her husband brings in pictures and other mementos of their life together to create a scrapbook. As she continues these conversations and activities over the course of a week, her husband acknowledges to Kirsten that his wife is approaching the end of her life. He requests that she be able to stay on the unit until her death as she "takes comfort" in the relationships she has developed with the staff. She loses consciousness several days later and dies with her husband and sister by her side.

Although Ruby had poorly controlled physical symptoms, like David, she is not inscribed as experiencing total pain until it becomes clear she presents a blockage of efficient trajectory work, or, in the language of the chart notes, "potential challenges for determining the appropriate care pathway." In this account, the "back room" designation of total pain initially references the patient's: (1) physical pain, (2) her and her husband's resistance to open awareness, (3) repeated requests for continuation of curative (or life-extending) treatment, and (4) resistance to transitioning along the terminal care pathway. However, this designation of Ruby as a site of contested practice and relational challenges does not initially facilitate any new practices of care other than a continued focus on physical symptom management. This corporeal focus is cemented even before the palliative consultant introduces herself, is reinforced in the consultant's identification as there to help with "pain and a possible tune up," and is continued with the patient's and husband's focus on stabilization and discharge. This mutually agreed public framing of the purpose of care as appropriately focused *only* on physical symptoms then enables Ruby and her husband to continue resisting transferring location of care. Her clinicians are therefore required to engage in sustained yet conflicting negotiations (continuing treatments but pushing for a palliative transfer) over several weeks regarding the appropriate direction and outcome of care. Eventually, through negotiations of increasingly visible relations of unequal power where clinicians repeatedly "pressure"

transfer over multiple conversations, everyone conditionally agrees on a narrative framing for the transfer as in the best interest of “symptom management needs.” Subsequently, even when Ruby’s location of care changes, this coauthored “front-room” narrative of attending only to her physical concerns continue to frame the basis for understanding the purpose and outcome of care. This framing is buttressed further as discussions of treatment options continue to be explored (including surgical possibilities) even after transfer. In turn, this troubles all of the palliative clinicians’ capacity to enact practices of total care and resolve her suffering even as they continue to reference the discourse of total pain amongst themselves. Without knowledge of Ruby’s subjective experiences to generate individualized knowledge of her life world, as exemplified when Ruby repeatedly refuses to “confess” the source of her embodied distress, clinicians continued to be blocked in their ability to address her total pain. In spite of this resistance, they persevere and consciously attempt to increase their efforts, only to be frustrated by the instrumental requirements of task-based care.

The unresolved tension between these two narrative frames (total pain for end-of-life care versus physical symptom management for stabilization and discharge) requires the palliative clinician to engage in ongoing negotiations as Ruby and her husband continue to use clinical feeling rules to bolster their right to maintain intensive investigations and treatments. At the same time, they also appeal to empathic framing rules, citing Ruby’s age and her motherhood. In response, the clinician invokes an explicit rule reminder that simultaneously references her own clinical authority and expertise, the uncertainty of Ruby’s prognosis, and the requirement for open awareness when she states that, “I understand that you need to hope for the best but you also need to prepare for the worst.” Even after this explicit rule reminder signifying the need to rework hope, there is no mutual agreement, and the clinicians themselves increasingly question the direction and purpose of their care.

In this example, the patient’s open awareness does not emerge from the designation of total pain or the clinicians’ accompanying emotional labour techniques within practices of total care. Ruby acknowledges and begins to accept that she is dying only once she starts to *physically deteriorate*. It is only once this decline occurs that Ruby initiates articulating her distress in terms of sadness and loss, and her previously

disordered embodied affect then becomes narrated as specific emotions. This ordering provides staff with a language, and concomitant practices of resolution (talk therapy and legacy work), from which to coauthor appropriate orientation and behaviours to acknowledge the end of her life. These practices allowed for a partial resolution of total pain, where Ruby and her husband were able to find meaning in these activities and express a desire to stay on the unit due to the development of caring relations.

Understood within an affective economic framework, this example highlights how the discourse of total pain may at best facilitate ambivalent and partial practices of resolution in attempts to achieve the six ideal outcomes of care that constitute the good death. In this instance, the relations of power and knowledge that were articulated through the designator of total pain and its attendant practices of total care were only partially able to provide catharsis for the patient or her husband, the staff, and the institution of care. This returns me to my earlier thoughts in Chapter Four regarding tensions to successful therapeutic relationships as emerging from two sets of contradictory discourses that define contemporary hospitalized palliative care. The first discourse vaunts palliative care as a specialty that is designed to meet the unique needs of those at the end of life while *at the same time* appropriate for those who are not at the end of life. The second discourse champions empathic claims to patient and family member autonomy *and* clinicians' medico-cultural authority to define direction and outcome of care. In this instance, while invoking the descriptor of total pain oriented clinicians to a site of contested negotiations and requiring therapeutic intervention, Ruby and her husband were able to use the contradictions within the two discourses to contest the authoritative basis of the framing and feeling rules that ordered her emergent physical state and concomitant emotional expressions of hospitalized dying.

Subsequently, the palliative clinicians were, for a significant period of time, unable to orient Ruby or her husband to the impending death through practices of total care. Transforming their orientation then required the palliative clinician to engage in sustained and ambivalent negotiations. This challenged efficient trajectory work, disrupted the unit's sentimental order, rendered visible relations of power, and challenged clinicians' professional identity as both compassionate and efficient. Instead of concluding that in this instance the discourse of total pain functioned primarily as a

nomenclature of inscription, I suggest that it can also be understood as a nomenclature of facilitation. While practices of care were contested, thereby rendering them partially visible as relations of unequal power, both Ruby and her husband also expressed feelings of comfort and of being cared for within therapeutic relationships that eventually developed through specialist practices that attempted to resolve her multifaceted distress. Near the end of her care, everyone mutually collaborated through their emotional labour in creating an affective environment that facilitated a negotiated good enough death.

Although the experiences of total pain explored in the examples of David and Rudy were by far the most common in my observation, I also observed instances where invoking this descriptor did not facilitate *any* of the six ideal outcomes of care and it functioned primarily as a nomenclature of inscription. With these patients, clinicians were not able to negotiate a good death, or even a good enough death, and the best outcome that could be achieved was a physically peaceful death.

Total Pain in the Contested Peaceful Death – Tony

November, 2009: Tony, a man in his late sixties, is admitted to the unit with complex symptom management needs. Although he has a prognosis of “up to a year,” due to his recent estrangement from wife and family, he lives alone and is unable to regularly administer his own medications. Unit staff report that he is often “withdrawn and uncommunicative,” prone to swearing and crying out loudly when in pain. Diagnostic testing indicates that his disease has rapidly progressed, and that he is potentially hospice appropriate. After a week of intensive pharmacological treatments, his symptoms begin to stabilize and his clinician Gina decides that it is time to begin discussing a transfer to hospice. However, each time she tries to do so, Tony turns his face to the wall and refuses to communicate. The one time he expresses willingness to talk about it he soon begins shaking and crying, saying “I don’t want to die.” He then asks for a feeding tube to be inserted as he is having trouble eating. This request causes serious consternation amongst all of the clinicians regarding goals of care, as well as concerns about an indefinite admission. In the weekly rounds meeting there is a protracted debate about “what to do with him...as he is clearly suffering.” Most of the staff express the belief that if Tony wants this form of treatment he should be on a non-

palliative unit. Gina agrees, stating that Tony “needs to be educated why this is not a viable option.” Two other senior clinicians disagree, stating that his desire should be pursued and not be a barrier to continued admission.

As his physical decline continues over the next 10 days and clinicians struggle to prevent regular pain crises, a specialist finds Tony’s health too fragile for the procedure. The unit staff begins to question if he can be discharged to hospice or if he will die on the unit. After Gina informs him that he is “not a candidate” for the feeding tube, he often talks—in a loud voice—about how he wants enough medication to “kill me.” He is adamant that it is his “right” to choose when to die, that he didn’t think palliative care was “going to be like this,” that he is in continuous physical pain, and that since he’s had an unhappy life he doesn’t want an unhappy death. He says that if the staff can’t help him with this then he just wants to go home. Several different clinicians attempt to talk with Tony about his suffering, and he is willing to acknowledge that he feels like he’s “just sitting on a shelf like a broken part with no use.” However, when they ask him to explore his feelings further, he directs the conversation away from himself either through humour, denying any troubles, or refusing to talk.

Expressing concern that Tony may have “previously undiagnosed mental health issues,” Gina requests a psychiatric evaluation. In the ensuing medical meeting, the psychiatrist reports “possible”³⁸ symptoms of early dementia, potentially making him a poor candidate for hospice. Upon hearing the news his clinician sighs and remarks, “he’s a total pain patient if I ever saw one.” The next day the senior unit staff gather for another meeting to talk about Tony’s now “intractable pain,” and the possibility of terminal sedation³⁹. While some favour sedation, others wonder if “this is the best path” as he may find peace in a possible visit with his family that they have been trying to organize.

³⁸ Given that there was no medical consensus as to whether Tony had any mental health issues or cognitive impairments, my own questioning of the psychiatrist, and ongoing discussions with Tony, I believe my processes of informed consent were ethically sound.

³⁹ Like almost every other term to describe practices in palliative care, there is no one standard definition of terminal sedation. Most definitions do contain some variant of the following criteria: (1) the patient is terminally ill and near the end of life, (2) treatment consists of continuous deep sedation until death follows, (3) the suffering is refractory to treatment, and (4) the intent of the sedation is to control the patient’s suffering and not to hasten the patient’s death.

There is no agreement, and the consensus is to “wait for a few days” with the hope that his symptoms will resolve allowing for discharge to hospice and/or that his family will come to visit. Two days later Tony has an acute pain crisis that does not resolve; he is heavily sedated and dies soon after without regaining consciousness.

Echoing the examples of Ruby and David, Tony is not explicitly inscribed as having total pain until he presents a blockage along the terminal care pathway. In this instance, the inscription is clearly tethered to the relational challenges and contested understandings he presents to clinicians. While the designation includes reference to his poorly controlled physical symptoms, it also encompasses: (1) his disordered and, at times, disruptive, expressions of embodied distress; (2) his estranged family relations; (3) his refusal of open awareness; and (4) his desire for aggressive treatment which, when no longer possible, becomes an assertion of his “right” to physician-assisted suicide. While it is clear to the clinicians that Tony is “suffering,” invoking the concept of total pain does not provide them any clarity regarding practices of resolution or direction of care. Similar to Ruby, due to prognostic uncertainty and fluctuating symptoms, clinicians are required to take a “wait and see” attitude. Although Ruby expressed *resistance* to her clinician’s authority within negotiations regarding the purpose and outcome of care, Tony *refused* to negotiate the framing rules that would give meaning to his expressions of distress. Even as his clinician, and others, repeatedly attempted to engage in practices of resolution, the therapeutic relationship in this instance is primarily marked by open and entrenched conflict. Furthermore, he repeatedly asserts that care practices are *increasing* his suffering. The clinicians are then unable to coauthor knowledge about Tony’s life world from which to inform practices of total care to resolve his suffering. Consequently, unlike Ruby and her husband who were eventually able to experience partial resolution of total pain and in the last days of care expressed gratitude for the therapeutic relations developed, Tony does not experience any catharsis.

Differing from the experiences of David and Ruby, Tony does not articulate any “natural” progression of role acceptance that ideally accompanies open awareness. When Tony does express open awareness, this does not translate into his taking on the responsibilities of conduct that inhere in the dying role. Instead, he interprets his awareness through unyielding framing rules to advocate for his autonomous “rights” as a

dying person. While Tony does order some of his distress through reference to multiple sources of his suffering (e.g., constant physical pain, an unhappy life, feelings of uselessness), these moments do not lead to therapeutic relationship building, and he remains resolute in his claim to narrative authority. Combined with his uncertain prognosis, clinicians remain divided as to the appropriate ethical care pathway, leaving unanswered the question “what to do with him.” While it is at this point that the discourse of total pain is explicitly invoked, this framing did not offer a clear ethical care pathway for its resolution. The clinician’s understanding of Tony’s distress is then rendered through a conventional biomedical framing, requiring psychiatric intervention. For the staff, this rendering then also requires a narrative reframing of Tony’s suffering as “intractable,” and as potentially best resolved by pharmacological options that would essentially provide the death Tony has been advocating. There is a collective reluctance, however, to completely reframe the patient’s total pain through this biomedical narrative. Resolution is then conceptualized as occurring in the *future*, through the passage of time. In the end, this waiting period does not provide the desired outcome as it is truncated by a pain crisis requiring terminal sedation. In this instance the clinicians’ labour is only able to facilitate a physically peaceful death.

Within an affective economy framework, this account highlights how the discourse of total pain does not necessarily facilitate any of the six ideal outcomes of care. In this example, the relations of power and knowledge that comprised Tony’s care were not experienced by him as beneficial or cathartic. When the designator of total pain was finally invoked, it does not resolve Tony’s distress, the staff concerns about their care practices, nor does benefit the institution of care in facilitating transition through the terminal care pathway. While his clinician engaged in multiple attempts to transform Tony’s understanding regarding the purpose and outcome of care, even when he “confess” open awareness, he refuses to engage in any negotiations regarding the responsibilities of the dying role. This open, sustained, and irresolvable dissonance then blocked efficient trajectory work, rendered visible hierarchal relations of repressive power, continuously violated symbiotic niceness, and thereby disrupted the unit’s sentimental order. His refusal to coauthor a mutually agreed understanding of the dying process was then also a refusal to naturalize the direction and outcome of care, which causes clinicians to repeatedly question the purpose of their care practices, even at the

very end of Tony's life. In turn, clinicians were challenged in their ability to identify as either compassionate or efficient. In this example, care practices did not generate any new knowledge about the dying process or justify the need for increased palliative-specific intervention. Given that Tony was only inscribed with total pain after he completely blocked movement along the terminal care pathway, did not successfully orient clinicians' understanding of appropriate care, or resolve any of the patient's suffering, I suggest that in this instance that the discourse of total pain functioned primarily as a nomenclature of inscription. In so suggesting, I also understand it as generated through concerns for facilitation, in that it was at least partially invoked as an identifier of the multifaceted and individualized distress that the patient was clearly expressing.

This section has focused on exploring how the discourse of total pain, and clinicians' resulting emotional labour practices, both creates and reflects an ambivalent and fluctuating affective environment that, through ongoing negotiations with patients and family members, fundamentally shapes experiences of hospitalized dying. As evidenced, palliative clinicians are also required to negotiate within an affective environment that, similar to their patients, is never entirely within their control. In particular, the practices to resolve to total pain are shaped by tensions emerging from the evolution and mainstreaming of hospitalized palliative care in conjunction with increased patient and family member involvement.

Tensions in Addressing Total Pain

Framing the purpose of care as primarily for acute physical symptom management, as evidenced in Ruby's account, is both a product and process of the expansion of palliative expertise. This shift away from the centrality of total pain and attendant practices of total care is reflected in the changing definitions of palliative care. In 1997, the World Health Organization stated palliative care as "*the active total care of patients whose disease is not responsive to curative treatment* [emphasis added]. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount" (quoted in O'Neill & Fallon, 1997, para. 1). While the current WHO definition still addresses the need for "relief of suffering" caused by physical,

psychosocial and spiritual issues, practices are now centered on “early identification and impeccable assessment...applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life...and includes those investigations needed to better understand and manage distressing clinical complications” (WHO, 2014, para. 1). Some practitioners are even more assertive in merging palliative care with conventional biomedical priorities, stating that their specialty is an appropriate form of care for those still pursuing curative treatments (Byock, 1998; Meghani, 2004; Meyers & Linder, 2003).

As highlighted in the previous chapters, palliative care has become part of the mainstream of hospital-based care, and clinicians now regularly engage with patient populations that have increased prognostic uncertainty and high symptom management needs. As exemplified by Ruby’s example, this can lead to the continuation of aggressive treatment, even once a hospitalized patient has been transferred to the palliative unit. This focus may naturalize a “cultural script” (Timmermans, 2005) of physical symptom management, even at the very end of life, over total pain and practices of total care. In this prioritization, the continuation of aggressive care at the end of life necessarily increases the probability that patients will have further, and heightened, physical symptom management needs. This creates a tension between the centrality of total care and a conventional biomedical frame as the most appropriate clinical narrative within which clinicians understand the purposes and outcomes of hospitalized palliative care. One clinician articulated the complexities of this tension as emerging from their own professional desires, and corresponding successes, to be “translatable” within a conventional biomedical paradigm:

June: [Palliative care] has become way more clinically sophisticated; way more. Fentanyl infusions,⁴⁰ methadone, Ketamine,⁴¹ pigtail catheters⁴² in every body part, reverse hypodermoclysis⁴³ in the legs...I think what happened is that palliative care felt this need to justify itself as a scientifically-based, rational practice. Practitioners had this sense that other [non-palliative physicians] thought it was too fluffy, that it was not rigorous enough. And so I think the pendulum has swung a little too much in that rigour. Not that we shouldn't be rigorous in our caregiving, but sometimes we have embraced the scientific model in such a way that we forget that there has to be a balance between rigorous impeccable science and heart, and we need to have a balance of those two things. And I think in some ways we've lost that.

Even so, not all patients or family members express a desire for this emotional labour expertise, or what June calls "heart." As evidenced in the examples of this chapter, patients and/or family members may express reluctance and even sustained resistance to clinicians' attempts to access and transform their subjective experiences through therapeutic relationship building. They may choose to frame both the location and purpose of care within a conventional biomedical framework of continuing aggressive life-extending therapies and specialist symptom management for the purpose of stabilization and discharge home. Furthermore, even though the majority of the patients and family members I observed acknowledged the presence of a (potentially) terminal illness, few initially expressed any awareness that their current admission had a significant possibility of ending in their death or discharge to hospice. Given their location within an acute hospital setting, the continuation of life-extending therapies across locations of care, and the often explicit communication that the purpose of transfer to the palliative unit is for physical symptom management, stabilization and discharge, patients

⁴⁰ Fentanyl is a synthetic opioid analgesic approximately 80 to 100 times more potent than morphine and many times more potent than heroin.

⁴¹ Ketamine is an anaesthetic agent used with specialist supervision as a "third line" analgesic to manage very complex pain.

⁴² A drainage catheter with side holes, used for draining clear non-viscid or coagulable collections of bile, urine, or pancreatic fluids, and even air.

⁴³ Subcutaneous drainage with needles to control swelling caused by excess fluid trapped in the body's tissues.

and/or family members may construct a rights-based narrative based on these clinical framing rules. In this conventional biomedical framing there is an embedded moral position to the goals of care where, although curative therapies may no longer be available, there should be a continuation of treatment to *extend* life, even within a palliative-specific context.⁴⁴

The impacts of these changes were a frequent topic of conversation amongst the clinicians I observed, both during formal interviews and informally during daily practice. This is exemplified in the following quote from a senior clinician who interweaves practice changes, disease progression, treatment opportunities, clinicians' focus of care, and patient and family member involvement to acknowledge an affective environment in which palliative clinicians are fundamentally challenged in their ability to facilitate a good death.

Carol: People are living longer with their illness. On the oncology and surgery units, people who used to die of their liver [metastases] are now having them taken out and going on to get spine [metastases], so then they get more pain. People are having their metastatic brain tumours removed. That didn't used to happen, so people are getting more treatment, [and] living longer so they're having more symptoms at the end of life because they're having more disease. There's also the mentality of patients and families of "why now," like "why can't I have an MRI, there's all of these tests and availability of things," so...And also, our relationship with patients has changed...Now people's care is so fragmented, nobody takes ownership and everybody keeps doing things without stepping back and saying, "OK, really you've got to die of something so maybe this is the time we maybe shouldn't be pursuing all of these things." So people's expectations, our own expectations as health care workers, well we can do this or this [offering possible treatments]. Another little secret is I think we're going away from clinical diagnosis and people are relying way more on [medical] tests. Younger [palliative] physicians, they order tests, because that's what they do.

⁴⁴ Alternatively, this shift towards a rights-based narrative grounded in clinical framing rules may also be invoked in desires to hasten the end of life as Tony exemplified. Unpinning both of these seemingly contradictory narrative claims (life-extending treatment versus physician-assisted suicide) are the first principles vaunted in the discourse of total pain: facilitating a good death through listening to, and acting on, the subjective experiences of a patient in order to safeguard their autonomy, resolve their suffering, and to define the appropriate direction of care.

In combination with these challenges, some clinicians articulated a seemingly paradoxical knowledge of their patients' total pain at the same time they acknowledged practices of total care as outside their mandate or capacity.

Penny: I was talking [with a patient] this morning and she was saying that she's so lonely and afraid, and I don't know what to do for her, the psychosocial. What do we do? It's total pain, what can we do because the pills aren't working, what else can we do? We don't know how to deal with her suffering so we give her another pill. It's so ridiculous. Why can't [clinicians] cope with [witnessing] anxiety? Because we can deal with the physical pain. I want to fix it [patient's anxiety], so if I can sedate then at least she'll be calm. I don't know how to fix it, and I'm not there to fix it...the psychosocial is not dealt with ...I know that if it was physical pain we'd be all over it, but because it's psych-social [sic]...we recognize it but we don't know what to do with it...We just medicate people with anxiety.

It is telling that Penny, in speaking from her status as a clinician, understands total pain as located both outside her knowledge as a palliative specialist ("I don't know how to fix it") as well as outside her professional mandate ("I'm not there to fix it"), even as she continues to invoke the specialist discourse that defines her expertise .

The ability to resolve total pain is problematized by clinicians' own care practices when they are confined to, or choose, narratives that reference only the *physical* aspects of medical care. Consequently, resolution of suffering may emerge only due to the passage of time and the corresponding physical deterioration of the patient (and/or increasing amounts of sedation) than from clinicians' emotional labour expressed through therapeutic relations of addressing total pain. In turn, these experiences can have significant impact on clinicians' moral and professional identity (Byock, 2004; Kovacs, Bellin, & Fauri, 2006; McNamara, 2004).

Impact on Clinical Identity

The majority of clinicians expressed an understanding of the potential benefits that expansion of specialty and increased patient and family member input provided to their daily practice. Many of the same clinicians, like Carol, also expressed ambivalence towards these changes, and identified numerous challenges that accrued to their capacity to facilitate the six idealized outcomes of care, including their own moral and professional identity.

Donna: I don't think we do palliative care here. If you ask me, we do palliative medicine, and I don't consider them to be the same thing. Palliative care involves taking care of the physical, emotional, spiritual and psychosocial aspects of a patient...which I think is really important. And because of the workload and because of the acuity, sometimes we don't have the time to spend with the patients and families on the psychosocial, emotional side. Palliative medicine is symptom control...[Although] I don't take the patients home with me, I sort of take that culture home with me, because it bothers me, and frustrates me. I guess that other people's standards aren't the same as mine, so what can you do? So sometimes I tell myself, quite often, "Just do your work. You have your high standards and you can meet those and it's not your problem to worry about everybody else." But I do (laughs).

As Donna highlights, practice changes that minimize total care can lead to personal questioning about the purpose of clinical practice, where palliative care becomes "just another specialty" focused on symptomology (Kearney, 1992), and/or understood as relatively estranged labour, conceptualized as paid "work," and framed primarily for its exchange value (Hochschild, 1983). However, not all clinicians expressed personal or professional discomfort about these changes. The evolution of palliative care towards a specialty focused on physical symptom management was also referenced by clinicians as a positive source of professional identity, as a benefit to patients and their families, and as a way to further the expansion of palliative-specific expertise.

Gina: [Palliative care] is developing; it's becoming more of a specialty. It's a more specialized area in medicine; it's evolving and maturing and growing and has more confidence. It's becoming more technical so it's not just withdrawing things and giving opioids and letting people die; it's more going after things and investigating and trying different approaches sometimes...I really enjoy that part of it; it's like solving a puzzle.

Kelly: Sometimes we [palliative consultants] are asked to say that we're coming because of symptom management, that we're skilled in symptom management rather than palliative care, because [the requesting clinician] is already aware that this information would upset the family. So that's not a problem for me to go in and say "I'm here to talk to you about your pain; the doctors wanted me to meet you because you have pain."

As evidenced in the previous examples, this perspective may or may not ever reference the discourse of total pain. Expressions of distress may then once again be ignored, pathologized, or seen as best resolved by pharmacological interventions than through

the therapeutic relations of palliative care (as evidenced in Penny's quote) (McNamara, 2004).

Revisiting Total Pain within an Affective Economy of Hospitalized Palliative Care

As an affective economy framework requires an exploration as to how relations produce the object of their inquiry, I have examined the moments within which the discourse of total pain comes into being *in situ*. My intention in exploring clinicians' care of David, Ruby, and Tony has been to trace how the discourse of total pain, and the attendant practices of total care, can be understood as having the capacity to simultaneously generate practices of facilitation and of inscription. Put another way, I have used these accounts to explore how total pain necessarily summons both nomenclatures symbiotically although not necessarily equally. From this grounding, I was then able to suggest how these ostensibly contradictory nomenclatures are both inherent characteristics, where care outcomes are constituted as much by their ongoing negotiations and disjunctures as by their mutuality and cooperation.

In their labour to facilitate experiences of embodied distress as articulable, and, therefore, as ordered emotions of suffering, clinicians' negotiate emergent and situated orientations to the dying process, and thereby enable particular types of subjects with particular forms of capacity within an ambivalent, and at times conflicting, environment (Gordon, 1991; Massumi, 2002; Richard & Rudnykyj, 2009). I have discussed total pain as a foundational discourse through which patients' and family members' affective experiences of dying are shaped by clinicians into specific and coauthored emotional meanings and states that attempt to facilitate the six idealized outcomes of care. Even as I have analyzed total pain as a discourse that clinicians use to circulate and privilege certain understandings of the troubled emergent states of terminally ill patients, this understanding does not automatically lead to practices of resolution that either "repress" or "enable" the capacity of the patient and her social networks. Rather I have traced, in three accounts of negotiation, how clinicians' practices to transform patients' and family members' subjective experiences of distress are best explored within the simultaneous fluid and situated contexts of their generation.

Through my recounting of these negotiated moments, I have suggested that the discourse of total pain is best understood as ongoing relations of knowledge and power, emerging as the productive intersection between technologies of power and technologies of the self (Foucault, 1988). As a technology of power, the discourse of total pain renders patients' experiences of embodied distress as a necessary site for the application of medical expertise. I observed how this occurs through invoking the clinical descriptor of total pain that provides an orienting function for clinicians to signify sites of relational challenges and contested negotiations. From this perspective, clinicians' are understood as engaging in practices of care that are repressive and/or disciplinary in their attempt to generate "appropriate" conduct for those at the end of life. The multifaceted components of "suffering" are then rendered as a site for the generation of clinical knowledge and further the dominance of biomedical relations of power. As a technology of the self, the discourse of total pain may also facilitate deeply felt catharsis by facilitating capacity in generating personal and social meaning from an embodied process within a secular culture that holds dying as frightening, dangerous, liminal, and meaningless. In this interpretation, the practices of resolution that emerge from this discourse—such as listening, talk therapy, family meetings, and legacy and hope work—are then also understood as emancipatory therapeutic spaces within which the affective environment of care is both created and reflected through ongoing negotiations of all involved.

Rather than collapsing my perspective to either end of this spectrum, I have paid attention as to how the discourses that constitute the larger discursive formation of hospitalized palliative care are not necessarily unified and may require ongoing mediation by clinicians in their attempts to negotiate resulting practice tensions. As highlighted previously, the first discourse of palliative care designates it as a specialty focused on the unique needs of those at end of life while *at the same time* appropriate for those who are receiving life-extending and even curative-oriented therapies. The second discourse champions empathic claims to patient and family member autonomy *and* clinicians' medico-cultural authority to define direction and outcome of care. Returning to Foucault (1972), I understand that this contradiction does not necessarily indicate instability. In context of total pain, however, I propose that as a descriptor of sites of contested negotiation within relationships in hospitalized palliative care provision,

the term also functions as a sliding signifier (Ahmed, 2004) that identifies sites where clinicians' own negotiations between these discourses *are* unstable and contested. Clinicians' practices of resolving total pain then also necessarily emerge from the emotional labour that is required to negotiate the ambivalences between patient, professional, and system requirements. Consequently, when clinicians invoke the discourse of total pain, they both summon and negotiate nomenclatures of facilitation and of inscription for patients, family members, and for themselves. In this way, I have used Foucault's understanding of discourse to frame total pain as a set of practices where the contradictory and/or competing components may or may not provide ballast for overall stability, where the economy of their generation is defined as much by breaks and ruptures as by unified themes. I believe this framing may also provide a potential resolution to Clark's (1999) assertion that the concept has "some contradictory tendencies" (p. 728) through understanding these ostensible paradoxes as constitutive, if at times competing, components of the governmental practices that constitute total pain within an affective economy of hospitalized palliative care.

Chapter Six: The Dying Role

Sometimes you see patients and families that are very much [accepting of impending death]...but more often than not you see quite a process in coming to terms with what's going on, and you just don't know how that's going to play itself out. So the idea that you can potentially bring some skills to that and hopefully make some difference has been an incredibly fulfilling part of the job. (Palliative clinician)

The previous chapter explored the concept of total pain and the attendant therapeutic relations that work to facilitate its resolution. I suggested that a key requirement for the resolution of total pain occurred through confession—the acknowledgement—on the part of patients and their family members of the impending death, which leads to an open awareness context. As was evidenced, even when an open awareness context occurred, this did not *automatically* lead to a good death. Rather, what was required were patients' and/or family members' expressions of open awareness *and* engagement in certain behaviours, activities, and emotional orientations that I conceptualize in this chapter as a holistic entity: the dying role. I explore the dying role as a hybrid public performance and personal subject position that signifies not only awareness, but also *acceptance*, of the impending, if temporally uncertain, death. I also analyze clinicians' understandings of their emotional labour techniques for offering the dying role, including “educating” patients and family members, use of “quality of life” and “goals of care” rhetoric, the work of reframing hope, use of physical signifiers of decline, and hospice conversations. Collectively, I construct the dying role within hospitalized palliative care as: (1) emerging from a set of feeling rules organized by clinicians' emotional labour techniques; (2) facilitating clinicians' ability to publically orchestrate the emotional experiences of dying; and (3) negotiated, accepted, and/or contested within ongoing relations between all those involved in the provision, and uptake, of care.

Similar to the previous chapters, I use an affective economy framing to examine, through clinician interviews, fieldnotes, and an *in situ* example, how this specific form of emotional labour attempts to meet the six ideal outcomes of care. I also discuss key tensions that both create and reflect an ambivalent care environment, which in turn shape the clinician's ability and desire to introduce the dying role.

Defining the Contemporary Western Dying Role

Similar to other concepts in palliative care, there is no one mutually agreed definition of the dying role. Medical sociologist David Field (1996) argues that the dying role is best described as a "role loss," which contains five main characteristics: (1) involuntary entry defined by a terminal prognosis, (2) loss of activities and other roles, (3) little prior socialization to the role, (4) few or no rites of passage to signal transition, and (5) devalued status (p. 261). While Glaser and Strauss (1965, 1968) also suggest that the modern form of dying functions as a "non-scheduled status passage," they also found that it usually includes open awareness, control, and acceptance of impending death. Some scholars choose to focus on the "rights" based aspects of the dying role, addressing the need for autonomy and control, articulated by the dying individual's active participation in planning the last days and weeks of life (Byock, 2011; Kuhl, 2006; Walter, 1994).⁴⁵ Other scholars include the "responsibilities" of the role, or what Emanuel, Bennett, and Richardson (2007) articulate as "the expectations that the dying person will have awareness of dying-related losses and *will engage in adjustments to those losses* [emphasis added]" (p. 164). For example, Parker-Oliver (1999) contrasts Parson's "sick role" to the dying role, and suggests that while the dying individual has both rights and obligations, in the former role, the person is obligated to get well; in the case of the latter role, the person is obligated to die (p. 494). From a clinical context, Prigerson (1992) echoes these responsibilities, stating that constitution of the dying role

⁴⁵ Other rights preclude but are not limited to: (1) dying with unbearable symptoms; (2) prolongation of dying against a patient's will; (3) dying alone or in negligence; (4) dying with fear of being a social burden; (5) limitation of life-sustaining therapy for economic reasons; and (6) insufficient allocation of funds and resources for adequate supportive care of terminally ill or dying persons (Council of Europe No. 1418, 1999).

necessarily includes both acknowledgement of death *and* willingness to receive comfort-only services (p. 379).

The dying role is constituted by personal, practical, and relational rights and responsibilities that shape the dying individual's emotional orientation to, and expressions of, the experiences of dying. It is a subject position that:

[...] facilitates an understanding of important experiences about who the person is and how dying affects or informs that identity; it does so within a framework that provides prescriptive guidance, informing expectations, social norms, and a sense of social acceptance if the role is fulfilled. Entry into the dying role is often accompanied by profoundly meaningful personal events that are transforming. (Emanuel et al., 2007, p. 163)

The dying individual indicates their acceptance of this role by expressing open awareness, accompanied by expressions of acceptance, courage, and stoicism, as well as a modeling a pleasing and agreeable affect (Copp, 1998; Li, 2004; Hockey, 1986; van Brussel, 2010). Other common indicators include finalizing practical concerns such as estate planning, engaging in legacy work for surviving loved ones, and saying goodbyes (Sadler-Gerhardt & Hollenbach, 2011; Ramondetta & Jenkins, 2007). The most in-depth study of the contemporary dying role was undertaken by Clive Seale (2002) in his interviews with 250 relatives of people who were dying. He found that the confessional activities of open awareness, specific behaviours and emotional expressions, and the corresponding social acceptance of the dying were mutually constituted and together facilitate the good, or what he terms the "heroic," death. Seale suggests that a heroic death provides an "appropriate script" to construct the dying process as an:

[...] opportunity to display great courage in the eventual facing of the final threat: death itself. The reward for those who completed this heroic task [is] the realization and enactment of intimate emotions, in which the dying bond between self and others [is] affirmed...In these deaths we can see that speakers' accounts are in alignment with revivalist discourse on the benefits of the aware death, appropriating elements of this script in order to imbue terminal illness with meaning and offering a secure membership up to the point of death. (pp. 173-175)

While each of the scholars above focus on somewhat different aspects of the dying role, they collectively highlight how the role emerges within a set of social

expectations that the dying individual: (1) express open awareness, (2) display emotional orientations of acceptance, (3) understand their experiences as having personal and spiritual value, and (4) engage in activities of “closure.” Taken together, these activities publically “signal” that the dying individual is both *aware* of their diminished capacity to strive, as well as *accepting* that this diminishment will soon lead to death. Without these activities, the critically ill individual remains in a liminal social status and signifies a continuing threat to normative boundaries, including between health and illness, autonomy and dependency, and, ultimately, between the living and the dead (Lawton, 1998; Waskul & van der Reet, 2002). Subsequently, when a critically ill individual models the bundle of behaviours that constitute the dying role, the individual and social threat signified by the dying person is sutured by a new identity, and they are enabled to understand their experiences as a source of deep meaning and ensure the continuation of intimate bonds and valued membership within society.

Origins of the Dying Role

Historically, the Judeo-Christian religious narrative provided the social norms for dying well within the European countries from which Canadian society claims ideological heritage (Aries, 1974; Verhey, 2011; Walter, 1994). Within this discourse, dying was a time “where the individual understood their life as standing outside the mundane concerns of everyday life, giving them the opportunity to define their fate by engaging in moral behaviour, sacrifice, bravery and spiritual adventure” (Seale, 1995, p. 598). A compelling example from Medieval Europe is the *Ars morendi*, a literal “cultural script” that constructed dying well as both an ethical art and a religious imperative. Composed in 1415 by an anonymous Dominican friar, the *Ars morendi* was a popular text (accompanied by woodcut illustrations) that offered advice on how to ensure a good death according to Christian precepts of the Late Middle Ages. Its contents included: how not to fear death, how to avoid temptations that beset a dying person, questions to ask a dying person, the redemptive powers of Christ’s love, and appropriate behaviour while attending the deathbed (such as prayers). By following these strictures, dying was understood to be a “dramatic” (defined as public enactment) process of meaning making that required the dying individual to model certain behaviours in relation to their

community (e.g., reciting prayers and hymns, seeking and giving forgiveness, and taking leave of family and friends) and in reference to an ultimate spiritual authority. Although the script offered by the *Ars morendi* must be understood as an idealized set of practices emerging from the aftermath of the Black Death, it serves as a particularly clear example of an early discourse⁴⁶ that was used to understand and proselytize a specific set of social behaviours that scholars today term the dying role.

The content, if not the purpose, of the dying role continues to evolve within epistemic changes that shape the processes of dying, including the now dominant secular discourse for generating knowledge of the human body and experience at the end of life. As discussed previously, this discursive change was both cause and effect of dying being constructed as a physiological process located within individual bodies, and due to the rise of empirical knowledge generated by the medical “gaze” to organize and control these processes (Armstrong, 1981; Foucault, 2003). I propose that the rise of this secular discourse is further evidenced in our current understandings and enactments of the contemporary Western dying role. While historic forms of the dying role included the requirement for acceptance, this emotional orientation was structured within a communal script of eternal salvation from a transcendent deity. In the contemporary dying role, salvation is secularized within the monotheism of psychology, where the individuated and autonomous self has become the locus of power and transcendence and the experiences of dying become, as Kübler-Ross (1975) articulated, the “last stage of growth.” The contemporary dying role is therefore an entwining of the historic social “dramatic self” with the modern autonomous “narrating self,” where the dying person ideally exhibits appropriate social behaviours by publically enacting *autonomous*, *individual*, and *personalized* expressions of acceptance.⁴⁷ This perspective is evidenced in palliative care, where practitioners encourage individuals to write their own “expressive” scripts for dying (McNamara, 2004; Walter, 2003). The increasing focus on

⁴⁶ Other less well-known examples from the Western canon include *The Waye of Dyenge Well* (1530), *The Sick Mannes Salve* (1553), and *Holy Living and Holy Dying* (1650).

⁴⁷ Here I follow Foucault’s (1990) understanding that current knowledge of the self is grounded within programs of conduct taken from Medieval Christianity, where narratives and disclosure of the private *self* become the ground for the public dramatic performance of individualized salvation, and are constituted within “techniques of verbalization” (p. 46).

secularized individualism, however, does not translate to lay individuals having the cultural authority to self-enrol or announce their entry into the dying role.

Clinicians as “Moral Entrepreneurs” within an Affective Economy of Hospitalized Palliative Care

As the development of knowledge generated by “the gaze” increasingly shaped the meanings and enactments of the dying role, the discourse of medicine came to replace the cultural authority of the individual to define when they began their dying process. Walter (2003) provides the following account of a French peasant dying in the 19th century to illustrate how the social norms of a good death have shifted from self-enrolment in the dying role, religious discourse, and prevalence of death due to infectious diseases.

She contracted a summer cholera. After four days she asked to see the village priest, who came and wanted to give her the last rites. “Not yet, M. le curé; I’ll let you know when the time comes.” Two days later: “Go and tell M. le curé to bring me Extreme Unction.” (p. 218)

This example highlights how the dying role, like other roles, is generated within a diversity of historical, social, and individual influences. When faced with the contemporary experiences of dying, however, few Canadians have personal experiences with the range of medical ambiguities that can arise, much less with the organizational structures that must be navigated at the end of life. Since the majority of Canadians now die within a hospital setting after a protracted illness, this institution often becomes the primary site in which patients and family members are informed of an anticipated, if temporally uncertain, death.⁴⁸ Hospital clinicians become responsible for generating open awareness by “confessing” (disclosing) knowledge of impending death

⁴⁸ It is arguable that non-hospital specialists who provide the initial terminal diagnosis are also responsible for entry into the dying role. The majority of these clinicians, however, focus on treatment possibilities and statistical averages, and talking about death with their patients is still considered taboo (Edmonds & Rogers, 2003; McNamara, 2004; Russ & Kaufman, 2005).

to the unknowing, if suspicious, patient and/or their families.⁴⁹ Within this confessional relation, the patient and/or their families reciprocate by acknowledging the authority of the clinician to define this truth, which ideally results in mutual open awareness.

Scholars interested in open awareness contexts have explored how hospital clinicians use this awareness to mediate entry into the contemporary dying role (Field, 1996; Glasser & Strauss, 1965, 1968; Kaufman, 2005; Perakyla, 1991; Timmermans, 1994, 2005). Perhaps the best known research comes from Glaser and Strauss's (1965) work. As reviewed in Chapter Two, Glaser and Strauss found that clinicians' authority, articulated within the discourse of medical expertise, enabled them to construct and circulate signifiers of a patient's illness as a coherent "dying trajectory." Clinicians constructed this trajectory and ordered their patients' experience of dying by: defining its "temporal dimensions," timing announcements, and coordinating transitions. Through these social interactions, clinicians legitimized and organized the dying trajectory as a "status passage," albeit an unscheduled one. Other scholars, also reviewed in Chapter Two, conceptualize this labour as a form of "moral entrepreneurship" (Field, 1996) requiring clinicians to engage in "death brokering" (Timmermans, 2005) as "cultural experts" (Seale, 2002) who offer specific "cultural scripts" for dying well (Seale, 2002; see also Kaufman, 2005; Perakyla, 1991; Timmermans, 2005). Although none of these scholars specifically use the term "dying role," each focus on the techniques clinicians employ, not only to organize the patient's dying trajectory, but also to secure the patient and family members' acceptance of the trajectory. This acceptance is exhibited by a "common sense" understanding that continuing life-extending treatments are futile and not in the best interest of the patient's quality of life, and, as such, produce the conditions for death (Kaufman, 2005; May, 1992; Perakyla, 1991). Consequently, although framed within a rhetoric of autonomy where the dying individual controls the dying process, modern hospitalized dying remains a socialized role shaped by normative expectations of what a good death entails. Similar to the perspectives of the affective economists reviewed in Chapter Three (Ahmed, 2004; Buchbinder & Timmermans, 2014; Richard & Rudnycky, 2009), and echoing the authors above, I suggest that

⁴⁹ Even if a person suspects they or a family member are critically ill, awareness of dying must be (at a minimum) corroborated by a physician, and is usually confirmed by multiple diagnostic tests.

clinicians' emotional labour in providing the feeling rules that shape the dying role to make sense of and so order the dying trajectory is a prime example as to how "socially situated discursive practices...variously evoke, represent, and transform emotional experience" (Buchbinder & Timmermans, 2014, p. 105).

Western clinicians express an understanding that it is their moral obligation to communicate knowledge of "bad news" (Butow, Tattersall, Clayton, & Goldstein, 2013; Suri, McKneally, & Devon, 2014). While hospital clinicians have a responsibility to "tell the truth" of a patient's diagnosis and prognosis, many report they are unable and/or unwilling to clearly communicate information that a patient is nearing death (Back et al., 2007; Baile, Lenzi, Parker, Buckman, & Cohen, 2002; Fallowfield et al., 2002; Mack & Smith, 2012). Palliative advocates suggest that this absence of awareness may negatively affect a patient's quality of life by inappropriately keeping them in a sick role (Byock, 1996; Parker-Oliver, 1999; Kuhl, 2006). The lack of role transition is therefore understood by palliative clinicians as reducing the possibility of a good death, and it highlights their use of life-course stages to discuss appropriate psychosocial development at the end of life (Byock, 1996; Chochinov & Breitbart, 2009; Kuber-Ross, 1974).

Exemplifying this perspective is a training model for clinicians developed by The American Academy of Hospice and Palliative Medicine (2007). The model outlines the "core developmental tasks" required for a person to die well, including: (1) developing a renewed sense of personhood and meaning, (2) bringing closure to personal and community relationships, (3) bringing closure to worldly affairs, and (4) accepting the finality of life and surrender to transcendence (quoted in Ramondetta & Jenkins, 2007, p. 182). While these activities are ultimately the responsibility of the dying individual, they are also understood as requiring palliative specialist skills to maximize the patient's "openness and adaptability" to these tasks (Canadian Hospice Palliative Care, 2002; Parker-Oliver, 2000). Palliative clinicians are responsible, therefore, not only for generating open awareness, but in facilitating a patient's emotional expressions of, and actions reflecting, this awareness. This dual outcome is generated by clinicians' willingness and ability to communicate, however uncertainly, an anticipated end to an individual's life, and to provide a set of feeling rules to orient patients and family

members to the appropriate expressions of psychosocial development at the end of life. Through these practices, palliative clinicians champion the patient's "right" to medical knowledge, and so allow control of the dying process by an aware and autonomous individual. At the same time, this understanding naturalizes the "right" of clinicians as facilitators of the dying role. Subsequently, even though there is very little research within palliative care literature that conceptualizes this work as socialization into a cohesive dying role, the importance of this work is signified by a plethora of research that surrounds these concerns, such as: the importance of "hope work" (Breitbart & Heller, 2003; Duggleby & Wright, 2004; Feudtner, 2005; Herth & Cutcliffe, 2002; Macleod & Carter, 1999); how to successfully transition patients from acute to palliative care (Back et al., 2007; Fallowfield et al., 2002; Ronaldson & Devery, 2001; Schofield et al., 2006); and how to facilitate "meaning" at the end of life (Breitbart et al., 2004; Chochinov, 2002; Neimeyer, 2005).

From an affective economy perspective, the ways in which patients and family members understand and express the experience of hospitalized dying has a history of production shaped by diverse relations of knowledge and power. These understandings and expressions are negotiated within therapeutic relations that inscribe a patient's emergent physical decline (the dying trajectory) with certain modes of thinking about this decline (the dying role). Consequently, following Ahmed (2004), I propose that, for those receiving hospitalized palliative care, emotional orientations to the anticipated end of life seem to be an autonomous and "common sense" outcome only as "an effect of a certain history, a history that may operate by concealing its own traces including histories of production (labour and labour time), as well as circulation or exchange" (p. 119). The dying role is then an exercise in governmentality—it organizes the capacity of individuals to self-govern at the end of life (Foucault, 1991). It does so by guiding the possibility of conduct within framing rules that naturalize an emotional orientation of "openness and adaptability" to the knowledge that the sick role is no longer appropriate. As a practice of governmentality, the dying role is constituted within the intersection of technologies of power and technologies of the self. Understood as a technology of power, the dying role facilitates palliative clinicians' ability as "moral entrepreneurs" (Field, 1996) to govern the biological processes of their patients by ordering the temporally uncertain process that is contemporary hospitalized dying. Understood as a technology of the self, the role

provides meaning and identity in a socially liminal time, and thereby engenders capacity even at the end of life.

If, following Massumi (1995), emotions are understood as expressions of the experiences of affect that emerge through relations of cultural mediation, then the work to transform patients' and family members' emotional orientations is at one and the same time work that transforms their capacity to act. In this understanding, the dying role is a relational practice that shapes patients' affect—their preconscious will to strive—by *ordering* their expressions of the inability to strive. In accepting the meanings and social status provided by the dying role, patients' inability to strive is replaced with new forms of capacity as someone who, although at end of life, continues to have specific rights and responsibilities. Through this emotional labour of transitioning patients and/or her family members into the dying role, clinicians facilitate the six ideal outcomes of hospitalized palliative care. First, in willingly acknowledgment of the dying trajectory, patients are accorded specific rights and obligations which serve to reincorporate them as valued—if diminished—members of society. Secondly, the dying role provides a script for generating meanings to make sense of their inchoate experience of the decreasing capacity to strive and increasing dependency on others. This leads to the third ideal outcome, where social dislocations threatened by the dying process are sutured and therefore preserve the stability of organizations and relationships. This includes modeling what a good death “looks like” for those who are not yet at end of life. Fourth, occupation of the dying role naturalizes direction and outcomes of care practices and ensures smooth transitions along the terminal care pathway amidst the prognostic and subsequent emotional uncertainties that are part of the hospitalized dying process. This enables the fifth and sixth ideal outcomes, where clinicians are able to identify as both compassionate and efficient, while simultaneously ensuring the need for increased specialist intervention and application of their unique expertise. Through this emotional labour, all involved parties (including clinicians themselves) ideally find meaning, order, and purpose.

While the scholars I have discussed here highlight diverse individual, social, and institutional aspects of the dying role, including attention as to who offers the dying role, when, and for what purpose, I know of no research that has focused on techniques

clinicians use that are specific to *hospitalized palliative care* populations. Additionally, clinicians' emotional labour practices within end-of-life care are processes by which everyone involved in the dying process conducts themselves and others, simultaneously producing those who enact it and those upon who it acts. While clinicians may be privileged cultural brokers for the shaping of patient and family conduct, their practices of care also shape their own potential for capacity and generate the terrain for being acted on. Using an affective economy framework enables me to address how patients, family members, and clinicians are *simultaneously* (if differentially) made capable of acting, and being acted upon, and highlights that emotional orientations to the dying trajectory occur within specific moments and contexts that require ongoing relations and negotiation.⁵⁰ Subsequently, and in response to Richard and Rudnyckij's (2009) assertion that an affective economy framework requires exploration as to how governmental practices are experienced and reflected upon in the everyday life of individuals, I now turn to examples of, and clinicians' reflections on, their practices that facilitate entry into the dying role.

Clinicians' Emotional Labour and the Dying Role in Hospitalized Palliative Care

The clinicians I observed never conceptualized their labour as structuring a cohesive "dying role." They did, however, articulate a range of emotional labour practices, manifested within conversational techniques, which they use to orient patient and family member behaviours regarding an anticipated, if temporally uncertain, death. I also observed orienting techniques that clinicians did not articulate. Collectively, these practices include: (1) "educating" patients and family members regarding appropriate treatment pathways, (2) quality of life and goals of care conversations, (3) the work of dismantling hope, (4) use of corporeal signifiers, and (5) hospice conversations. I will now discuss each emotional labour practice in further detail by drawing on both interviews and my field notes.

⁵⁰ While Li's (2004) work on "symbiotic niceness" as a collaborative practice between nurses and hospice patients addresses how emotional labour practices affect nurses' professional identity, she does not connect this to larger concerns of ordering the dying trajectory.

Educating

Clinicians often used terms such as “educating” or “teaching” a patient or family member about the appropriate care pathway at the end of life.⁵¹ This pedagogical labour was understood as enabling patients and their networks to learn how to make the “right” choices and is evidenced in the following two encounters:

Penny: It’s really hard to resist not forcing transitions on patients. It’s also hard to face the decisions that patients/family members make if I don’t agree with them. I think they would make different decisions if they KNEW what was going to face them, so that’s where aggregate information and teaching is important.

Eileen: [Discussing her conversation with a non-palliative clinician] I said it wouldn’t be right to ask [patient] to sign a DNR as she’s not there yet. [Patient] told me she’s still learning about palliative care....It may take some time for her to process but I think she’ll eventually come around.

As evidenced by Penny, the clinical narratives within which the dying role—or what she terms “transitions”—is offered may be couched in “common sense” understandings based on assumptions of rational information processing.⁵² While Eileen’s recounting highlights that clinicians are aware and respect that these transitions may take time, here too is the expectation that the patient will “come around” once she has had enough time to “process.” As a framing rule, this understanding naturalizes expectations that with the “facts,” patients will willingly, if at times reluctantly, accept impending death with emotional stoicism and dignity, indicated by discontinuing or declining further treatments, and so transition efficiently through the institutional care pathway. Yet, as evidenced in the previous chapter with Ruby’s continued desire for treatment, the sharing of information does not *necessarily* lead to open awareness and acceptance of the dying role. In these instances, when patients and family members express “suspended” or “uncertain” awareness contexts (Timmermans, 1994) and/or

⁵¹ These terms were also used to describe the need for providing skills and information to non-palliative clinicians caring for patients at the end of life.

⁵² This was evidenced in the last chapter, where Tony’s request for a tube feed prompted his clinician to remark that he needed to be “educated” as to why it wasn’t a viable option.

where care outcomes remain uncertain, clinicians use other emotional labour techniques to implicitly orient patients and family members to the dying role.

Quality of Life Conversations

In my observations, I found that the desire to “educate” translated to a significant rhetorical emphasis on “goals of care” conversations about “quality of life” with patients and family members. This narrative framing occurred within a diversity of relations and contexts, in both structured and unstructured formats, such as family meetings, medical meetings, rounds, and during informal hallway or room conversations between clinicians, patients, and family members during task-based care. Although the term “quality of life” is commonly used in palliative care, the concept has no single agreed on definition (Carr & Higginson, 2001; Jocham, Dassen, Widdershoven, & Halfens, 2006; Skevington, Lotfy, & O’Connell, 2004).⁵³ Due to this lack of definition, quality of life is primarily understood in palliative care as an “outcome measure” in clinical research and is hard to translate into clinical practice and corresponding care goals. Quality of life measurements are therefore rarely used in routine clinical practice, and the concept is primarily “operationalized” dependent on clinicians’ own understanding of the term (Higginson & Carr, 2001) (including at the two hospitals where I did my research). This also holds true for the term “goals of care,” where there is a lack of consensus regarding the type and number of goals that should be considered (Kaldjian, Curtis, Shinkunas, & Cannon, 2009).⁵⁴ Similar to “total pain,” as discussed in Chapter Five, these phrases operate as sliding signifiers (Ahmed, 2004) where their meanings are dependent on how, when, and why clinicians invoke the terms.

The ubiquity and flexibility of these terms permeated my field notes and was a constitutive part of the everyday language of care as evidenced in the following excerpts.

⁵³ In their meta-review of the term within palliative care literature, Kaasa and Loge (2003) found a wide range of possible indicators that may or may not be used, including: symptoms, functioning, psychological, and social well-being.

⁵⁴ In their meta-review of the term within palliative care literature, the authors articulate six areas that may or may not be included in goals of care discussions: (1) to be cured, (2) to live longer, (3) to improve or maintain function/quality of life/ independence, (4) to be comfortable, (5) to achieve life goals, and (6) to provide support for family/caregiver.

December 2008: A wife of a patient is expressing increasing levels of distress about her husband's deteriorating status and the care he is receiving, and she wants further interventionist treatment. The clinician tells the wife that "Our goal here [on the unit] is to make him comfortable and that the [requested treatments] won't make him comfortable, so this might be the right direction of care for his quality of life." She asks the wife if, "She has had a good discussion with her husband about the goals of care" and the wife replies that she has.

May 2009: In my conversation with a palliative consultant today, she tells me about a patient's son who told her that while he knows his mother is ill, she is not going to die. The consultant says she tried to, "Engage him in why he thought this" but he just smiled, so the consultant said she, "Just backed off and said it might be a good idea if there was a medial meeting with the family to talk about goals of care and his mother's quality of life."

Sept 2009: A consult patient, who is aware of her prognosis of less than six months, feels that neither she nor her husband are able to cope with the level of expertise required for receiving TPN⁵⁵ at home. She had the procedure in the hope that her strength will increase and she'll be able to resume her chemo. Chart notes written by the palliative consultant state: "TPN was put in for quality of life and to decrease frequency and severity of aspiration pneumonias...Long discussion with patient re: TPN in cancer and importance of 'trial' as some patients may not benefit but find have decreased QoL [quality of life] with no added strength or weight and we have to constantly re-evaluate risks and benefits. Patient does feel TPN has greatly improved her hunger which is an important consideration."

These examples demonstrate how, by invoking the terms "quality of life" and "goals of care," clinicians include patients and families in the coauthorship of care direction, as well as signifying clinical justification for continuing or discontinuing treatments. At the

⁵⁵ Total Parenteral Nutrition (TPN) is a continuous intravenous feeding procedure by way of a central vein, bypassing the processes of eating and digesting. Possible complications are significant and include: infection, blood clots, gallbladder inflammation and blockage, and fatty liver and liver failure. Many palliative units are extremely reluctant to admit patients receiving this treatment.

same time, these phrases can be utilized as a narrative orienting device by clinicians to identify and demarcate potential sites of tension between themselves, patients, and family members regarding current or future care pathways.⁵⁶ These phrases then also function as an “educational shorthand”—a feeling rule and/or rule reminder based on clinicians’ expertise—to facilitate patients’ and family members’ “active” open awareness contexts. This is similar to Kaufman’s (2005) findings in intensive care and Timmermans’ (2004) work in a generalist setting where clinicians used similar language to naturalize discontinuation of acute care. Yet while these terms are powerful feeling rules invoked by clinicians to orient purpose and outcomes of care within uncertain contexts, I also wish to highlight how these terms may, *at the same time*, facilitate patient and family member claims to autonomy in defining their own preferred care pathway. Additionally, in the rhetoric of goals of care discussions, the desire to maximize “quality of life” may come to replace conversations that explicitly reference death and dying (Clark, 2002) and provide further capacity for patients and families to advocate continuing aggressive life-extending therapies.

Dismantling Hope

Another common tactic that clinicians explicitly referenced as a socializing technique into acceptance of impending death is the labour of dismantling hope.

Gina: I tell them [patients and families] that you have to be hopeful, and I share their hope with them, but there’s going to come a time when that hope has to change...If the patient is really hopeful, I might separate the family and just say, “Look, where are you at? What is your understanding?” And if they are as hopeful [as the patient] I might say, “It’s difficult, but I’ve seen enough to help me know and to realize that there’s a point when the situation has changed and you need to accept that.” And those who can accept that, well it’s a much nicer death than people who kick and scream going...And I think that’s where palliative care helps.

Kirsten: You cannot just say, “Oh that’s not going to happen” [when people are hoping for cure or stabilization]. It’s kind of their hope, and without hope it’s really hard to go through all the difficult times. So what I usually think or say [is], “What I believe actually is that we have to switch

⁵⁶ Whereas total pain signifies *actual* sites of tension.

hope to a different area.” Hope is not that they can get well or that the cancer will be cured, but more like changing, shifting their focus to more like quality of life, or family time together. But that doesn’t always work out (laughs), but you try to really remind them that this is a good time to think about not focusing on the disease but also on the other aspects of life so they can have closure.

As Kirsten highlights, “quality of life” is a common phrase in the emotional labour of dismantling hope. Another common rhetorical framing device that clinicians use, and evidenced in Ruby’s case in the last chapter, is the often-invoked and generic phrase “hope for the best, prepare for the worst.” This serves to orient the patient and family member to an understanding that, while they still have the right to hope, they are now also responsible for preparing for the impending death. Here we see how clinicians’ emotional labour, enacted within the therapeutic relationship, attempts to construct an awareness context that also has specific *responsibilities* attached to it. This responsibility is to exhibit the appropriate emotional orientation and associated behaviours of the dying role, including accepting the authority of the clinicians to define the direction and content of hope. As both of the clinicians above point out, their labour is undertaken in the compassionate hopes that patients and families will be able to get through “difficult times,” achieve “closure,” and achieve a “much nicer death.” Simultaneously, as evidenced in Gina’s comments, in the work of dismantling hope, clinicians also attempt to naturalize entitlement claims based on their specialist expertise to frame patients’ and family members’ understandings of the dying process. Similar to Perakyla’s (1991) findings in a general hospital setting, my palliative-specific research also reflects that hope work functions to continuously reestablish the expertise of clinicians to define the clinical and temporal aspects of the dying process as well as the appropriate emotional orientations to this process. The work of reframing hope is then understandable as a technique that simultaneously shapes the ability to govern the conduct of critically ill populations *and* to generate self-governed understandings and orientations to the dying process.

Use of Physical Signifiers

When invoking claims to authority through education, rhetoric of quality of life and goals of care, and dismantling hope are not successful pedagogical techniques for

socialization into the dying role, clinicians use physical signifiers of disease progression. In these instances, the dying role is implicitly offered by constructing the deteriorating body as a corporeal signifier of impending death. This requires rendering visible the disease process and the body's response to this process as out of the control of any one individual (including the clinicians). The ascription of agency to the disease than to a sentient actor constructs the controlling factor determining the appropriate care pathway as based in nature. In the following example, a clinician combines education, the work of reframing hope, and the use of physical signifiers in her emotional labour to orient the patient and his wife to the dying role, or what she terms "reframing" work.

May 2009: A patient on the unit who has rapidly advancing cancer wants to know about treatment options, but his clinician [Penny] feels that the test results they are waiting for are going to indicate that he is too sick to receive any further chemotherapy. However, when she approached the topic previously, both the patient and his wife stated their belief that he's sick because he's not eating and want to know what they can do to increase his appetite. Before entering the room Penny states, "It's so hard to reframe why he's not eating...we need to reinforce that the reason that he's not well enough for the chemo is because he's too sick, not because he's not eating." Once in the room she does exactly that, informing them that the reason he is not eating is because he's not feeling well rather than the other way around. She states that, "It's not your fault, it's not your wife's fault, and it's not our fault. You don't want to eat because the disease is so advanced and your tumour is very large and that's why you don't want to eat." She then turns to the wife and says, "You need to switch it around, in that he's not eating because he's not well. Yes?" The wife nods her head in agreement but doesn't make eye contact. Penny continues, "You have to prepare for both; that you might not get well enough for chemotherapy or you may get well enough to go for it. Regardless of what happens, we will take care of you and make sure your pain is well controlled. Right now you're not strong enough for the chemotherapy, and that's not your fault, it's the cancer's fault. The cancer has grown and advanced, and you might get weaker." She continues to discuss how they will manage his pain no matter what happens, after which there are a few moments of mutual silence before she stands up and says that she will return for further discussion once the test results are back.

Penny is attempting to transition the patient and his wife from an uncertain awareness context to an active one by eliciting a mutual acknowledgement that preparation for the worst may be required. By referencing the instability of the disease process, Penny is able to articulate the need of the patient and his wife to occupy a liminal position whereby they are potentially “prepared” for the upcoming death without explicit reference to dying. In this instance, the clinician removes responsibility for getting better, a requirement of the sick role, with the responsibility of acknowledging the advance of the disease, a requirement of the dying role. This framing of the dying role as acceptance of existing biological deterioration and the probability of its advancement then works to naturalize the patient’s and his wife’s emotional orientation to the likelihood that treatments will not resume. This ambivalent position provides the feeling rules for future conversations, where if the patient does not stabilize, the clinician has provided initiation into the dying role. Ideally, this narrative technique functions to proactively resolve any potential blockage along the terminal care pathway as patients and family members accept movement based on a coauthored and “common sense” understanding of disease progression, and thereby occupy the role without overt coercion or pressure. Yet, as we saw in the last chapter with Ruby’s desire for continued treatment, and in Tony’s demands for euthanasia, the awareness emerging from physical deterioration may or may not be successful in transitioning patients into the dying role. While the use of corporeal signifiers as a feeling rule to socialize patients and family members into the dying role may or may not work well, it may also become the default approach as the speciality increasingly focuses on acute symptom management even at the very end of life.

Hospice Conversations

In my observation at both hospitals, conversations about hospice transitions were a daily practice that socialized patients and their family members to the dying role.⁵⁷ Unlike admission criteria, there are no official discharge criteria at either palliative unit, yet it is difficult to overstate the importance of hospice transfers to daily practice. Questions as to when it was clinically and/or emotionally appropriate to approach patients and families about possible discharge, timing of follow-up conversations, when to “push” for discharge, and when to provide “space” for processing information, when to request a hospice bed, and when it was appropriate to formally transfer patients, took up an enormous amount of clinicians’ resources and emotional labour. Conversations between clinicians about patients almost always included estimations of when discharge could or should occur. As well, discussions of patients’ physical and psychosocial symptoms, and the possible treatment of these, were framed within concerns as to whether these issues would block or facilitate potential transfers. This perspective is given voice by Michelle, a senior clinician who stated:

Nobody wants to move, I mean nobody. But we spend time going through the process...It’s an awful lot of time to spend and that can be a big frustration...[sometimes] I just kind of say we’re going to stop talking about it, it’s a waste of our time. Sometimes we’re spending like two hours a day stressing about [certain families] because THEY’RE so stressed out about leaving and it’s wasting our time so [I make the decision that] we’re just not going to talk about it anymore.

The ubiquity and seemingly endless nature of these negotiations were described by clinicians as an “ongoing performance,” the predominant “background noise” against which daily care was provided, and as “death by a thousand cuts” that often drains the emotional, administrative, and temporal resources of the unit.

⁵⁷ While the majority of patients and family members wished to be discharged home, this was often not possible due to the care needs of the patient and/or the capacities of the caregiver(s). Subsequently, while clinicians often included home as a tentative option in their discharge conversations with patients and family members, the possibility of hospice was almost always also included in these discussions. I do not have exact numbers of patients discharged home versus hospice, but discharge to hospice was more common at both hospitals. Although there were several instances of patients being discharged to long-term care, this was seen by both patients and clinicians as the least-desired option.

The emergent meme of *hospitalized* palliative care is that services are no longer dependent on prognosis but on acute symptom management needs for purposes of stabilization (Field & Addington-Hall, 1999; Foley, 2005; Traue & Ross, 2005). On the other end of the spectrum, *hospice* palliative care has admission criteria based on a prognosis of three months or less, and those admitted are usually in the last few weeks of life.⁵⁸ Accordingly, medical treatment at hospice focuses on oral pain medications and sedatives, as well as other non-invasive practices for care, and emphasizes physical and emotional comfort without aggressive treatment interventions (Fraser Health, 2011; St. James Service Society, 2011). Within the hospitalized palliative context, discharge conversations then discursively construct hospice rather than the palliative unit as the legitimate location of care once a dying patient becomes relatively asymptomatic but cannot be discharged home. Given the hospice admission criteria, in initiating and sustaining conversations about hospice discharge, and deciding if and when a patient is appropriate to be transferred, clinicians define the patient as in the very last stages of life. As evidenced in the perspective of the following clinicians, hospice discharge conversations thereby provide them the authority to both define and naturalize when it is appropriate to take on the dying role (than leaving it up to the patient and their families).

Donna: This time around when he [a patient who had previously been discharged] was readmitted, we weren't as cuddly, in the sense that up until that point we were saying, "Yes, you can go back home and we'll be your back up and stuff." But we...were sensing that he was kind of declining, that he was getting sicker. And so we said, "We are worried that maybe home is not an option for you anymore, you should be thinking about hospice." And I think sensing that change of tone on our part, and talking about hospice, made him very sad. Because up to then we had kind of been about hope...So I think it was like acknowledging, "You know what? Things are changing now, and maybe you are getting closer [to dying] now."

Eileen: You really try and start off this piece [hospice conversations] with offering control, in terms of "I want to give you as much control as possible"...[but] it's kind of an illusion of control in the sense that there's really no choice about going to hospice...and nobody wants to go

⁵⁸ While some hospices have short-stay programs such as respite and/or symptom management where the intent is for the patient to return home, virtually all hospice patients die on their initial admission.

because they know that this means they are dying, and soon...but damned if I'm going to say that they don't have control. So we try very hard with that, but then eventually with some families [who refuse to transition], you just have to say, "It's a medical decision now."

Some may argue that clinicians' power to define the appropriate location for institutionalized dying does not necessarily indicate the offering of an accompanying dying role. What this perspective overlooks is how conversations regarding locations of care occur within therapeutic relationships that work to define the parameters of the real and true (Foucault, 1988). Clinicians are aware that both they, and those they care for, associate hospice with dying and death. Further, in their reflections, both Donna and Eileen implicitly associate the unit with interventionist care than as the appropriate location for end-of-life care. Yet, as noted earlier, during the course of my observations, the majority of patients died on the unit on first admission without transfer to hospice. Given this pattern, I propose that hospice transition conversations can be understood as an important emotional labour practice clinicians use to socialize patients into accepting the dying trajectory—a key responsibility of the dying role—*whether or not they are actually transferred*. As conversations about appropriate location of care (ideally) occur within a coauthored therapeutic space, these discussions then function as powerful orienting techniques for facilitating patients' and family members' acceptance of the dying role and concomitant transition through the terminal care pathway. Consequently, while not all patients and family members challenged discharge to hospice, I observed relatively few instances where clinicians were not met with some resistance when the subject was initially broached.

Although clinicians do not expect imminent death for all of their patients, the overwhelming majority of their patients are considered to be at least *nearing* the end stage of a terminal illness as well as having problematic or uncontrolled symptoms. This patient population also has a high incident rate of rapid deterioration and "unexpected" complications. This means that clinicians must be able to work within an environment of, at times, radical uncertainty as to what care outcomes will be.

Sally: You have to have the ability to be comfortable with the reality that a lot of what we do is unknown. It's a hard place to be...Everything we do is

gray, we don't necessarily know, [and] we're just trying to do the best we can.

Gina: The uncertainty, well it's always there in our work, it's an undercurrent....If something does change and you weren't expecting it, or you're not sure what's going to happen, you do your best to cope with the consequences of what's happening.

Diane: The most complicated [part of care] is related to prognosis and our ability to prognosticate. We all prognosticate on different feelings and skill sets...If we knew somebody was only going to live for a week, and had that as a fact, it would make it easier.

This emotionally intense, fluctuating, and uncertain environment requires those who labour within it to develop skills that help manage the unknowns—what Sally calls “the ability to be comfortable” and Gina terms “coping.” In using the techniques of educating patients and family members of appropriate care pathways, rhetoric of quality of life and goals of care, working to dismantle hope, use of corporeal signifiers, and/or hospice conversations, clinicians offer specific feeling rules that collectively and proactively orient themselves, their patients, and their families to the real, if temporally uncertain, possibility that death will be the outcome of their current admission. Further, these techniques enable to clinicians to do so *often without reference to the words death or dying*.

In this section I have explored how clinicians socialize patients and family members into the dying role through education of anticipated care outcomes, rhetoric of quality of life, dismantling hope, reference to physical decline, and/or hospice conversations. I have also proposed that these emotional labour practices are a significant way that clinicians order the prognostic and subsequent emotional uncertainties that are part of the hospitalized dying process, and thereby engender their capacity to meet the six ideal outcomes of care. Yet how the role is negotiated *in situ* is dependent on a range of contextual factors that include but are not limited to: diagnosis, prognosis, individual and family dynamics, expanding professional boundaries, institutional imperatives, and location of care. I now turn to an example where I observed the role being negotiated over time to better understand both the processes and situated outcomes of clinicians offering this role. Given that negotiation of the dying role in a

seamless good death requires little of clinicians' emotional labour, I have chosen to focus on an example that has processes of a contested peaceful death, but through negotiation, ends in an outcome of a good enough death.

The Dying Role in the Negotiated Good Enough Death - Jake

October 2009: Jake is a middle-aged man with metastasized cancer who has been seen by the consult team for several weeks during a lengthy admission for repeated acute pain crises. Undergoing aggressive treatments, he and his wife are ambivalent about receiving palliative consult care, where his wife Samantha has remarked several times, "Remember, they are here to deal with your pain and FOR NO OTHER REASON." Jake's prognosis is uncertain; if he responds well to the current round of chemotherapy and radiation therapy his specialist cautiously estimates up to two years. However, he is currently experiencing significant side-effects and his attending clinician is concerned that he may be too sick to continue the treatments. Due to these concerns, a consult has been requested to "revisit" goals of care.

Before we enter the room the palliative consultant [Sally] turns to me, sighs and states, "This is going to be a hard one; they're not going to want to hear what I have to say, so we'll have to see how it goes." Sally introduces the topic by reviewing the results of the most recent tests, stating that they are "uncertain" as to how he will react as treatment progresses and she wants to "check in" with what their understanding of the situation is. Both Jake and Samantha are clear that they are still hopeful for a cure; at worst stabilization with several years at home. Sally cautions that, "It's understandable that you want to hope for the best, but it's also important to prepare for the worst. The tumour is growing and causing [increasing symptoms] and I want to make sure that you have the capability and time to make the care decisions you want." This is met with silence, and after a few moments the clinician asks if there is anything that he or his wife wants to talk about today. Jake says, "No, I'm having a happy day. I just want to have a good day." After we leave Sally says, "What makes it hard is that he might bounce back and have a decent quality of life for some time. It's hard to know in this case what to do."

Jake quickly and visibly declines, resulting in the medical decision to stop most of the treatments to see if he can get "stronger" before resuming them. Over the next 10 days,

Sally makes regular visits as his symptoms are becoming increasingly distressing and the attending physician is strenuously advocating a transfer to the palliative unit as “the most appropriate location for care.” The attending also starts paperwork for a hospice transfer, although this is not discussed with Jake or his wife, and causes Sally a great deal of frustration. She writes in the chart notes that the key barrier to transfer, a signed DNR, “Is not yet in the patient’s best interest as he and his wife are still transitioning and slowly learning the benefits of palliative care.” However she agrees to continue to advocate for transfer to the unit and does so over the next few visits, citing what the unit can provide regarding “quality of life for someone at this stage of the disease process.” At this point Samantha tells Sally privately that while she knows her husband “might” be dying, they “need to fight in order to know that we have done everything that we can”. She states that transferring to the palliative unit means “that there’s nothing more to do but die” and that even though Sally’s “heart is in a good place” that they have a “right to continue treatment, regardless of what anyone else thinks is best.” She feels that hospital staff, including the consultant, has been “forcing” them to acknowledge that Jake is dying, and that stopping treatment may be a punitive measure because they refuse to do so. She acknowledges “this may be irrational but that’s how it feels.”

Another week passes, and Jake continues to deteriorate rapidly. He begins to acknowledge that he is “tired,” stating that, “Some days I don’t know if I want to struggle too much longer, but then other days I’m game to battle on.” He tells Sally that he’s glad when she “comes to visit.” Both Jake and Samantha express their gratitude to Sally for her ability to address key symptom management issues, and now state a willingness to “think about” transfer to the palliative unit or hospice. As negotiations about transfer or discharge continue, Jake begins to slip in and out of consciousness, and dies a short time later. Afterwards, Samantha hand-delivers a note to Sally that says, “Thank you, for everything you did.”

Within an affective economy framing, the emotional labour negotiations that construct entry into the dying role are understood as an intersection between technologies of power and technologies of the self, within which possibilities for action at the end of life are circulated, negotiated, and/or contested (Foucault, 1988). In this example, all of the clinicians, including Sally, privilege and circulate an understanding of

Jake's physical state as one of terminal decline, and therefore requiring of emotional acceptance of the dying role. Both the patient and his wife, however, refute this understanding and corresponding emotional orientation. His palliative consultant then must use the techniques of education, goals of care, and quality of life conversations, reframing hope, physical signifiers of decline, and the possibility of transfer to negotiate a mutually coauthored "truth" of the patient's emergent physical state. As the feeling rules generated by these techniques are resisted by Jake and Samantha's counter-claims to narrative authority, negotiations become a site of visible and sustained tensions regarding the patient's capacity to strive, and do not significantly facilitate his or his wife's occupation of the dying role. In turn, this continued striving for life fundamentally challenges the consultant's capacity to facilitate the six ideal outcomes of care.

Initially, in the desire to proactively order Jake's uncertain prognosis and corresponding care pathway, clinicians implicitly structure and tentatively broker entry into the dying role through a mundane technology of power—the administrative process of calling for a palliative consult to "revisit" goals of care. In the face of his rapid physical deterioration, clinicians further naturalize his appropriateness for the role with medical-administrative signifiers such as requiring a signed DNR, charting the need for transfer or discharge, and the withdrawal of life-extending treatments. Yet Jake's (and his wife's) enactment of technologies of the self—their practices for generating identity and capacity—do not match with these signifiers. In the face of initiation into the dying role, Jake and Samantha exhibit emotional orientations and actions consistent with the will to strive (including ongoing requests for treatment and refusal to transfer to the palliative unit).

Subsequently, the palliative consultant had to negotiate within and between the dominant clinical narrative and the patient and family member empathic counter-narrative regarding appropriate "goals of care," which required sustained amounts of her emotional labour expertise. For example, in the initial meeting I observed, while Sally's ostensible goal is to take direction from Jake and Samantha, it is also clear that she understands her job as finding a way to communicate potential "bad news" that will result in a willingness to anticipate a possible transition through the terminal care

pathway. She negotiates this dual outcome by attempting to orient the patient and his wife to the dying role in her emotional labour of dismantling hope, signified by the generic “hope but prepare” feeling rule, referring to the patient’s physical deterioration by referencing the growing tumour, and in her rhetoric of autonomy regarding goals of care constructed by the phrases of “time” and “capacity” to “make decisions [they] want.”⁵⁹ These narrative techniques give structure to the responsibilities of the dying role and proactively order the terminal care pathway, even as Sally (privately) expresses initial uncertainty about the patient’s prognosis. Neither Jake nor Samantha, however, are willing to express open awareness, and continue to invoke strong empathic claims to authority to counter the clinicians’ authority in defining appropriate goals of care. This requires that Sally continue in her emotional labour attempts to orient them to the dying role, using ongoing rule reminders to “educate” them of the benefits of a palliative transfer based on quality of care goals for “someone at this stage of the disease process.”

This continued ambivalence puts Sally in a complex position where she becomes an intermediary between the attending physician and her patient, having to invoke rule reminders to each party regarding the appropriate care pathway. She continues to advocate for the *rights* of the dying role in relation to non-palliative clinicians while simultaneously educating the patient and his wife on the *responsibilities* of the dying role. In directing her emotional labour towards Jake’s attending clinician, Sally is providing a rule reminder that the dying role as an emotional and temporal transition that often requires specialist techniques within developing therapeutic relations. This perspective, however, may challenge palliative consultants’ perceived usefulness in efficiently transitioning patients through the terminal care pathway, and thereby trouble the desire by non-palliative clinicians to call for specialist palliative consults. Sally’s intermediary position then problematizes her ability to identify as simultaneously compassionate and efficient, either to other clinicians, or to the patient and his wife. This calls into question the “naturalized” understanding regarding the benefits of palliative

⁵⁹ Kaufman (2005) labels this contradictory process in attempts to adhere to the movement imperative while honouring patient and family wishes as “doublespeak,” where clinicians unwittingly rhetorically construct conversations as “Take your time, but make a decision (hopefully one that moves things along) now” (p. 176).

care and the need for increased specialist mediation in these types of cases. While her educational admonishment towards the attending clinician results in a temporary reprieve for the patient, her advocacy does not have the desired effects on Jake and Samantha, as they continue to strenuously resist the responsibilities of a role they construct as diminishing personal agency and devoid of spiritual meaning, encompassed by Samantha statement of “nothing left to do but die.”

Similar to the stories of Ruby and Tony in the previous chapter, when Jake and Samantha do finally begin to express uncertain open awareness, this acknowledgement emerges due to Jake’s deteriorating physical state, made official by the withdrawal of treatment. And, like Ruby, their awareness does not translate into an acceptance of the diminished capacity to strive—even as Jake expresses weariness he also continues to articulate his willingness to “battle on” in his desire for life. Subsequently, Sally’s diverse and sustained use of rule reminders to socialize Jake and his wife into the dying role are then understood by the patient and his wife as an unequal relation of punitive power. Similar to Ruby’s example in the last chapter, Samantha’s remarks as to the “force” she and her husband experience renders visible how therapeutic relations are relations of power that privilege clinical authority. Her comments signal a partial breakdown of the ability of the consultant to produce an impression of a “nice organization” (Li, 2004) even as they acknowledge Sally’s compassion in acting from her “heart.”

Yet for all of the tensions that emerged from these negotiations, I propose that Sally was able to facilitate a “good enough” death and thereby succeeded in achieving some of the ideal palliative goals of care. Although Jake dies without having fully transitioned into the dying role, there was never a complete breakdown in communication nor was Sally forced to use her authority to invoke the ultimate rule reminder: transfer against his will. Further, Sally was able to develop therapeutic relations that both the patient and his wife express gratitude for as evidenced in even the most difficult negotiations. Jake spoke to his feelings of pleasure in Sally’s company, and both he and his wife remarked on the benefits of receiving specialist care. They were also able, albeit when Jake was very close to death, to tentatively acknowledge that the most appropriate direction of care was palliative-only services. Finally, Samantha’s note of thanks was a poignant artefact of the impact of the consultant’s labour to facilitate a

negotiated "good enough" death, articulated in large part through her attempts to initiate them into the dying role.

While this example is only one of the dozens I witnessed, it contains many common elements I observed across the vast majority of the patients and family members who were part of my research. In my time on both units, there were patients and family members who had already accepted the dying role previous to or soon after admission. Others refuted it entirely, or, in a few instances, were not offered any aspect of the role at all. In my observations, however, almost all clinicians engaged in a series of emotional labour negotiations with their patients that resulted in the patients taking on, to a greater or lesser degree, at least some of the rights and responsibilities specific to the dying role. My observations therefore support other findings, discussed previously in this chapter, that clinicians are "moral entrepreneurs" (Field, 1996) and "cultural experts" (Seale, 2002) who engage in "death brokering" (Timmermans, 2005) by offering specific "cultural scripts" (Kaufman, 2005; Perakyla, 1991; Timmermans, 2005) and so initiate the patient into the "non-scheduled status passage" of dying (Glaser & Strauss, 1965, 1968). At the same time, I understand the outcomes of these practices as *negotiated*, and as generated within an ambivalent and fluctuating affective environment constituted by the emotional labour of *all* involved parties.

This understanding combines Foucault's theorizations on relations of power, governmentality, and subjectivity with Hochschild's work on emotional labour to understand clinicians' work to emotionally orient patients and family members as a "means through which people both conduct themselves and conduct others by structuring possible courses of action...that simultaneously produces those who enact it and those upon who it acts" (Richard & Rudnyckij, 2009, p. 61). Subsequently, an affective economy framing requires that equal attention be given to questions as to how the affective environment of hospitalized palliative care shapes clinicians' *own* formations of identity and practice as they engage in practices that shape their patients' and family members' identity. Similar to the previous chapters, I focus on the tensions of: (1) expansion of care with populations who may or may not be imminently dying, (2) institutional imperatives for rapid transition through the terminal care pathway, and (3) location of care within tertiary care hospitals. I now turn to a discussion of each of these

in order to explore how they are interwoven components that both generate, and reflect, a complex affective economy of hospitalized palliative care.

Tensions in offering the dying role

Expansion of Practice

Palliative clinicians are now engaging with increasing numbers of patients, like Jake, who are inscribed as appropriate for palliative services, yet are simultaneously continuing to seek curative or life-extending therapies. These patients may enter a prognostic zone of indistinction (Bern-Klug, 2004; Kaufman, 2005) where they are neither healthy enough to be considered medically stable nor, as a result of continuing treatments, are they imminently dying. The consequence is that more and more patients may reside within this clinical and social “liminal” state and so trouble the capacity of the palliative clinicians who care for them to facilitate the six ideal outcomes of care. The following clinician addresses how practice expansion and corresponding treatments may benefit her patients while simultaneously challenging her ability to know if and when to use her emotional expertise to initiate patients into the dying role.

Ruth: In the last few years I've seen palliative care become a bit more nebulous in the sense that there are more options. We can give chemo for palliative care; we can do [other treatment interventions] and so on. And once that starts, what you find is that sometimes the pain or the symptoms are very well managed. Sometimes you find that's the only way of managing the symptoms; now that you've opened that door it's unethical to turn back and say, “we're going to take it back” because you know the symptoms are going to come back at that point in time. These treatments may also be prolonging their lives but also increasing their symptoms... Sometimes it's hard to know what to do with them.

Most palliative clinicians advocate for expanding their services to hospital patients with “ambiguous dying syndrome,” those people who face a greater risk of dying than the general hospital population, although the timing of their deaths may be radically uncertain and potentially not occur for several years (Bern-Klug, 2004; Clark, 2007; Rodriguez, Barnato, & Arnold, 2007). In generating new forms of specialist symptom management knowledge about *potentially* dying bodies, palliative clinicians are enabled

to apply this knowledge across a broad range of newly appropriate hospitalized patients. This expansion of practice increasingly requires a discursive framing that champions hospitalized palliative care as primarily acute symptom management for those with “life-limiting” illnesses (than one focused on the needs of the terminally ill). While the professional rhetoric champions the ability of palliative care to expand with little practice or philosophical implications for practitioners, many of the clinicians I worked with expressed significant, or at least some, reservations regarding this “upstreaming”⁶⁰ of care.

Similar to the concept and attendant practices of addressing total pain, clinicians’ understanding of the dying role in relation to practice expansion was a source of uncertainty, disagreement, and ambivalence, as well as one that led to questions as to how to differentiate their work as a professionally and/or ethically superior form of care for this “ambiguous” population who are often receiving a range of other specialist services.

Diane: What I hope for is that there [will be] more distinction between hospice and acute palliative care. And it’s not clear yet for a lot of people, even some people on the [palliative] team, and I see there being a very clear distinction.

Penny: Good palliation of symptoms now requires us to do investigations [and therefore is] also appropriate to patients who are not at the end of life.

Jane: If we are no longer dealing with patients who are dying [then] palliative care needs to have a goals of care conversation with itself.

As evidenced by Diane and Penny, expansion of practice can result in clinicians discursively associating hospitalized palliative care with active interventions rather than end-of-life care. Consequently, while some clinicians like Jane continue to connect palliative and hospice care populations, the philosophical and practice differences

⁶⁰ This is a term used by some clinicians to describe the delivery of palliative care at an earlier stage in the trajectory of a life limiting condition, when a patient may still be continuing life-extending or potentially curative treatments.

between the two, which were once downplayed (Mount, 1976; Saunders, 1978), are now increasingly championed, particularly by younger clinicians. In turn, this framing renders less valuable the emotional labour expertise in transitioning patients through to a good death by initiating them into the dying role.

Institutional Imperatives for Hospice Transfer

I have explored how hospice conversations are narrative techniques clinicians use to simultaneously facilitate acceptance to the dying role and to mark professional boundaries as hospitalized palliative care continues to expand to new patient populations who inhabit an earlier stage in their disease trajectory. As highlighted by the following two clinicians, though, hospice conversation may serve one care outcome in particular: rapid transition through the terminal care pathway.

Gina: From an institutional point of view, we have only so many beds here...so there's always a struggle to make sure there are enough beds for all our patients. The institution has now established all kinds of mechanisms to monitor length of stay, bed utilization, all that stuff. So week after week, you feel like you're kind of justifying why certain people have to be here. And there's a certain advantage to that; it keeps everybody on their toes...But there's also an element where you feel like certain patients have to be here because they're on [treatments they couldn't receive elsewhere]...then it gets a little bit frustrating having to justify week after week why those folks are here...it creates a different political dimension in itself because then the institution says, "Well if there's empty hospice beds how come you've got patients here for 60-70 days?" so you really have to explain that all of that stuff.

Carol: The issue in length of stay is the pressure from the institution to have more deaths in the community [home or hospice], but some people don't want to die at home, and some people don't want to die in the community...I don't really have a problem with people being cared for here, it's just the institution tells us that we can't be using expensive beds.

The clinicians I worked with were all well-aware of the institutional pressures to move patients rapidly through to discharge. Many, like Gina and Carol above, clearly articulated how their care practices are powerfully influenced by the bureaucratic imperatives emerging from daily and weekly meetings regarding bed counts and length

of stay, internal health authority guidelines meant to streamline care processes for purposes of efficiency, and from administrators concerned about the statistical averages of their domains in relation to lowering costs. Although concerned with ethical patient care at the end of life, hospital administrators also champion palliative care with the expectation of cost savings accrued by decreasing length of stay or reducing resource use associated with terminal hospitalizations (Davis, Walsh, & Nelson, 2002; Rodriguez et al., 2007). Conversations about hospice discharge can therefore serve as a powerful rhetorical device not only to orient patients to the dying role, but also to cut through the seemingly Gordian knot created by increasingly interventionist practices and efficiently move patients who cannot go home along the institutional care pathway. As potential points of transition, however, these negotiations were at times fraught with clinicians' openly expressing ambivalence regarding the ethical and clinical implications to goals of care. While this ambivalence stemmed from prognostic uncertainty, it also emerged from an understanding that their emotional labour expertise is, at times, instrumentalized for institutional purposes of efficient transition through the care pathway rather than to a good death. While ideally these needs are coterminous, the examples presented in this dissertation highlight how this is not an automatic process but one that may require sustained emotional labour practices, and, at best, result in a good enough death. The requirement for rapid transition as the primary desired outcome of occupying the hospitalized dying role may then render visible—to all parties—how therapeutic relationships developed by palliative clinicians can operate as relations of disciplinary power as much as relations that facilitate patient and family member capacity. Yet as evidenced in the palliative consultant's interactions with Jake's attending clinician, relations of power within hospitalized palliative care shape the conduct of *all* involved in the provision and uptake of hospitalized palliative care (not just that of patients and families). As palliative care expands and increasingly interfaces with other specialties, these relations of power have increasing saliency to the ability of its practitioners to shape the purpose and outcomes of this form of care.

The Negotiation of the Dying Role within Hospital Settings

Individuals dying within hospital settings acknowledge a range of open, uncertain, and suspended awareness contexts (Glaser & Strauss, 1965, 1968; Timmermans, 1994). As exemplified in Jake's example, while some patients and families

may use open or uncertain awareness to invoke the *rights* that inhere in the dying role, awareness in and of itself does not automatically signify willingness to take on all the *responsibilities* of the dying role. In these instances, patients and families may be willing to acknowledge impending death, but only in combination with ongoing treatment within an acute care context. This may hold particular veracity for patients receiving consultant services but who are physically located in acute or sub-acute units, where the explicit goal of care is to stabilize patients by way of aggressive life-extending therapies. Many of the consult patients I observed, similar to Jake, did not want transfer to the palliative unit, expressing awareness that their current physical location signified the possibility for continued treatments and a continued, if fragile, hope of stabilization and discharge home. Ironically, given the advertising that the palliative unit is an appropriate location of care for those still pursuing life-extending treatment, this perspective was also evident in many of the patients and family members who were on the palliative unit in relation to a hospice discharge. For both of these sets of patients, while they were willing to take on some of the responsibilities of the dying role, this only occurred within a rights-based context of acute medicine that continued to value their identity and bodies as worthy of hospital resources and interventions. Transitioning to the palliative unit (or, if on the unit, to hospice) then medically signified a devaluation of status, and ongoing treatments were a source of hope, comfort, and validation even as they acknowledged death was (likely) approaching. The attempt to construct transfer to the palliative unit or hospice as a naturalized responsibility of the dying role may therefore be strenuously resisted regardless of care location in the hospital. Clinicians' sustained attempts to transition patients into the dying role through transfer in location of care may then amplify the patients' and their families' distress—the very thing that palliative care was designed to ameliorate.

Given that the care I observed occurred within hospitals focused on acute care interventions, palliative clinicians—and consultants in particular—may be fundamentally challenged in their emotional labour attempts to orient patients to the dying role. Due to the acute location of care, clinicians may increasingly turn to biological signifiers as the appropriate premise for their cultural work of orienting individuals to the dying role. Yet as seen in this research, patients and family members may appropriate these markers as the authoritative ground for the right to continued aggressive treatments to mitigate

these symptoms, even as they openly or uncertainly acknowledged end of life. Subsequently, while clinicians understand the imperative to transition patients quickly, unless they are willing to invoke the ultimate rule reminder—transfer or discharge against patient and/or family member wishes—they are often forced to wait until physical symptoms are so pronounced they can no longer be denied as the precursors to death. In these instances, the corporeal symptoms of deterioration may then become the dominant signifiers of the necessity of accepting the responsibilities of the dying role. This reality is stated by one clinician who acknowledged that:

With most families now I find they eventually come to that page [accepting the dying role], not because of the work we've done but because it's so blindly obvious when they see the family member just declining and deteriorating despite whatever we've done.

Similar to other studies of role acceptance at the end of life, my research suggests that the determining factor for many individuals in accepting the role in its entirety may be intimately connected to the geography of care within which this role is played out (Emanuel et al., 2007; Parker-Oliver, 1999; Prigerson, 1992). My observations also partially support the understanding that: “[U]ntil they begin to experience rapid physical deterioration, the response of individuals receiving palliative care to illness is remarkably similar to the experience of other ill individuals” (Olson, Morse, Smith, Mayan, & Hammond, 2000, p. 293).

Revisiting the Dying Role within an Affective Economy of Hospitalized Palliative Care

Some may challenge my assertion that contemporary hospital-based palliative clinicians use their emotional labour to orient patients and family members to a dying *role*, instead suggesting that their work ends once symptoms have been controlled and/or communication of prognosis has occurred. Indeed, I did observe instances where clinicians voiced their belief that a specific patient would “die the way they lived,” usually in reference to a particularly recalcitrant patient. I also recorded instances, similar to Jake’s, where a clinician strongly advocated the right of a patient and or her family member to refuse signifiers of the dying role, such as transfer to the palliative unit.

Additionally, as noted previously in this chapter, there were a few instances when I observed a trajectory of care where no emotional labour tactic was used to orient a patient or family member to an anticipated death. As evidenced in my review of professional literature, however, and in the observations and conversations I document here, clinicians continue to demonstrate an ongoing concern as to how to best facilitate open awareness as well as how to facilitate the patient's emotional expressions of, and actions reflecting, this awareness. The multiple examples detailed here evidence how this labour is a constitutive and daily practice in the trajectory work of hospital based palliative clinicians.

An affective economy framing informs existing research on the dying role in multiple ways. First, in reference to Ahmed (2004), Richard and Rudnycky (2009), and Buchbinder and Timmermans' (2014) work, I trace how the labour of palliative clinicians to publically order the emotional experiences of hospitalized dying by offering the dying role both reflects and constructs an affective economy of hospitalized palliative care. Second, I am able to conceptualize the practices and outcomes of this labour as governmental, where historically contingent framing and feeling rules work to generate a dying role that (ideally) results in a hybrid public performance and personal subject position that signifies not only awareness, but also *acceptance* of the impending (if temporally uncertain) death. Third, exploring the provision and uptake of the hospitalized dying role as a governmental practice within an affective economy allows me to examine the dying role as a technology for guiding conduct at the end of life, one which emerges from the intersection between technologies of power and technologies of the self. As a technology of power, offering the dying role enables clinicians' to govern both the conduct and the biological processes of their patients, and therefore order the temporally uncertain process that is contemporary hospitalized dying. Simultaneously, I am able to investigate how these emotional labour practices operate as technologies of the self, where patients and family members may use the meanings and emotional orientations that accrue to the role for self-governed understandings and orientations to the dying process. Finally, in focusing on clinicians' emotional labour practices, I articulate how they work to facilitate a good death through offering the dying role as a constitutive aspect to achieving the six ideal outcomes of care.

As an affective economy framing encourages exploration as to how emotional labour practices simultaneously produces those who enact it and those upon who it acts, my work further asks how clinicians' offering of the dying role shapes their own professional identity and orientations to the dying process and is therefore a practice within which *everyone* involved conducts themselves and others. Subsequently, as I address how the rights and responsibilities of the dying role are offered through specific techniques (such as educating patients and family members regarding potential outcome of care, rhetoric of quality of life and goals of care, reframing hope, invoking physical signifiers of decline, and hospice conversations), I suggest that this role is rarely cohesive, explicit, or fully enacted. How the dying role is constructed, who offers it, when and for what purpose, and, most importantly, how these moments are negotiated, are then understood as both reflecting and creating an affective economy of hospitalized palliative care that is continuously ambivalent and fluctuating.

Conclusion

The overarching goal of this research has been to explore how hospital-based palliative clinicians organize the dying process to facilitate a good death. Within an affective economy framework, primary attention was given to relational practices of knowledge and power that circulate and privilege clinicians' understandings of the emergent physical states of the patient, which are coterminous with clinicians' cultural authority to define the appropriate emotional orientations to these understandings. I delineated how this economy operates to order the affective experiences of dying (i.e., the diminished capacity to strive) through coproduction of emotional orientations that create individual meaning, provide collective social order in the face of loss and mortality, and increase the ability to govern the biological processes of dying for the population as a whole. I have proposed that both the practices and outcomes of this labour are governmental, where the historically contingent framing and feeling rules within the provision of hospitalized palliative care enable specific emotions that shape our capacity to enact, experience, and understand the dying process in specific ways. Subsequently, I recognize the "good death" within hospitalized palliative care not as a single physical act, but as the negotiated outcome of a series of social processes and relations which I have termed the dying process.

Collectively, my research supports existing findings that clinicians are privileged cultural experts who engage in death brokering by offering specific understandings to patients and family members regarding the good death within the context of hospitalized dying. At the same time, my work contributes three unique insights into the provision of end-of-life care within this setting. First, no one has yet conceptualized hospitalized palliative care as an affective economy. In doing so, the specific moments and networks of relations that constitute this form of care become understandable as a cultural system that attempts to make human capacities productive, even at the very end of life. Secondly, through this framework, I am able to forward an understanding of clinicians'

privileged position as one that often occurs within active and sustained negotiations, where emotional orientations to the dying process are generated, validated, and/or contested through the perceived rights and obligations of all involved parties. Third, this framing encourages an understanding of hospitalized palliative care in contemporary Canadian hospitals as necessarily fluid and ambivalent, defined as much by its practices of negotiation as by mutuality and cooperation.

In conjunction with these three contributions, the iteration of an affective economy used here also enables a distinction between affect and emotions. This distinction allows for a nuanced understanding of emotions as the describable experiences of affect, where the preconscious will to strive that generates the capacity to act (affect) is either increased or decreased through its expression (emotion) within culturally mediated relations with other bodies (the provision and uptake of hospitalized palliative care). This delineation between affect and emotions encouraged inquiry as to how an affective economy of hospitalized palliative care mediates the capacity of everyone involved, including clinicians themselves. Finally, using this framework required an examination of the “hidden” traces of palliative care’s history of production, where therapeutic relationships, total pain, the dying role are not inherent practices of this form of care, but have a history constituted within biomedical discourses and institutional processes for governing the biological processes of dying. An affective economy framing helped me articulate these understandings that have to date been underdeveloped in research on the social regulation of dying. It has also provided a middle path between scholars who focus on the disciplinary and/or repressive aspects of end-of-life care and those who focus on its emancipatory aspects. Through these contributions, I propose that conceptualizing the collective emotional labour of those providing, receiving, or otherwise involved in hospitalized palliative care as an affective economy may add to our knowledge of the dying process within these institutional settings. I also believe that this interdisciplinary understanding of an affective economy may be useful to those who, from diverse theoretical perspectives, are interested in exploring how emotions shape capacity in everyday contexts not specific to end of life.

Key Issues Informing Palliative Practice

My work has explored some of the complexities that constitute hospitalized palliative care provision *in situ* of daily practice. This included the evolution and mainstreaming of care, the rise of business modeling, and increased patient and family member involvement. I also articulated how the two dominant discourses that constitute the “truth” of hospitalized palliative care may be, depending on context, contradictory both in and of themselves and contrasted against each other. Rather than attempting to reconcile these practices and narratives, my goal has been to highlight that these tensions, disjunctures, and contradictions constitute the practices of hospitalized palliative care, as much as the desired outcome of facilitating a seamless good death.

Through this attention to the complexities of the lived experiences of practitioners, my hope is that my work informs understandings of hospitalized palliative for practitioners themselves, as well as for future researchers and theorists. While my research adds to the small body of work that explores the daily practice lives of hospital-based palliative clinicians generally, my focus on rendering visible their “indeterminate” emotional labour may in particular sensitize clinicians’ understandings of how they necessarily practice within the confluence of multiple, and at times competing, interests (including their own). Non-palliative clinicians may find my research useful to understand how institutional practices, such as their own reticence to address end-of-life issues with patients and family members, shape contemporary dying in hospitals. As palliative care continues to expand and interface with more acute life-extending specialties, this awareness may be particularly useful to all hospital clinicians’ appreciation of the emotional labour expended by palliative specialists, particularly in regards to the labour required to successfully negotiate the ethics and etiquette of consults. My work also serves to inform current and future palliative practitioners’ thoughts about the complexities in negotiating the dying process with patient populations receiving new forms of clinical treatments and/or who are considered “appropriate” for the amorphous “palliative approach.”

While my work has addressed a range of concerns within the contemporary provision of hospitalized palliative care, due to the strictures and proclivities of my own thought, as well as the nature of a dissertation format, there are underdeveloped aspects

of my work which necessarily remain open for further investigation for those researchers interested in using an affective economy perspective to understand these practices of care. In particular, I did not grapple with concerns of gender, ethno-cultural diversity, or the importance of life experiences outside of the hospital. Future thought as to the gendered nature of palliative care provision within an affective system framing may provide significant insights into the complex relations between cultural constructions of femininity, institutionalized care of the dying, and the public orchestration of emotions. In relation to ethno-cultural diversity, how individuals understand and enact the dying process is significantly impacted by their heritage. While my research included patients and family members who identified as South or East Asian, given my focus on clinicians' practices, I did not delve into any discussion of the differences I did or did not observe in the provision and uptake of care for these individuals. How immigrants and those of later generations who continue to identify with non-Western European cultural practices negotiate hospital-based palliative services to coauthor a good death remains an important area of further exploration. This need for further study regarding the significance of life experiences before hospital admission also holds true more generally for all patients and family, in particular in considering how these experiences may shape their capacity to claim narrative authority.

Research Ethics in Hospitalized Palliative Care

One of the most difficult aspects of this research was the continual ethical negotiations I faced working with participants very near to their time of death. While I never had a patient or family member ask that I leave the room at any point in my research, there were times, as I spoke to earlier, where I chose not to observe interactions based on uncertainties related to communicating consent, family dynamics, and/or symptom burden. I would have benefitted greatly from knowing how other researchers negotiated these moments, but I could find no published accounts. This gap in the methodological literature is a serious one. While researching with palliative populations does not *automatically* create unique ethical challenges, the belief that it does is often used to buttress the reticence of ethics boards to approve research with this population. I suggest that this reservation is also reflective of a broader cultural reticence to value those at the end of life. When the dying are unreflexively held apart from the rest of us, it evidences the poverty in our culture as it continues to marginalize

the dying under the guise of protection. Given this unease, many researchers are understandably hesitant to discuss the ethical challenges they may encounter in the field when doing work that includes the biological “margins” between life and death. For those such as myself who do research that engenders affective ties encompassing the very end stages of the dying process, we can only benefit from publically contributing our (and hearing others’) experiences about the ethical complexities in these mutually intense and vulnerable contexts.

I strongly advocate for the need of further discussion and reflection around the ethics of ethnographic research at the very end of life, not necessarily to resolve these issues, but rather as a way of generating a diversity of understandings and approaches to inform this work. As I noted earlier, institutional culture is not something that we as researchers study from the “outside” as we are immediately and continuously affected by the same environment as our participants. The need to foster our capacity to sit with, and publically grapple with, ethical uncertainties and situational ambivalences in working with the hospitalized dying highlights the fact that researchers working with these populations have moral responsibilities equal (if significantly different) to those providing care. Finally, I believe that future qualitative research in hospital-based palliative care will greatly benefit from diverse participants’ willingness to explore how the ethical review and informed consent processes shape the ability to discuss examples of serious and sustained disagreement and/or ethical conflicts between practitioners providing care. While I acknowledge the need for caution and deliberation in publically examining these moments, when amorphous but ever-present litigation concerns of an institution trump clinicians’ desires to open their practice to critical reflection in order to benefit both themselves and for those they care, researchers are effectively silenced.

Hospital Palliative Care in the era of Physician-Assisted Suicide

I cannot finish without a nod to recent developments regarding the discursive shift in public discourse on death and dying. In the last few years, concerns about how we die have been at the centre of numerous social debates and political initiatives, culminating in the recent unanimous decision by the Supreme Court of Canada to allow

physician-assisted suicide.⁶¹ This ruling enshrines Canadians' constitutional right to end one's own life in contexts of "a grievous and irremediable condition (including an illness, disease or disability)" (*Carter vs. Canada*, para. 4, 2015). For proponents of the right-to-die movement, this victory will result in honouring people's dignity and autonomy at the end of life. For most palliative care advocates, the counter-assertion centres on the lack of specialist services as the primary challenge to autonomy and capacity for those at end of life. Yet in the midst of these duelling discourses about the ideal death, both proponents and detractors of this decision invoke the same dominant framing rule for their arguments—the primacy of autonomy. As my work has shown, this championing of autonomy at the end of life creates a complex moral and medical terrain that is increasingly challenging for everyone, including palliative clinicians, to negotiate successfully.

While physician-assisted suicide may face further challenges before becoming law, the "right" to a speedy and efficient death will become a reality in Canada sooner than later. This raises interesting questions for future researchers interested in end-of-life care. Within the current affective economy of hospitalized palliative care, while timing an efficient and painless death functions as a core purpose, it is not the *only* purpose of clinicians' emotional labour. What will be the primary functions of this economy, and the cultural authority of its practitioners, when patients can pursue curative and life-extending therapies until they "choose" death without the messiness and complexities of the dying process? How will physician-assisted suicide shape the speciality of palliative care in an era where the dying process becomes "optional"? At least in the short term, perhaps not very much. Looking at other countries where physician-assisted suicide is legal (such as Switzerland, Germany, Japan, and several U.S. states), utilization rates remain very low.⁶² Such statistics indicate that having this choice will not necessarily "threaten" conventional forms of end-of-life care, including palliative care. It may even

⁶¹ This ruling proceeds Quebec's passing of Bill 52 (June 2014) legalizing medically assisted death in Quebec for terminally ill patients with "unbearable suffering."

⁶² In Oregon, for example, where physician-assisted suicide has been legal since 1997, there have been a total of 752 deaths attributed to this method (Oregon Public Health Division, 2014).

have the opposite effect, where increased interest and knowledge about end-of-life options make people more amenable to palliative services as they retain ultimate authority and control over their deaths. Alternatively, hospitalized palliative care practices may eventually become obsolete or increasingly polarized, primarily focused on life-extending treatments or withdrawal of treatment. Researchers also need to start asking questions about what legalizing physician-assisted suicide means to the larger culture within which hospitalized palliative care is situated. For better or worse, relations of dependency bind us together through our shared vulnerability. Will these relations at the end of life become reframed primarily through the spectre of “consumer choice” that circumnavigates the need to be vulnerable? Will autonomy at end of life become synonymous with capacity to end our lives? In turn, how will these changes inform future iterations of the discourse of autonomy within palliative care? While pondering further on these questions lie outside of this research, I look forward to participating in, and hearing about, future work in this area.

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It has been many years now since my sister and brother died, and many years as well since I began this project. I am conscious that this work has been a significant component of my grieving; part of my own emotional labour practice by which I continuously searched for narratives to give meaning to my experiences of death and dying (albeit within an academic framework). In so doing, it was perhaps unavoidable that I was drawn to exploring how others—in particular, palliative clinicians—also grapple with similar challenges within their own professional framework. Sharing this understanding then explicitly locates me within the very processes under examination, those by which we as a culture, and as individuals within that culture, negotiate understandings of a good death. Like any scholar, I am certain to return to these thoughts in years to come with different eyes that see different things. In the meantime, I have laboured to provide an understanding of hospitalized palliative care that others may find “good to think with” as they too grapple with their own personal challenges and professional interests as to how we currently organize the dying process within these institutional settings.

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Appendix A

Illness Trajectories and Palliative Care (Murray, Kendall, Boyd, & Sheikh, 2005)

