An Emergent Form of Life: Advanced Cancer Patients’ Active Search for Life-Extension through Treatment

by

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Lawrence S. Bloomberg Faculty of Nursing
University of Toronto

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Abstract

Despite the risks of side effects or the lack of prognostic benefits, patients with advanced cancer sometimes search for biomedical treatments intended to extend life. The current literature suggests that these individuals may be in denial of their poor prognosis or passively reliant on healthcare providers for such treatments. Drawing on a Foucauldian theoretical framework, this study generated a deeper understanding of how individuals might actively generate their own therapeutic possibilities. The purpose of this study was to examine the types of discourses that constitute the search for life-extension. The second purpose was to characterize the types of subjectivities that are produced by these discourses. Using case study as a methodological approach, seven cases were collected that included 20 semi-structured interviews (with patients, family, a natural healer, nurses, and physicians), 30 documents, and observations. Four major discourses were in operation: (1) Biomedicine, (2) Self-Care, (3) Palliative Care, and (4) Self-Healing. Eight types of subjectivities were identified: (1) The Cancer Expert, (2) The Proactive, (3) The Productive, (4) The Mistrusting, (5) The Model Patient, (6) The Positive Thinking, (7) The Suffering, and (8) The Challenged Clinician. Produced by the tensions between discourses and the incompatibility between subjectivities, this study characterized an emergent “form of life” that was governed by the difficult task of prolonging life despite having an incurable
disease. Participants described much suffering as a result of this elusive pursuit. More than procuring treatment, the search for life-extension became an aesthetical process of shaping the self in order to become robust subjects that survive cancer. Relying on their own curative capacities, this emerging category of the chronically dying often challenged the traditional arrangements of bio-scientific knowledge and curative treatment practices. Generating social tensions in the clinical setting, participants exercised power/knowledge relationships with healthcare providers in increasingly assertive ways.
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This thesis is dedicated to the memory of my mother Adele Sotomayor Mohammed.
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Prologue

Like many others, cancer has marked my life since childhood. When I was three years old, my mother was diagnosed with an invasive form of metastatic breast cancer that had quickly spread to her bones and liver. The news was devastating; she had immigrated to Canada a few years prior, was recently married, in her mid-thirties, and had an emerging career as a mental health nurse. Despite radiation, chemotherapy, and a mastectomy of her breast, her disease became increasingly worse, as is sometimes the case in younger woman afflicted with breast cancer. Although she never lost her hair, she endured much physical and emotional suffering as a result of the extensive side effects of treatment. After several unsuccessful attempts to slow down the progression of the disease, she gradually tapered off her search for conventional biomedical treatment. Returning home from the hospital, she reshaped her therapeutic approach to her cancer by using alternative therapies such as meditation, yoga, and macrobiotic cookery. Despite her efforts to slow down her cancer even towards the later stages of disease, she died when I was four years old. In many ways, her illness, search for life-extension, and death have shaped by interest to pursue this study.

My complicated relationship with the treatment of advanced cancer continued into my clinical work with patients enduring haematological diseases (for example, leukemia and lymphoma). When I reflect on my eight-year career as a bedside nurse, two significant clinical scenarios come to mind that highlight some of the tensions related to this issue. In the first example, I remember caring for a man in his late-thirties with a haematological cancer who had several young children. The medical team had given him one round of induction chemotherapy (the first-line attempt to eradicate the disease with harsh cytotoxic drugs), which had proved unsuccessful in slowing his cancer. Oncologists offered him the opportunity to receive a second round of induction therapy, which caused him and his wife to seriously contemplate what to do about the treatment. After about a week of deliberation and many informal discussions with nurses, they decided to relinquish his search for curative treatment and instead receive palliative and supportive care. Given the seriousness of his cancer sub-type and the adverse effects of his first round of treatment, the medical team accepted his decision. Although he and his wife never fully disclosed their rationale, I initially viewed his decision to stop the search for life-extension as an open and brave acknowledgement of his dying. Because he was able to spend his last few weeks
playing with his children, as opposed to feeling incapacitated from chemo-related nausea and fatigue that burdened my other patients, I felt that his dying was somehow given a purpose. By choosing a non-invasive route, I applauded him for “going quietly” and cultivating what I considered to be a dignified death. He had died peacefully with his family around him very early one morning. At the same time, when I briefly spoke to his wife the following week, she had hinted at some feelings of regret. Even after the peacefulness of her husbands’ death, she wondered if perhaps they should have tried the additional round of chemotherapy, just to be sure that they had exhausted every therapeutic option possible. I tried to reassure her about her decision, but our short discussion had seeded a slight but yet uncomfortable sense that perhaps they relinquished the search for biomedical treatment a bit too early.

The other memorable clinical example was a 75-year-old woman who had been recently diagnosed with another type of advanced cancer who was admitted to the haematology unit to be treated with curative chemotherapy. Upon admission this woman was somewhat weak, but began to deteriorate rapidly after receiving induction treatment. I remember caring for her during a night shift where her room was at the opposite end of the nurses’ station. Wanting someone to be close to her, she continually pressed the call bell because she was frightened and wanted some reassurance that her chemotherapy was properly infusing through her intravenous line. Unlike the man in his late-thirties, caring for this woman made me feel highly anxious, in part because of my sense that she could not accept the possibilities of her own death. I also felt guilty that I had to participate in this situation by actually giving her the chemotherapy at the bedside. As opposed to suffering from the many treatment side effects, I wished that she could have spent her last few days in peace. After she lapsed into a coma, her son and daughter grew disappointed with the care received by the healthcare team and demanded they try a new form of chemotherapy. During a tense family meeting regarding the intent of treatment, her son defiantly declared that his mother was a brave and strong woman and would survive both this hospital and this disease. This claim unsettled the nursing and medical staff; this family was labelled demanding and unreasonable by the staff.

This woman began to exhibit end stage physiological manifestations of dying. Despite family consultations with oncologists, nurse manager, and the social worker, her induction chemotherapy continued to infuse. One early morning her breathing stopped and the healthcare team was forced to run cardiopulmonary resuscitation oh her. Surviving the procedure with
several broken ribs from compressions, she was moved to an intensive care unit. She died two
weeks later. Although I was morally troubled about how this situation unfolded, the family felt
differently. Despite their initial anger, this woman’s adult children came back to the unit to thank
the healthcare team for allowing their mother the opportunity to “fight” her cancer. One of the
children mentioned that her mother “died in the same way she lived.” They were grateful for the
extra time with their mother in the intense care unit, although she could not speak because she
was intubated. They also felt proud that their mother was willing to endure all attempts at
survival, demonstrating her strength and resilience.

These two clinical examples highlight some of the tensions involved in the search for life-
extension that persuaded me to study this phenomenon. On one hand, patients and family may be
doubtful if they did not undertake the search for treatment aggressively enough. On the other
hand, the healthcare team sometimes penalized patients and families if they pushed for
treatments too assertively, yet still participated in its provision by prescribing and administering
often invasive forms of treatment, albeit with certain hesitations. In both clinical examples, I
wanted to know more about the perceptions of patients at the centre of care, but my role as a
clinician in each scenario limited my abilities to engage in a deeper exploration. I became both
fascinated and troubled by these individuals’ intense drive to locate biomedical treatment that
may or may not lead to life-extension, but would certainly lead to certain physical and emotional
side effects. This study was also driven by my sense that individuals are often under immense
pressure to locate a cure for a disease that is largely incurable. Undertaking this research has lead
to a cathartic exploration of my own anxieties, discomforts, and assumptions around death and
advance cancer. Although the process has been challenging in an intellectual and emotional
sense, it has also been very meaningful to me.
Chapter 1
Introduction

In the introduction to this thesis, I first map out some of the current discursive contexts that surround the research topic, the search for life-extension in advanced cancer. I then outline the research questions used in this study. Next, I provide operational definitions of key terms used in this thesis, such as advanced cancer. To conclude this chapter, I provide a summary of the upcoming chapters in order to better orient the reader about what is to follow in this thesis.

1 Situating this Study within a Discursive Context:
Advanced Cancer in the 21st Century

In this section, I situate individuals’ search for life-extension from advanced cancer within wider historical, political, social, and biomedical contexts. The contexts I discuss include the growing chronicity of advanced cancer, palliative care as an integrated approach, the rise of current social discourses about health, and the emphasis on promoting personal control for the dying.

Cancer has an extensive historical background that may influence how it is viewed culturally today. The word *karkinos* (from the Greek word for “crab”) first appeared in scholarly descriptions to denote cancer around 400 BC during the time of Hippocrates, an ancient Greek physician (Mukherjee, 2010). Hippocrates used the visual metaphor of a crab to denote the appearance of a tumour and its swollen blood vessels. The word *onkos* imagined cancer as a mysterious disease that greatly burdened the body and almost always was deadly in nature (Mukherjee). In her well-rendowned work on illness as metaphor, Susan Sontag (1989) mapped out the long standing historical associations between cancer and death, which took prominence in the 19th century, but is still played out today in culturally endorsed crusades against cancer as a deadly enemy. Sontag goes on to suggest that not only does the construction of cancer as a “ruthless, secret invasion” (p. 5) have a metaphorical relationship with death, but the disease itself is sometimes viewed as obscene and “repugnant to the senses”. (p. 9). As the paradigmatic disease of the 20th century, until it was replaced by the appearance of AIDS (Sontag), cancer was often associated with different forms of cultural stigma that continue today. In a renowned
example, Sontag observed that obituaries would often use the euphemism, “died after a long illness” (p. 14), rather than name cancer in order to diminish a sense of shame.

Despite these powerful historical metaphors, having certain forms of cancer may no longer represent an automatic death sentence. The 20th century was marked by the increased ability of biomedicine to treat previously untreatable diseases. Following the heavy US government investment in scientific research during the early 1950s, which was spawned by the economic boom following World War II, chemotherapy arose as an effective anti-cancer treatment first against childhood leukaemia and then other forms of cancer (Cantor, 2007). Richard Nixon signed the National Cancer Act in 1971, which marked a significant increase in the vigour and magnitude of North American cancer research (Mukherjee, 2010). By the end of the 20th century highly calculated combinations of surgery, radiotherapy, and chemotherapy would become the standard therapies (Pickstone, 2007). Later developments in genomic medicine, immunological treatments, and anti-cancer vaccines also intensified a widespread optimism about the curative potential of oncological medicine. Although these therapies could ultimately not cure or reverse the progression of certain metastatic forms of the disease, the cultural perception of cancer as an acute illness that brought about certain death gradually shifted towards a chronic illness that one could potentially survive (Seale, 2000; Sontag, 1989; Phillips & Currow, 2010).

As the face of the dying changed from those who died suddenly to a longer and slower progression to death (Zimmermann, 2004; Seale, 2000), the conditions for palliative and other end of life care practices were drawn. Palliative medicine became a recognized medical speciality of the UK Royal College of Physicians in 1987, legitimising it as a formal medical practice (Hibbert et al., 2003). When cardiopulmonary resuscitation and intensive care measures like mechanical ventilation became standard hospital procedures, palliative care sought to problematize the growing technologization of the dying body (Peerson, 1995). By bringing the suffering experience for those near the end of life to the forefront, palliative care sought to renegotiate biomedicine’s ethically ambiguous role in prolonging the dying process through medical intervention (Lock, 2000). As opposed to aggressive medical treatments that delay death at the expense of physical suffering, palliative care emphasized comfort and respect for the personhood of individuals. Challenging the traditional binary model of disease-treatment, this form of medical care emphasised the enhancing quality of life, optimising physical and
emotional function, helping with treatment decision-making, and providing opportunities for personal growth in the preparation for death (Pastrana et al., 2008).

Palliative care has gone through several important transitions since the start of the 21st century, which has ultimately resulted in even longer survival periods for those with advanced disease. In 2000, a national report from the Canadian Senate asserted that every Canadian was entitled to “die in relative comfort, as free as possible from physical, emotional, psychological, and spiritual distress with access to skilled, compassionate, and respectful care” (Williams et al., 2010 p. 148). The Senate recommendations also called for increased educational resources for healthcare providers, more effective integration of palliative services, and improved economic investment in this end of life care (Williams et al.). At the time of the report, only five percent of Canadians with terminal illness were receiving specialist palliative care services (Chochinov, 2001). Over the last fifteen years, palliative care services have expanded their status and scope in acute care settings, often taking the form of specialist interdisciplinary teams that are integrated into other healthcare services (Yang, Ewing, & Booth, 2011).

In the American context, the number of palliative care programs within hospital settings has grown from 600 in the year 2000 to more than 1500 in 2010, an increase of approximately 138 percent (Centre to Advance Palliative Care, 2010). Using sophisticated technologies such as diagnostic imaging, palliative radiotherapy, and lower-dose chemotherapy, palliative care teams are not only involved in the psychosocial mediation of dying, but also the intricate biomedical management of disease-related physical symptoms (Yang et al., 2011). Specialist palliative care also began to be integrated across the entire spectrum of care: discharge planning, inpatient consultations for those near death, and outpatient clinics for individuals with serious forms of illness but who are not actively dying (Yang et al.). As a result of this expansion, receiving high quality palliative care is increasingly viewed in the health science literature as a vital component to both extending the longevity of those with advanced cancer (Temel et al., 2010) and improving their quality of life (Meyers et al., 2011; Bakitas et al., 2009). At the same time, other scholars have suggested that more research needs to be conducted to determine the specific benefits and social implications of specialized palliative care for those with terminal illness (Zimmermann et al., 2008).
Establishing an important backdrop to this study, the structuring of oncological care for those with advanced cancer is currently in a state of reorganization, particular around the goals of treatment and the trajectory of cancer. In the traditional course of disease, one might first attempt curative oncological treatments, and then in the event the cancer does not respond to the treatment, transition to palliative care in preparation for death. A recent shift in the model of care, there is currently a move towards the early integration of palliative care into traditional oncological treatments that are intended to eradicate disease from the body (Smith et al., 2012; Hauser at al., 2011; Gaertner, et al., 2011; Bruera & Hui, 2010). As a result of this transition, more individuals with metastatic disease than ever are concurrently receiving invasive oncological treatments along side supportive palliative interventions. The social implications of concurrently receiving these seemingly oppositional approaches to care remain under researched, but yet form an important research topic.

Unlike ten years ago, individuals with advanced cancer are living longer with the persistent threat of dying, which is a reflection of the present state of oncological medicine (Canadian Cancer Society [CCS], 2013; American Cancer Society [ACS], 2013; Lage & Crombet, 2011; Ferris et al., 2009). Between 2001 and 2008, the overall rates of mortality declined by 1.9 per year for males and by 1.2 percent for females (CCS). Whereas mortality rates for certain cancers like liver have increased between 2000 and 2009, mortality rates have declined by at least two percent on average in certain common cancers such as prostate, breast, colorectal, non-Hodgkin’s lymphoma, and stomach (CCS). These individuals now comprise a new category of the chronically dying; patients who require long-term and complex medical management because of severe disease (Lage & Crombert), but live at home and participate in everyday social life. Despite the advancement in longevity, individuals still continue to die from cancer. According to recent epidemiological data, one in every four Canadians with cancer will die from the disease (CCS). Cancer is the leading cause of premature death in Canada and represents over 32 percent of years of life lost prematurely (CCS). Although it varies by type of cancer, approximately 37 percent of individuals are expected to die within five years after being diagnosed (CCS).

Paradoxically, the advancement of the biomedical science has created a climate of anxiety regarding life-threatening illnesses, reinforcing unrealistic expectations of cure that make untreatable and unavoidable diseases seem incomprehensible (Barsky, 1988). Encouraging a
view that death is an illegitimate disturbance to the normal disease-free existence that everyone has a right to expect, medical treatment thus involves a contemporary “anaesthetic solution to suffering” (Seale, 2000, p. 927). Death is then transformed from a fixed physiological reality and human inevitability into a medically contingent event, leading to much disillusionment when the progression of advanced cancer exposes the possibility of dying (Barsky). Ironically, despite the rise of palliative care within the mainstream cancer care system, the cultural preoccupation with curing advanced cancer may be more potent than ever. Forming an intriguing area of inquiry, the present search for life-extension may also transverse into unforeseen possibilities that lie beyond the scope of biomedicine.

A prominent poststructural scholar, Rose (2007) examined the rise of “biological citizenship” (p. 131) in the late 20\textsuperscript{th} century to describe how individuals increasingly define their citizenship in terms of their rights and obligations to life, health, and cure. Through different collective patient movements, individuals sought to gain better lay access to biomedical knowledge, end stigma, gain access to services, and develop a sense of their rights as patients (Rabinow & Rose, 2006; Rose, 2007). Some of these movements resist medical authority, whereas others operate in a manner that remains open to established biomedical knowledge and expertise (Rose). The rise of the cancer survivorship movement, particularly in high profile case of women with breast cancer (Kaiser, 2008), is a powerful example of patients’ collective political mobilization and an articulation of patients’ right to more effective cancer treatments that may extend life.

The demand for better cancer treatment has not only shaped collective social movements, but also has moulded the individual health practices of patients and family members at a more local level, which is a focus of this study. Because of the assumption that individuals may play a role in the causation of their cancer (Sontag, 1989; Willig, 2011), there may be a hidden, but still potent, cultural requirement that individuals should actively participate in the search for life-extension. At the same time, individuals are bound by their physical vulnerabilities, expectations to adopt a sick role (Frank, 2013), and the traditional parameters of what it means to be a “good” patient in an increasingly constrained healthcare system. The opposition between locating a cure and being severely ill may lead to certain social tensions for those who search for life-extension in advanced disease. Facilitated by the current discourses of active citizenship, this contemporary form of a patient may move away from being a passive recipient of biomedicine towards an
active consumer with the capacity for rational health choices (Moore, 2004; Rose, 2007). Increasingly, individuals in the present arrangement of health actively choose and consume biomedicine, pharmaceuticals, alternative medicine, and self-psychology in order to maximize and enhance the vitality of life (Rose). Immersed in neoliberalism, this contemporary self acts in a calculated manner in order to engage in a project of self-improvement (Lupton, 1997). Rose (2007) notes that in this bio-political climate, health is understood as an imperative for the self to “maximize the vital forces and potentialities of the living body” (p. 23). How patients with metastatic and debilitating cancers, often considered by many to the most ill and vulnerable in society, maximize their health potential through the search for treatment will be examined in this study.

The fluid renegotiation of traditional power relations between physicians and patients at this point in time also frames this study. Much of the current scholarship on this transition has focused on the shift towards the physician-patient “encounter” away from the physician-patient “relationship” in the Western world (Potter & McKinlay, 2005). Leading to the loss of social status for physicians at the beginning of the 21st century, healthcare is increasingly viewed as a financial commodity that is susceptible to the pressures of corporatization (Potter & McKinlay; Lupton, 1997). In exchange for a consumerist framing of the clinical encounter (Potter & McKinlay), the paternalistic approach of physicians becomes more open to critique from patients, thus opening up the possibilities for the mistrust and reshaping of traditional roles in the system. Similar to purchasing goods in a retail store, interactions with physicians now serve as a commercialized space where patients act as savvy consumers, consider different health options, feel entitled to have every option presented to them, and eventually “purchase” biomedical treatments (Potter & McKinlay; Lupton).

The search for life-extension despite advanced cancer is also presently located within the increased insistence by those with terminally ill disease to retain control over the dying process. Although the rhetoric of patient autonomy has already shaped numerous clinical practices (for example, patient-centred care), the treatment of the dying is increasingly moulded by the centrality of individuality and personal control as central ethical principles of healthcare (McNamara, 2004). Facilitated by patient advocacy groups, the recent emergence of the controversial euthanasia debate in Quebec exemplifies the new social emphasis on obtaining the
perspectives of those at end of life around the self-mediation of the dying process (Assemblee Nationale Quebec, 2010). Although the push for life-extension through biomedical treatment and the move to assist someone to end their life are different clinical issues, both highlight the importance of understanding the prolonged period of dying, the need to acknowledge contemporary forms of suffering at the end of life, and the willingness of the terminally ill to participate in the politics of health.

2 Research Questions

This study is guided by two research questions. The first research question is:

- How do discourses constitute the search for life-extension through biomedical treatments for those with advanced cancer?

Building on this first question, the second research question is:

- What kinds of subjectivities are produced by the discourses in operation when individuals with advanced cancer seek life-extension through biomedical treatments?

In this study, I critically explore the discourses in operation that constitute the search for life-extension in advanced cancer and I also examine the subjectivities that result from these discourses. Drawing upon Foucault’s (1972) concept of discourses as a set of principles that leads to the formation of knowledge, I contemplate how the search for life-extension is not necessarily determined by a single unified body such as biomedicine, but rather is presently formed by the complex interrelation of numerous discourses in fractured, uneven, and occasionally antagonistic ways. As discourses exist as practices that constitute the objects of which they speak (Foucault, 1972), I also interrogate how discourses shape the thoughts, actions, and conduct of patients, family members, and healthcare providers. By situating different social actors within these discourses, I also consider the process of subjectification or how one becomes a subject (Foucault 1976). As the uniformity of any single subject is contested in poststructuralism (for example, the uninformed subject), this study generates a deeper understanding of how contemporary subjectivities are shaped by the pursuit of life-extension.
Since there is a long-standing tradition between poststructural thought and the examination of cases (Flyvberg, 2006), this study is guided by case study as a methodological approach (Creswell, 2009; Yin, 2009). Case study is the most fitting approach because it facilitated an investigation of the study phenomenon within its numerous real-life social circumstances and contextual influences, (Yin; Stake, 1995; 2009). Cases included interviews with patients, family members, a natural healer, and healthcare providers, the analysis of documents, and observations in the research field. To analyse the case data, I employ Foucauldian discourse analysis (Hook, 2001; Yates & Hiles, 2010) as a way to not only describe forms of knowledge, but also to describe the conditions of possibility that permit certain discourses to exist (Foucault, 1972). My analytical focus then turns to a concern with how participants become subjects (the process of subjectification) through the crystallization of multiple discourses (Mansfield, 2000; Yates & Hiles).

3 Key Definitions

3.1 Advanced Cancer

Cancer is known as a disease of “aberrant” cellular growth: cells undergo an anomalous transformation that leads to their unregulated reproduction, altered metabolism, and increased ability to travel and grow in the body (Yarbro, Goodman, & Frogge, 2005). Leading to pain, loss of organ and tissue function, the monopolization of physiological processes, and sometimes death, the metastases of cancer involves the spreading of cancer cells to previously unaffected areas of the body (Yarbro et al.). Generally unresponsive to treatment, invasive, recurrent, or highly metastatic, cancers that have a poor prognosis have multiple synonyms: late stage, incurable, progressive, or advanced cancer (Yarbro et al.). Depending on co-morbidity, age, cancer type, the extent of metastases, and other prognostic factors, some individuals with advanced cancer may survive their disease for an extended period and are not necessarily near death imminently (CCS, 2013; ACS, 2013). Other individuals, with a different set of disease related factors, may be very near near death.
3.2 The Biomedical Treatment of Cancer

The principle means for treating cancer (i.e. surgery, chemotherapy, radiation, and hormonal therapy) are frequently effective in slowing tumour progression, reducing pain and discomfort, and in certain cases, extending life or even promoting long-term remission (Lipscomb, Gotay, & Synder, 2007). In cases where the cancer has not previously responded well to treatment, the provision of additional biomedical treatment intended to eradicate cancer is a controversial clinical issue. On one hand, receiving these types of treatments may present an opportunity to extend life. On the other hand, there are harmful effects with receiving these kinds of treatments such as toxicity, physical and emotional pain, and hastened death (Lipscomb et al., 2007; Weeks et al., 1998). Treatments like chemotherapy, also known as cytotoxic agents, focus on eliminating cancerous cells, but often simultaneously destroy healthy cells in the process. The suitability of treatments in advanced disease likely depends on numerous case related factors such as the length of diagnosis, progression of metastases, age, comorbidity, and previous types of treatments.

Sometimes treatment is not necessarily being offered by physicians as a “cure” for advanced cancer, but is an attempt to control the disease, slow the progression, prevent further metastasises, and improve symptoms (Chow et al., 2001; Helsing, Bergman, Thaning, & Hero, 1998; Thongprasert, Sanguanmitra, Juthapan, & Clinch, 1998). For example, palliative radiotherapy is offered not necessarily to eradicate advanced brain tumours, but to alleviate symptoms like headaches and pain (Perez, Brady, & Halperin, 2008). Although certain forms of palliative treatment may in fact lead to life-extension (Temel et al., 2010), it is typically less invasive and dosed lower than aggressive therapies. Sometimes categorized as aggressive care or treatments with “curative” purposes, more invasive forms of cancer treatment (for example, induction chemotherapy) are normally administered at a higher and potentially toxic dosages than treatments prescribed by physicians to alleviate symptoms. By attempting to produce the remission of cancer or the elimination of cancerous cells, one of the goals of curative treatments is to generate life-extension.
4 The Description of the Chapters

In this section, I briefly describe the upcoming chapters that form the body of this thesis. Chapter Two situates the aims of this study within previous research that has examined the factors that lead to the search for life-extension. Chapter Three outlines the theoretical framework, the work of Michel Foucault and poststructuralism, in particular, exploring the concepts of discourse, subjectivity, care of the self, and neoliberalism. Chapter Four describes the methodological approach of this study, qualitative case study, and describes how Foucauldian discourse analysis is used as an analytical framework. Answering the first research question, Chapter Five presents the results of the data analysis by mapping out the discourses in operation around the search for life-extension. Examining the second research question, Chapter Six characterizes different the subjectivities that are shaped by these numerous discourses. Chapter Seven discusses the study results and places the findings within a poststructural and wider scholarly perspective. Concluding this thesis, Chapter Eight considers the important clinical and scholarly contributions of this study and draws some overall assertions about seeking life-extension in the 21st century for people with life threatening cancer.
Chapter 2
Literature Review

5 Introduction to Chapter

In this chapter, I situate the aims of this study within the body of empirical literature that has previously researched the search for life-extension in advanced cancer. By both critically reviewing and appraising the literature through a poststructural framework, I also draw attention to some of the assumptions that underlie the current research in this area. Whenever possible, I draw on empirical studies that utilized a poststructural theoretical framework. As this literature review will highlight, few studies have examined the search for life-extension through biomedical treatment and even fewer have utilized a poststructural perspective. This chapter is divided into six main sections:

1. I first describe the epidemiological research on the prevalence and contributing factors to the provision of curative biomedical treatment late in the disease trajectory.

2. Next, I review the studies that have examined the clinical contexts that surround the search for life-extension. In particular, I consider how this issue is often problematized by the health science literature as “aggressive” and/or “futile” care. I also review studies that have considered the cultural role of biomedical science in the treatment of incurable disease, as well as the emergence of complementary and alternative medicine.

3. In the third section, I review the mostly biomedical studies that have examined the kinds of rationales cancer patients might employ to drive their pursuit for life-extension. I categorize this literature into three groups: (1) The first group of studies suggests that cancer patients are often willing to receive more invasive forms of cancer therapy in exchange for relatively small gains in the length of survival. (2) The second group suggests that individuals with advanced cancer often overestimate the curative potential of medical treatments that they are receiving. (3) The third group of studies suggests that individuals who seek life-extension may not fully comprehend the possibilities of dying from their disease.
4. I then move on from reviewing patients’ understanding of disease prognosis and treatment, to consider the emotional or psychosocial factors that may influence the search for treatment. In particular, I review studies on the meaning of illness, end of life transitions, the hope for survival, patients’ needs beyond cancer treatment, suffering, and positive thinking.

5. In the fifth section, I explore some of the relational factors that may lead to the search for treatment. After considering the relational dynamics between individuals with cancer and their family members, I then consider the studies that examine the social tensions between patients and healthcare providers that are generated by the negotiation of treatment. In particular, I examine the literature on the trust and mistrust of physicians.

6. To conclude this chapter, I discuss the overall results of this literature review and place these broader findings within the empirical and theoretical concerns of this study.

6 Search Strategies for the Literature

To identify relevant articles, I systematically searched 11 electronic databases, using the date parameters of 1990 to 2010. I performed this search from January 2010 to June 2010. The databases were: CINAHL, MEDLINE, Pubmed, EMBASE, Web of Science, PsychINFO, The Cochrane Library, Health STAR, Scholars Portal, Sociological Abstracts, and Google Scholar. Moving from general to specific terms, I utilized the following key words in my search (in various combinations): cancer, advanced cancer, metastatic cancer, incurable cancer, treatment, patient preferences, terminal illness, death, dying, patient choices, prognosis, life-extension, end of life, palliative care, quality of life, patient information, meaning of illness, transition, life stage, hope, spirituality, religion, prognostic communication, subjectivity, identity, family, aggressive care, medical futility, and moral distress. I also checked the reference lists of selected papers to identify additional articles. I limited the articles to original empirical research and systematic reviews of empirical research. Searching beyond the health science literature, I also examined relevant sociological, political science, anthropological, and educational research. Where possible, I limited my search to studies that examined patients with advanced cancer (as
opposed to newly diagnosed) and focused on cancer treatment after it has been diagnosed (as opposed to cancer screening).

During the period of May 2013 to August 2013, I conducted a follow up literature search that employed the same electronic databases and keywords as the original search, but between the parameters of 2011 to 2013. In order to review the literature on new topics uncovered since the first literature search, I used new keywords in different combinations: clinical trials, experimental treatments, self-care, self-healing, self-help, health literacy, lay understanding of scientific research, positive thinking, expertise, trust, mistrust, and suffering.

7 Epidemiological Research

Patients’ search for life-extension may be difficult to measure quantitatively because it is nuanced, contextual, and sometimes difficult to conceptualize. Because it is part of the everyday tensions of oncology practice, this issue may also go undocumented. Accurate estimates of this issue in advanced cancer populations, yet are not imminently dying are difficult to obtain from the literature. As a result, one has to infer its magnitude based on larger population studies that have examined the kinds of cancer treatments individuals have received near the time of death.

Several population-based studies suggest that a proportion of cancer patients may receive chemotherapy treatment close to the time of death. A retrospective cohort study in Ontario, Canada by Barbera, Paszat, and Chartier (2006) found that 15.8 percent of patients received chemotherapy and five percent of patients had an intensive care unit (ICU) visit in the last two weeks of life. Using a broad registry of all cancer types, Barbera et al. (2006) located key treatment predictors for chemotherapy utilization such as age (mean 65.5), gender (46.1 percent female), and location (23.0 percent received treatment in a large urban centre). Cancers of the lung, gastrointestinal tract, and lymphoma/leukaemia were more likely to be treated near death. The predictors of ICU admission followed a similar pattern. As Barbera et al. (2006) did not identify whether the chemotherapies provided were to reduce symptoms or to eradicate cancer, it was difficult to determine if life-extension was the principle intension.
By examining US Medicare data sets, Earle et al. (2008) suggest that whereas the average time it takes to approach the end of life in cancer has remained steady over the last ten years, the overall utilization of chemotherapy has increased two percent. Earle et al. conclude that there has been no increase in the clinical effectiveness of chemotherapy given near the time death in over a decade. Using logistical regression, Earle et al. suggest that patients who are elderly, female, non-Caucasian, and unmarried were less likely to receive chemotherapy near the end of life. At the same time, these particular factors may be reflective of populations that are less likely to be covered by US healthcare insurance, as opposed to demographic predictors of treatment. A similar, but more recent Swedish study by Randen, Helde-Frankling, Runesdotter, and Strang (2013) found that 32 percent of metastatic cancer patients (n = 346) received chemotherapy during the last month of life and 46 percent were given curative treatments. The studies by Earle et al., (2008), Barbera et al. (2006), and Randen et al. (2013) were limited in their scope because they were descriptive, retrospective, and used secondary data from administrative databases. Still, these studies provide a crude indicator of the usage of potentially life-extending cancer treatment in clinical practice.

By measuring the number of times chemotherapy was attempted but did not produce remission, Murillo and Koeller (2006) was one of the few in the literature to estimate the degree of “treatment aggressiveness” in advanced cancer. From a sample of stage three and four lung cancer patients (n = 417), approximately 84 percent received first line chemotherapy, 56 percent received second-line therapy, 26 percent third-line, ten percent fourth-line, and five percent fifth-line (Murillo & Koeller). Individuals were administered a mean of 6.1 cycles of chemotherapy that was largely intended to extend survival (Murillo & Koeller). While additional studies with greater statistically power are needed, Murillo and Koeller suggest that lung cancer patients are receiving chemotherapy for longer periods and are also receiving multiple rounds of treatment, despite their advanced disease status.
8 The Clinical Contexts of the Search for Life-extension

8.1 The Clinical Appropriateness of Receiving Potentially Life-Extending Treatment

The provision of invasive treatments intended to eradicate advanced cancer is a controversial clinical issue. On one hand, receiving these types of treatments may present an opportunity to extend life. On the other hand, there are associated effects such as treatment toxicity, physical pain, and hastened death (Lipscomb et al., 2007). A number of studies have considered the clinical appropriateness of receiving these forms of therapy, although there are divergent viewpoints in the literature.

Some studies suggest that that biomedical treatment may not extend life in certain forms of progressive cancer. In an older, but still well cited, prospective cohort study of metastatic lung and colon cancer, Weeks et al. (1998) suggest that there is little association between the invasiveness of treatment and the length of survival. Patients who received treatments with curative intent had the same survival rate as those who received non-curative and palliative treatments, but were more likely to have a hospital readmission, undergo attempted resuscitation, or die while receiving ICU interventions (Weeks et al.).

Although some feel that invasive treatments are clinically appropriate in advanced cancer, other research suggests that such treatments are often provided regardless of its effectiveness. In a large study of US Medicare data (n = 7919), Emanuel at al. (2003) estimated that chemotherapy use during the last three months of life was similar for cancers that generally responded well to treatment (listed as breast, colon, and ovarian) and cancers considered generally unresponsive to treatment (listed as pancreatic, hepatocellular, renal-cell cancer, and melanoma). These findings suggest that the cancer’s relative responsiveness to chemotherapy may not influence whether patients receive chemotherapy at the end of life or not (Emanuel at el.).
8.2 Treatment provided to Cure as opposed to Palliate

The search for life-extension exists within the current shift in practice regarding the timing of palliative care and curative oncological care in the disease trajectory. Emerging models of palliative care call for the early integration of palliative consultations and services (for instance, pain control, emotional support, advanced care planning, etc.) into the more curative protocols of cancer treatment.

As a result of this shift, more individuals with metastatic disease concurrently receive invasive oncological treatments along side supportive palliative interventions. To some, this is a controversial move because oncologists must expertly balance the consequences of drug toxicity with the prolongation of survival and promotion of quality of life (Thongprasert, Sanguanmitra, Juthapan, & Clinch, 1998). There are a number of conceptual and persuasive articles in the health science literature that advocate for the integration of palliative into oncological care (Smith et al., 2012; Hauser et al., 2011; Gaertner, et al., 2011; Bruera & Hui, 2010). Although there is growing scientific evidence that supports this transition, more research needs to be conducted about the social effects of this integration.

One of the most widely publicized clinical trials in the push for integrated palliative care, Temel et al. (2010)’s trial randomly assigned metastatic lung cancer patients to either two groups: (1) an early palliative care treatment combined with standard oncologic care, or (2) standard oncologic care alone. As expected, the early palliative care group had a better quality of life and fewer depressive symptoms (16 percent vs. 38 percent) than the standard care group (Temel et al.). Although their study lacked statistical power (n = 151), Temel et al. found that the standard group received more aggressive forms of therapy than the interventional group (54 percent versus 33 percent). Temel et al. defined aggressive care as chemotherapy administration, hospitalizations, and emergency room visitations. A key finding, early palliative care was associated with improved short-term survival when compared to standard care (11.6 months vs. 8.9 months). Since Temel et al. did not examine this relationship as a primary outcome; this finding was a secondary but no less important outcome. In a recent secondary analysis of Temel et al.’s data, Greer et al. (2012) found that the palliative care interventional group had almost half the odds of receiving chemotherapy within 60 days of death (0.47 versus 0.23) and also
experienced a longer time period between the last dose of intravenous chemotherapy and death (up to 406 days versus 287 days). A significant contribution to the literature, Temel et al. and Greer et al. raised questions about the relationships between the use of overly invasive cancer treatments and life-extension as an outcome.

In another clinical trial that focused on quality of life, Meyers et al. (2011) randomly assigned patient and caregiver dyads (n = 476 pairs) at three different cancer centres into either (1) a control group receiving phase I, II, or III trials or (2) a group enrolled in the same trials plus an educational intervention in supportive care. Interestingly, there was no difference in quality of life between the standard care group and the intervention group. Family caregivers in the interventional group, however, had significantly less decline in the spiritual, psychological, and social dimensions of quality of life over time (Meyers et al.). In a similar study, Bakitas et al. (2009) randomly allocated advanced cancer patients to either (1) standard oncological care (n = 161) or (2) standard care plus a psycho-educational, palliative intervention (n = 161). Bakitas et al. found a significant improvement in quality of life (p = 0.02) and a reduction in depressed mood (p = 0.02) for the interventional group. Those who died during the study derived even stronger benefits from the interview (Bakitas et al.).

The literature on integrated palliative care has pointed to the benefits of this comprehensive approach to improving both patient and caregiver outcomes (Temel et al., 2010; Meyers et al., 2011; Bakitas et al., 2009). At the same time, very few of these studies call for the reduction of treatment invasiveness in standard oncological treatments. Rather, curative cancer therapies remain the focus of care in this literature, whereas the palliative care tends to play only a secondary and supportive role (Smith et al., 2012; Hauser et al., 2011; Gaertner et al., 2011; Bruera & Hui, 2010).

### 8.3 Futile Care in Advanced Cancer

To some in the clinical world, the invasive treatment of metastatic disease with the intention to extend life is a medically futile endeavour because of the negative side effects and the possibility that it will not work (Weeks et al., 1998). A term often used in the bioethics literature, medical
futility is concerned with the clinical appropriateness of biomedical treatments, primarily from a physiological perspective (Moratti, 2009; Mohammed & Peter, 2009). Medical futility is defined as inappropriate or overly aggressive treatments that will not improve disease prognosis, alleviate physiological symptoms, or prolong survival (Scheiderman, Jecker, & Jonsen, 1996). Although medical futility may shape how life-extension is viewed in day-to-day clinical work, few empirical studies have examined this concept in advanced cancer. Focusing on the clinical experiences of healthcare professionals, previous studies on futility have instead directed their attention towards the provision of treatment like mechanical ventilation in the intensive care unit (Palda, Bowman, McLean, & Chapman, 2005; Heland, 2006; Sibbald, Downar, & Hawryluck, 2007).

In one of the few studies on futility in advanced cancer, Fede et al. (2011) and Riechelmann, Krzyzanowska, and Zimmermann (2009) examined the types of futile medications taken by advanced cancer patients. In both studies, futile drugs were defined as medications from the same pharmacological class that had no short-term benefit to survival, quality of life, or symptom control. Both studies did not classify curative forms of chemotherapies as futile, but only considered medications such as statins, benzodiazepines, aspirin, and multivitamins as futile (Fede et al.; Riechelmann et al.). In a systematic review of studies related to end of life decisions in ovarian cancer, von Gruenigen and Daly (2005) found that futile care is often provided because of the difficulty to establish clarity with patients and family members around the goals of care, the late timing in the transition from curative to palliative intent, and the lack of advanced planning to withhold aggressive interventions. Although there are a number of editorial and conceptual papers (Escalante, Martin, Elting, & Rubenstein, 1997), few empirical studies have applied the concept of medically futile care to cancer treatments.

8.4 Overly Aggressive Care in Advanced Cancer

Whereas futile care in oncology is not well researched, there are several studies that employ the concept of aggressive care to the biomedical treatment of advanced cancer, although there is no unifying definition of the term “aggressive.” The study by Earle et al. (2008) defines aggressive care as: “(1) the overuse of chemotherapy very near death; (2) and the possible misuse of
treatment resulting in high rates of emergency room visits, hospitalization, or intensive care unit stays for terminal patients” (p. 3860). This definition is similar to an older study by Earle et al. (2004) and Braga et al. (2007), as well as the more recent study of treatment aggressiveness by Temel et al. (2010). Although the distribution of aggressive care is well researched, very few studies have examined the social implications of aggressive care in everyday practice.

Clinicians sometimes experience ethical distress when they participate in aggressive or futile care. In one of the few studies to examine the distress of oncology nurses, McLennon et al. (2013) conducted a content analysis of narrative comments provided by 137 oncology nurses who completed an open-ended survey about the care of advanced cancer patients. Many of the nurses described feeling morally troubled about the lack of the prognostic information provided to patients (McLennon et al.). As a consequence, nurses described feeling uncomfortable when they were asked to explain the prognosis to patients, a task perceived as out of their professional scope (McLennon et al.). Nurses most often blamed oncologists for evading end of life discussions, which they felt led to unrealistic expectations and a false sense of optimism for patients (McLennon et al.).

When describing their views on aggressive treatment, nurses often referred to cases where cancer treatments greatly reduced the quality of life for terminally ill patients (McLennon et al.). Nurses seemed to experience higher levels of ethical distress when older adults received aggressive care. For instance, one nurse described a 95-year-old patient who was receiving chemotherapy because the family did not want to go against the oncologist’s recommendations. The findings by McLennon et al. are similar to an older study by Damrosch et al. (1993), which suggests that nurses have negative perceptions of aggressive care because they often bare first hand witness the suffering generated by treatment. Although the study by McLennon et al. began to describe how nurses view aggressive treatment, less is known about how physicians, patients, and family members perceive aggressive care in oncology.

In a key qualitative study, Kuuppelomäki and Lauri (1998) were one of the few in the literature to consider ethical dilemmas in cancer from multiple perspectives. Kuuppelomäki and Lauri conducted interviews with 32 cancer patients, 13 nurses, and 13 physicians from several hospitals in Finland. Despite having incurable disease, about two-thirds of participants were still
receiving chemotherapy. Whereas chemotherapy was reported as a major source of hope that motivated to keep patients engaged in treatment, the decision to discontinue chemotherapy signified giving up and a loss of hope (Kuuppelomäki & Lauri). Concerned about the deteriorating effects of treatment, nurses were often concerned that their patients would not be able to tolerate another round of chemotherapy. Because of the wide range of available treatments, the uncertainty about the patients’ condition, and the moral dis comforts about diminishing hope, physicians reported that making the decision to discontinue treatment was fraught with multiple ethical difficulties (Kuuppelomäki & Lauri). The decision to withhold chemotherapy was further complicated by the attitudes of family members who felt a sense of guilt about the prospects of withdrawing treatment (Kuuppelomäki & Lauri). Although chemotherapy at the end of life was the main source of ethical tensions, nurses and physicians also described the intravenous administration of antibiotics as problematic.

8.5 The Role of Biomedical Science in the Search for Life-extension

Despite the perception that treatments may be aggressive or medically futile, the growing possibilities of bio-scientific innovation in locating a cure for advanced cancer also frames this phenomenon. In an older but still well cited study of 51 oncologists at Harvard medical school, DelVecchio Good, Good, Schaffer, and Lind (1990) examined the associations between the hope for more effective cancer treatments and the perception of the “progressive efficacy of biotechnical interventions” (p. 59). In addition to the academic work of supervising residents, approximately 92 percent of the oncologists were involved in laboratory research and clinical trials. Oncologists often expressed their commitment to the field of oncology in terms of a solving a biomedical “challenge” – the challenge of caring for seriously ill individuals, engaging in the intellectual exercise of biomedical research, and the creation, testing, and utilization of potentially curative cancer therapies (DelVecchio Good et al.). According to DelVecchio Good at el., “the sense of confronting the biological frontiers of disease and the commitment to altering those frontiers” (p. 73), often frames how oncologists describe their medical work. As opposed to viewing biomedical treatments as futile, many reported that they expressed their care for patients
by offering different treatment choices, exhausting all therapeutic avenues, and seeing individuals through the trajectory of treatment (DelVecchio Good et al.). Shaping the clinical and research work of oncologists, the view that biomedical science will eventually eradicate cancer provided a broad and generally optimistic way of thinking about how biomedicine should approach treatment.

In a key study on the popularization of treatment, Camus (2009) conducted a critical discourse analysis of the scientific metaphors found in 37 articles about cancer research from the popular British newspaper, *The Guardian*. Resonating with the work of Sontag (1989), the most common recurrent conceptual metaphor was “cancer is war” that often portrayed cancer cells as an insidious and invading agent. Scientific research was thus directed towards developing a “bigger arsenal of weapons” (Camus, p. 475) in order to eradicate the invader, particularly if the cancer had colonized distant sites of the body. If the cancer remained somehow resistant to these different cancer-fighting agents (often described using militaristic metaphors), another set of scientific research (for example, immunoglobulin therapy) then focused on boosting the body’s own innate defences. Although the body’s healthy and non-cancerous cells may be compromised in the fight, many of these articles described the unavoidable sacrifices that sometimes need to be made when treating cancer (Camus). By generating a sense of optimism in technological care, the cultural metaphor of battling cancer through scientific innovation may shape how cancer treatments are culturally perceived.

Camus (2009) uncovered another unexpected metaphor: cancer exists as a puzzle that will gradually be solved by the gradual evolution of biomedical science. Obscuring the complexity of disease, the puzzle metaphor may relay the impression to a lay audience that understanding the pathological process (solving the puzzle) is possible once the pieces of the puzzle are correctly joined together through scientific innovation (Camus). An over simplification, the puzzle metaphor suggests the pieces of the puzzle will only fit together in one correct, yet achievable, way in order to realize a cure (Camus). When oncology as a clinical practice expresses itself through this metaphor, it often over emphasises solving the scientific puzzle of incurable cancer, rather than meeting the emotional or existential needs of the individuals themselves.
8.6 Experimental Clinical Trials and The Search for Life-Extension

Although clinical trials have been a major way to generate knowledge over the last thirty years, some have suggested that they are becoming an even more prominent facet in today’s clinical settings, often because of their ties to the biomedical industry (DeBruin, Liaschenko, & Fisher, 2011; Petryna, 2005). Although few studies exist, lay audiences may be increasingly exposed to clinical trials because of the widespread public discussions about experimental science on the Internet and other forms of mass media. To some, encouraging advanced cancer patients to enrol in trials is a productive practice because it provides patients an opportunity to try new therapies that their cancer might finally respond to, facilitates a sense of hope, and allows individuals an opportunity to contribute to society. To others, this practice raises certain ethical concerns because it may generate unrealistic expectations of a cure (Kass et al., 2010; Meropol et al., 2003; Sulmasy et al., 2010) and may compete with the complicated preparations of dying. Although Fisher (2008) has questioned the large corporatization of pharmaceutical trials as an industrial practice through a critical theoretical approach, few empirical studies have examined the local social implications of clinical trial participation for those with metastatic disease.

In a recent study of the motivators and barriers to participation in cancer-related clinical trials (n = 358), Jenkins et al. (2013) found that the primary reason given by patients for trial acceptance was altruism (40 percent) and the declining trust in their existing oncologist (28 percent). Only 18 percent of individuals listed the opportunity to receive the best cancer treatment as the primary reason to enrol in the trial (Jenkins et al.). When completing an open-ended question, one participant remarked, “I believe that doing the trial will keep the doctors more in touch with my condition” (Jenkins et al., p. 1404). The concern with betraying the trust of physicians (28 percent) and the expectation that physicians choose the trial option for them (14 percent) were the main reasons for declining trial participation. The findings by Jenkins et al. (2013) are similar to an older study by Jenkins and Fallowfield (2000).

Other researchers have suggested that the enrolment of individuals into cancer trials remains relatively low, despite the importance of these studies to scientific advancements (Weiss, 2007). Nass, Moses, and Mendelsohn (2010) estimate that only 60 percent of US National Cancer
Institute sponsored trials are actually completed and published. Because of the relatively poor response rate and the assumptions that certain patient populations (especially, different racial groups) are under-represented in trial research (Seifer, Michaels, & Collins, 2010), there is a current emphasis on the cancer care system to promote trial enrolment.

The attitudes of physicians towards trials are often examined in the literature as a barrier to enrolment. In a recent UK survey of the attitudes and practices of surgeons (who treat cancer but also other diseases) and oncologists (n = 87 total) towards clinical trials, Ford et al. (2011) found that more oncologists than surgeons endorsed prolonging the length of a patient’s life over improving quality of life. More often than surgeons, oncologists recruited more than 50 percent of their patients into trials and attended trial centered research conferences (Ford et al.). Ford et al. conclude that the wider availability of chemotherapy trials, as opposed to experimental surgical interventions and the broad perception that oncologists have a monopoly over experimental medicine, may lead to this discrepancy.

### 8.7 Complementary and Alternative Medicine

In addition to the increased public profile on bio-scientific research, complementary and alternative medicine (CAM) has emerged as an increasingly acceptable therapeutic tool in the treatment of advanced cancer. In large descriptive survey of 14 European countries, Molassiotis et al. (2005) found that 35.9 percent of patients were using CAM. Although herbal medicine was the most commonly used CAM modality, additional therapies included homeopathy, vitamins, spiritual therapies, and relaxation techniques (Molassiotis et al.). The main source of information about CAM was from friends, family, and the media, while healthcare professionals only played a minor role. Reporting satisfaction with their choice, participants often felt that CAM boosted the body’s innate ability to fight cancer and improved emotional and physical well being (Molassiotis et al.). In one of the few studies to examine the use of CAM by advanced cancer patients, Shen et al. (2002) conducted interviews with metastatic breast cancer patients. Approximately 73 percent of participants used CAM, with relaxation or meditative techniques and herbal remedies as being the most common. As with the study by Molassiotis et al., boosting
the immune system was the most commonly cited reason to use CAM and the media was the most commonly cited information source (Shen et al.).

Because of the risks of drug incompatibility and the lay perceptions of a cure, some clinicians view the use of CAM with certain reservations. In a mixed method study of how CAM is depicted in the Australian media, Mercurio and Ardath Eliott (2011) conducted a content analysis of 119 articles between 1998 and 2007. Quantitative analysis suggested that biologically based CAMs such as herbal medications were the most commonly described (39.4 percent), followed by mind-body energy (16.2 percent) and body-based treatments such as acupuncture (14.1 percent). Rarely mentioning the financial costs, the media discussed the potential benefits of CAM much more frequently than their potential risks (Mercurio & Ardath Eliott). Troubling to some, CAM was often constructed as a legitimate tool to assist biomedicine to prolong life or even cure cancer (38.73 percent of the articles). This was most often presented in the media in the form of anecdotes that followed a certain stylistic pattern. By combining CAM with biomedicine, a bleak outcome of cancer exclusively treated with conventional therapy was suddenly improved (Mercurio & Ardath Eliott). These articles often depicted CAM as commonplace, necessary, and useful in addressing the limitations of biomedicine (Mercurio & Ardath Eliott).

9 Patients’ Rationales Towards their Treatment and Disease

9.1 Cancer Patients’ Willingness to Receive Treatment

In this section, I review the literature on the types of rationales that cancer patients may employ to drive their search for life-extension. The first group of research suggests that cancer patients are often willing to receive more invasive forms of cancer therapy in exchange for relatively small gains in the length of survival. As many of these studies imply, individuals may be more likely to pursue more invasive therapeutic regimes if they believe that they can derive prognostic benefits from these treatments.
In an older prospective survey study, Slevin et al. (1990) found that 53 percent of newly diagnosed individuals would consider invasive chemotherapy if the chances of remission were improved by as little as one percent. Donovan, Greene, Shuster, Partridge, and Tucker (2002) found that 25 percent of recently diagnosed ovarian cancer patients would favour curative therapy even if survival were less than one week. In a comparative cohort study, Sahm, Will, and Hommel (2005) found that cancer patients favoured curative treatments significantly more often than control groups who were ill but did not have cancer. Hirose et al. (2005) quantitatively compared lung cancer patients to those with other respiratory diseases. Approximately 19 percent of cancer patients would choose intensive therapies if their lives could be prolonged for three months, which was significantly higher than non-cancerous patients (Hirose et al., 2005). In addition to life prolongation, the alleviation of physical symptoms may motivate some individuals to choose invasive treatment. For instance, 73 percent of individuals were willing to choose invasive chemotherapy when presented with a 70 percent chance of symptom relief (Hirose et al.).

The studies by Slevin et al. (1990), Donovan et al. (2002), Sahm et al. (2005), and Hirose et al. (2005) were descriptive and quantitative in their design, and did not explore the deeper mechanisms and contextual influences that may inform participants’ willingness to receive more invasive treatment. All of these studies presented hypothetical situations of prognostic risk/benefits (i.e. pessimistic versus optimistic) to newly diagnosed cancer patients who did not have advanced disease and compared these responses to a control group. In many of these studies, the duration of illness may play a role in individuals’ desires for treatment. Voogt et al. (2005) found that individuals with a history of cancer of less than six months were more inclined to prefer life prolongation than patients with a longer history of disease. Earle et al. (2008) found that individuals who relapsed after early-stage cancer and those with a longer duration of illness were less likely to be treated with curative intent. Because their study samples were limited to newly diagnosed individuals, the studies by Slevin et al., Donovan et al., Sahm et al., and Hirose et al. were limited in their generalizability to individuals with advanced cancer.
9.2 Patients’ Overestimation of the Curative Potential of Medical Treatment

Several studies have examined how individuals with advanced disease sometimes overestimate the curative value of biomedical treatment prescribed late in the disease trajectory. Chow et al., (2001) interviewed and surveyed individuals with advanced cancer (n = 60) before their initial consultation with a palliative care physician. Approximately 35 percent of patients believed that their cancer was curable and 20 percent believed that palliative radiation therapy was given to prolong their lives, as opposed to symptom management (Chow et al., 2001). In a study that examined the attitudes of recurrent ovarian cancer patients (n= 122) by Penson et al. (2004), 50 percent of patients believed that palliative chemotherapy would result in full remission and 15 percent thought it would cure their cancer completely. In a survey of 917 metastatic colon and lung cancer patients, Weeks et al. (1998) found that the degree to which individuals overestimated their survival positively influenced their preference for treatment. Individuals who were more likely to overestimate their chances of survival over six months were more likely to favour curative protocols over palliative care (Weeks et al., 1998).

In a more recent prospective cohort study of metastatic lung and colorectal cancer patients (n = 1193), Week et al. (2012) found that 69 percent of lung cancer patients and 81 percent of colorectal patients believed that their chemotherapy might cure their cancer. As this study conducted the surveyed four to seven months following their initial diagnosis (described as recently diagnosed), the results may not be generalizable to individuals who have endured a longer period with disease. In addition to chemotherapy, a study by Chen et al. (2013) suggested that individuals with incurable lung disease (n = 384) often overestimate the curative potential of palliative radiation therapy. Although 78 percent of patients believed that radiation therapy would help them live longer and 67 percent believed this therapy would help them alleviate cancer symptoms, 64 percent did not understand that radiation was not provided to cure them, but rather was given for symptom relief (Chen et al., 2013).

A mixed method study by Kass et al. (2010) discovered that some advanced cancer patients have positively skewed views of the therapeutic value of phase 1 experimental trials. Testing the initial safety and dosing of a new therapy, phase 1 trials are often offered to individuals who are
unresponsive to standard therapy. Supporting the results of an older study by Meropol et al. (2003), Kass et al. found that 17 percent of participants believed the phase 1 trial was provided to cure cancer. Oncologists often gave mixed messages when discussing this option, maintaining that the purpose of the trial was to ensure treatment safety, yet referring to the trial as an effective treatment with potentially positive therapeutic effects (Kass et al.). Using a phenomenological approach, Sulmasy et al. (2010) examined patients’ overestimation of the therapeutic benefits of early phase oncology trials. As individuals often clung to positive thinking as an important belief system, participants’ descriptions of the therapeutic benefits of trials were more about expressing a sense of optimism than with reporting accurate knowledge about the treatment effectiveness of the trial (Sulmasy et al.). Participants described the importance of being embedded in a culture of optimism in order to survive from cancer, where enrolment in a clinical trial became a concrete and meaningful way to consolidate these values (Sulmasy et al.). These findings are consistent with a recent qualitative study in Sweden by Godske sen et al. (2013), which described patients’ overly optimistic attitudes towards trials in oncology as a “therapeutic misconception” (p. 1891).

Many of the studies reviewed in this section, identified various clinical, demographic, and health system factors that may predict patients’ tendency to overestimate the curative value of treatment. By comparing individuals in the UK and the US, Penson et al. (2004) suggest that the cultural location of care may also be a contributing factor. More US patients (36 percent) thought that non-curative palliative treatment was an inappropriate option for a second recurrence of ovarian cancer than UK patients (12 percent) (Penson et al.). Although cultural location may be significant, Weeks et al. (1998) note that the relationship between the overestimation of survival and the desire for curative therapies were unchanged in logistical regression models that adjusted for age, sex, race, education, income, disease site and stage, duration since diagnosis, and functional status. Similarly, in a later study, Weeks et al. (2012) found that educational level and functional status did not influence the overestimation of the curative potential of treatment.

Although certain demographic factors may be insignificant, patients’ level of knowledge may play an important role in shaping this way of thinking about treatment. Chow et al. (2001) suggest that the knowledge deficiencies of patients regarding the prognosis and treatment of their advanced cancer may contribute to the overestimation of treatment effectiveness. For instance,
87 percent of patients were not familiar with the concept of radiation treatment, 78 percent reported that they were not given information about treatment, and 85 percent were not satisfied with the information that their physicians had provided (Chow et al.). Weeks et al. (1998) suggest that the less accurately physicians estimated and disclosed the probability of prognosis, the more likely patients desired life-extending cancer therapies. Individuals who were given a 10 percent probably of surviving six months were 8.5 times higher to prefer curative treatment than those given a 90 percent probability of surviving six months (Weeks et al., 1998).

Suggesting a link between physicians’ communication behaviours and patients understanding of treatment benefits, Weeks et al. (2012) found an association between “inaccurate beliefs” (p. 1622) about the likelihood of cure and higher ratings of patients’ satisfaction with their physicians. This suggests that patients sometimes perceive physicians as better communicators when they convey a more optimistic view of chemotherapy (Weeks et al., 2012). This tendency to prefer positive views of treatment may restrict the ability of healthcare providers to openly disclose prognoses that are poor.

### 9.3 Patients’ Understanding of their Disease and the Possibilities of Death

There is another body of literature that suggests that individuals who seek life-extension may not fully understand disease, treatment, and the likelihood of dying from cancer. Many studies have examined patients’ informational deficits as an important contributing factor to the search for further treatment.

Although most individuals with advanced cancer are generally well informed of their disease, some studies suggest that they often have certain gaps in their understanding of prognosis and treatment. In an Australian study, Tattersall, Gattellari, Voigt, and Butow (2002) examined audio taped in-person consultations between physicians and 118 patients with incurable cancer. Only 84.7 percent of patients were informed about the aim of treatment, 74.6 percent were told that their disease was incurable, and 57.6 percent were informed about life expectancy (Tattersall et al., 2002). However, only 44.1 percent of patients were presented an alternative to curative
cancer treatment and only 29.7 percent were offered a choice to manage their own care 
(Tattersall et al., 2002).

In a similar Canadian study, Chochinov, Tataryn, Wilson, Enns, and Lander (2000) found that 
73.5 percent of patients (n = 200) reported complete awareness of their terminal prognosis and 
shortened life expectancy, 17 percent were partially aware, and only 9.5 percent of patients 
actively denied being aware of their cancer. Several predicting factors were associated with 
prognostic denial in individuals. The prevalence of clinical depression was about three times 
greater (32 percent) in individuals who did not acknowledge their prognosis compared to the 
other groups (Chochinov et al., 2000). Significantly more men were found to endorse a position 
of partial to complete prognostic denial than women. At the same time, there was no significant 
association between prognostic awareness and survival time, educational background, pain, 
hopelessness, or a desire for death (Chochinov et al., 2000).

9.4 Physicians’ Hesitancy to Disclose Prognosis in Advanced Cancer

Although some literature suggests that individuals with cancer are well informed, other literature 
points to the hesitancy of physicians to disclose poor prognoses and when this does take place, 
the tendency to report optimistically skewed estimates. This knowledge discrepancy may lead to 
the perception that curative treatments are an appropriate course of action. In a survey of 
oncologists that formulated and disclosed prognosis for 326 patients, Lamont and Christakis 
(2001) found that physicians did not communicate any survival estimates 23 percent of the time 
and communicated a different estimate from the one they formulated 40 percent of time. Of the 
discrepant survival estimates, 70 percent were optimistically skewed (Lamont & Christakis). In a 
large meta-analysis of 51 studies, Hancock et al. (2007) confirmed the tendency of physicians to 
disclose inaccurate estimates of programs. Factors that contributed to this inaccurate disclosure 
include: participants not requesting information, a shortened life expectancy, older age, lack of 
time to discuss the issue, providers finding it stressful or uncomfortable discussing these issues, 
and the perceived inability of individuals to understand and handle the situation (Hancock et al.).
Underestimating patients’ need for information, physicians also overestimated patients’ understanding and awareness of their prognosis (Hancock et al.). In a survey of individuals with advanced lung cancer, Quirt et al. (1999) found that 36 percent of patients disagreed with their physician about the extent of the disease and 28 percent disagreed about the intent of treatment. In the cases where there was disagreement, the majority of patients underestimated the extent of advanced cancer and wanted more invasive forms of treatment commonly associated with a cure (Quirt et al., 1999).

9.5 The Types of Treatment Information Requested by Advanced Cancer Patients

The tendency of physicians to disclose overly optimistic prognoses may also impact the types of information about treatment requested by advanced cancer patients. In a survey of 126 individuals with metastatic disease, Hagerty et al. (2005) found that 98 percent wanted physicians to be realistic, yet 90 percent also wanted a discussion of the “latest and most up to date” curative medical treatment. In a focus group and interview study, Clayton, Butow, Arnold, and Tattersall (2000) suggest that patients wanted an honest disclosure of prognosis, an explanation of how physicians made certain decisions, and to be given rough estimates, rather than exact figures, of their survival time frame. Even in metastatic disease and late stage, some patients seem to request information about their curative treatment options (Clayton et al.).

In a quantitative survey of 128 advanced lung cancer patients in Belgium, Pardon et al. (2009) found that 88.2 percent of patients wanted information about diagnosis, treatment, and cure rates, whereas only 63.5 percent wanted information about palliation and 56.8 percent about end of life decision-making. As 71.1 percent of the sample was receiving curative treatment at the time of the study, and only 21.1 percent were receiving palliative treatments, the type of interventions individuals were currently receiving may have influenced the information requests of participants (Pardon et al.). This study also suggested that patient preferences for information might shift depending on disease related factors. For instance, individuals who experienced pain were more likely to want information about life expectancy than individuals with less pain (Pardon et al.). Patients who were informed about life expectancy were also more likely to want information on
palliative care and end of life issues (Pardon et al.). Pardon et al. conclude that when the
treatment goal is palliation, as opposed to life-extension, individuals appear more receptive to
information on death and dying. As this study was conducted in Belgium, where there may be a
more open cultural dialogue about death, it may not be as generalizable to a North American
context. Belgium, for example, legislated euthanasia as a choice for individuals in 2002, and 13
participants in this study wanted information about this practice (Pardon et al.). In a more recent
secondary analysis of this same data, Pardon et al. (2011) found similar results to their earlier
study.

In a multi-method study, Kutner et al. (1999) suggest that individuals’ information needs in
advanced illness are fraught with certain tensions. Kutner et al. first interviewed 22 terminally ill
patients about their needs, concerns, and expectations at the end of life. Seven key issues were
identified: change in functional status, change in social roles, physical symptoms, stress on
family members, loss of control, financial burden, and a conflict between wanting to know what
is going on and fearing bad news. Based on the interview data, Kutner et al. developed and tested
a quantitative psychometric instrument (n = 56) measuring patients’ perceptions of information
sources. Kutner et al. (1999) located a sense of conflict between patients wanting more
information from physicians, but simultaneously not wanting bad news. While 100 percent of
patients wanted physicians to be honest about disease progression, 91 percent also wanted an
optimistic prognosis (Kutner et al.). Although this study lacked statistical power, univariate
analysis failed to reveal the associations between patient characteristics (e.g. gender, education,
age) and information needs (Kutner et al.). In their study, Kutner et al. call into question the
assumption that individuals will utilize medical scientific information to make exclusively
“rational” choices about their treatment.

9.6 Information Sources Accessed by Patients with Advanced Cancer

Some studies suggest that individuals utilize a diverse range of information sources that
potentially shift as the cancer progresses. In a meta-analysis from 1980 to 2003, Rutten, Arora,
Bakos, Aziz, and Rowland (2005) looked across 45 relevant studies to examine the number of
times an information source was identified. During initial cancer treatments, Rutten et al. found that 26.9 percent of individuals identified health professionals as the main focus of information. After treatments were provided, the percentage for health professionals shifted to 40.6 percent, followed by 25.0 percent for non-professionals (such as family or friends), 21.9 percent for printed materials, 15.6 percent for mass media, and 12.5 percent for scientific data (Rutten et al., 2005).

In one of the few studies that closely examined information sources outside of the healthcare system, Carlsson (2000) noted that cancer patients (n = 192) actively sought out information from medical books (37 percent), anecdotal narratives (32 percent), and the Internet (6 percent). Individuals also inadvertently received information from newspapers (86 percent), television and radio (82 percent), friends (55 percent), and other patients (46 percent). The studies by Rutten et al. (2005) and Carlsson did not limit the study sample to individuals with advanced cancer, but instead examined all prognostic stages. As they are both descriptive, these two studies did not critically examine how treatment knowledge was generated, dispensed, and utilized in the context of advanced disease. Although some older studies have examined information sources in newly diagnosed individuals (Hinds, Streater, & Mood, 1995; Bilodeau & Degner, 1996), fewer studies have examined how having advanced cancer might impact the navigation of biomedical scientific knowledge.

In one of the few ethnographic studies about information sources in cancer, The, Hak, Koeter, and van der Wal, (2001) observed small-cell lung cancer patients to determine their information sources and how they accessed disease knowledge. The et al. (2001) found that some individuals believed they were provided false information about the severity of prognosis, especially during the initial course of chemotherapy or if the cancer could not be seen on x-ray. By piecing together clues from different sources that were often independent of medical professionals, individuals gradually became informed about their poor prognosis often through their own physical deterioration and their contacts with fellow patients (The et al., 2001).

In a more recent study, Walsh et al. (2010) examined the information seeking behaviours of breast, colorectal, lung, and prostate patients (n = 1784) from a variety of disease stages. Over 69 percent of participants reported obtaining information from a wide array of sources other than
healthcare providers (Walsh et al.). Significant predictors of the tendency to use a variety of information sources included younger age, higher income, higher education, use of alternative medicines, and shared decision making with physicians (Walsh et al.). Particularly when compared to those without a high school diploma, college educated individuals were more likely to use the Internet and scientific research report to influence their choices about treatment (Walsh et al.). These findings are like those of a Dutch study by Muusses, van Weert, van Dulmen, and Jansen (2012), although the study sample was limited to individuals receiving chemotherapy for the first time.

Although the information seeking behaviours of recently diagnosed individuals is relatively well studied, there are fewer studies that examine how patients with advanced cancer access different forms of knowledge. A larger study of individuals who accessed sources other than physicians, Smith-McLallen, Fishbein, and Hornik (2011) examined the information seeking behaviours of 1641 prostate, breast, and colon cancer patients from a variety of disease stages. A key finding, this study suggested that the increasing severity of cancer tends to intensify the search for more information. For instance, those with less advanced disease (stage 0, 1, and 2) had lower intentions to search for information than those with stage 3 and 4 cancer (Smith-McLallen et al.). The difference between stage 3 and 4 was not found to be statistically significant.

10 Psychosocial and Emotional Influences

In this section, I move on from discussing cancer individuals’ understanding of disease, prognosis, and treatment, to consider the emotional or psychosocial factors that may influence individuals with advanced cancer to search for life-extension. In particular, I survey the studies on death denial and anxiety, the meaning of illness, end of life transitions, and the hope for survival.
10.1 Death Anxiety and Death Denial

Advanced cancer patients may strive for life-extension in response to the anxiety of death (Sherman, Norma, & McSherry, 2010). Although studies have examined generalized anxiety in terminally ill populations (Kolva, et al., 2011), death anxiety specifically focuses on the existential anxiety aroused by the closeness of dying. In an interview study of women with advanced cancer living at home (n = 12), Grumann and Speigal (2003) found that the fear of death was intense and became something to be contemplated in everyday life. Death anxiety was intensified by the fear of dying in pain, being alone, having unresolved relationship issues, not having control, and the difficulties in saying goodbye to family (Grumann & Speigal). Although the mean time to death was 42 days, some women expressed the hope for a cure in terms of a religious or medical miracle (Grumann & Speigal). Study participants, however, did not describe how they might have acted on these wishes for a biomedical cure.

In another qualitative study on death anxiety of both patients and family members, Sand and Strang (2006) described how the intense anxiety around death led to a mutual sense of social isolation, as individuals realized that they no longer shared the same future. The anxiety around death made it difficult for individuals to communicate their fears, which further intensified their sense of anxiety (Sand & Strang). Leading to unwanted reminders of existential loneliness, the continual awkwardness around the fear of death often stunted existing relationships in everyday interactions (Sand & Strang).

The anxiety around the closeness of death may lead to its denial. Zimmermann (2004) conducted a discourse analysis of 30 scholarly articles on the denial of impending death from cancer as well as other fatal diseases. Originating within the individual, as opposed to the relationships between individuals, the concept of denial was often portrayed in the literature as an internal psychological state that acts as an unconscious protective mechanism to help one deal with the threat of impending death (Zimmermann). In keeping with the idea of denial as a defence mechanism, denial was viewed by certain studies as a “healthy” and temporary stage of coping with terminal disease (Zimmermann). In contrast, a different set of publications suggested that denial could be dysfunctional or pathological, especially when denial occurred beyond the normal timeframe as an appropriate defense mechanism. (Zimmermann). Whether or not the
patient responded to biomedical treatment was viewed as a strong indicator of whether or not denial was considered to be pathological. Whereas denial in the initial disease stages was viewed as a regular part of the coping process, denial in the later stages of disease was viewed as more problematic (Zimmermann). Representing “failure” for both curative and palliative medicine, such individuals were portrayed as ignoring reality, refusing to cooperate, and not following the “natural” path in the acceptance of death (Zimmermann). The link between the denial of death and the search for life-extension despite advanced cancer has not yet been explored in the literature.

10.2 The Meaning of Illness

Advanced cancer is marked by major disruptions to the self, such as the realization of the closeness of death, the loss of bodily control, and the appropriation of a different social identities (Taylor & Currow, 2003). In order to address the disruptions of severe illness, some view the search for the meaning of illness as an important process (La Cour, Johannessen, & Josephnsson, 2009). An opportunity for personal growth in the face of advanced disease; the quest for meaning in illness can be generated through the affirmation of one’s purpose in life, often through the conduct of everyday activities (Greenstein & Breitbart, 2000). In this section, I review the studies that have considered the association between the meaning of illness and the search for treatment.

Using a phenomenological study of advanced breast cancer patients, Luoma and Hakamines-Blomqvist (2004) found that the changes in physical functioning that resulted from medical treatment impacted individuals’ social functioning and led to a sense of social isolation. Participants derived much meaning from their commitment to cancer treatment (Luoma & Hakamines-Blomqvist). Participants viewed curative therapies as an enemy that made them sick and fatigued, but also as a source of meaning when their bodies responded to treatment, even if these gains were small (Luoma & Hakamines-Blomqvist). In a narrative study of seven individuals with advanced cancer, La Cour et al. (2009) explored how individuals negotiated their everyday lives in the face of the closeness of death. Similar to Luoma and Hakamines-Blomqvist, La Cour et al. located a narrative of “being healthy although ill” (p. 469) that spoke to the contradictions and ambiguities in alternatively feeling physically well and feeling severely
sick. In a qualitative study of the narratives of Chinese immigrants with metastatic cancer, Lin (2008) noted that although participants faced suffering, they also actively searched for meaning in their lives. Individuals readjusted and transcended suffering, preserved the positive elements of having advanced cancer and built a sense of hope by believing in an elusive cure (Lin, 2008). Although participants did not act on their desires for a cure, the belief in the possibilities of survival cultivated a sense of personal meaning that fortified the resilience of individuals.

Through a systematic review of the literature, Lee, Choen, Edgar, Laizner, and Gagnon (2004) found that most of the studies on meaning tended to focus on the early or mid phases of cancer, rather than on the advanced stages of disease. In addition, most studies employed a phenomenological or narrative approach to examine the lived experience of individuals, as opposed to a critical approach. The literature suggests that the abilities of individuals to generate meaning in their disease are often associated with the capacity of patients to reframe cancer positively in their everyday lives (Lee et al.). As opposed to a medical scientific or prognostic understanding, individuals with cancer often experience the meaning of their disease and medical treatment through their everyday lives (Lee et al.).

10.3 End of Life Transitions

The withdrawal of biomedical treatment with curative intent is sometimes recognized in the literature as an important transitional phase for advanced cancer patients as they move towards death. Emphasising dying as a real possibility, this withdrawal is viewed as an important process because it progresses patients forward in the dying process and helps them prepare for death (Murray, Kendall, Boyd, & Sheikh, 2005). Since they still may be motivated by the belief in a cure, individuals who search for potentially life-extending treatment may be impeding this transition to the end of life. Although many theoretical and conceptual papers have examined the notion of transition towards the end of life (Murray et al., 2005; Schofield, Carey, Love, Nehil, & Wein, 2006), few empirical studies have explored the possible associations between potentially delaying this transition by receiving curative treatment and end of life transitions.
One of the key studies in this area, Reinke et al. (2008) conducted a grounded theory study to compare the end of life transitions of advanced cancer patients with the perspectives of healthcare providers. Individuals viewed transitions in their lives in terms of their medical treatments and associated the offering of a new treatment with the renewal of hope (Reinke et al., 2008). A different kind of transition ensued when individuals realized that there were no more curative treatments options. While healthcare providers viewed this transition away from potentially life-extending treatment as a valuable opportunity to move the direction of care from curative to palliative, patients associated this transition with a deep disappointment in themselves, anger, and a deep resentment of their overall care (Reinke et al.).

### 10.4 Hope and Life-Extending Treatment

Individuals with advanced cancer who search for life-extending treatment may be motivated by the hope for a longer survival time or even the hope for an elusive cure. There are several studies that have explored the role of hope in advanced cancer and the possible connections between hope and seeking treatment. In a grounded theory study of the pain experience of elderly hospice patients with advanced cancer, Duggleby (2000) suggests that individuals often used hope as a tool to endure physical suffering. Individuals maintained hope through various mechanisms such as trusting in a higher spiritual being, dealing with uncertainty through caring relationships, accepting suffering, and finding meaning in everyday activities (Duggleby, 2000). In an interview study of 28 patients with terminally ill cancer, Eliott and Olver (2009) found that individuals often perceived hope as essential to the very fabric of human life, as opposed to merely viewing hope as a buffering agent against adversity. The link between hope and the cure for cancer, which individuals often associated with the statistical probabilities of survival, meant that hope diminished for individuals as the likelihood of death increased (Eliott & Olver, 2009).

In a survey of 179 advanced cancer patients that were enrolled in clinical trials, Helf, Hlubocky, Wen, and Daugherty (2003) found similar findings and discovered that a more accurate view of poor prognosis was associated with a reduction in hope. At the same time, Eliott and Olver (2009) found that the hope for cure and survival was coupled with the hope for comfort and for better relationships with loved ones. Participants described how the hope for a cure was situated
within a network of valued relationships with friends and family. Individuals in patient’s lives were often positioned as sharing in or endorsing the hopes of patients, however elusive they might be (Elliott & Olver, 2009). Luoma and Hakamines-Blomqvist (2004) noted that for some individuals, being in a clinical trial not only meant hope for an immediate response to treatment, but also represented hope for future cancer treatments. Hope, however, was conditioned on the curative intent of cancer therapy. Some individuals felt that hope was tangible as long as curative treatment was available and that stopping attempts at treatment meant relinquishing hope (Luoma & Hakamines-Blomqvist, 2004).

In an interview study of 200 cancer patients regarding their perception of numerical probabilities in prognostic communication with oncologists, Thorne, Hislop, Kuo, and Armstrong (2006) found that numerical information often shaped the experience of hope. Thorne et al. (2006) identified a sense of discord between the perspectives of patients and healthcare providers. For patients, statistical information became a focus for making sense of uncertainties, exploring emotions surrounding the possibilities of survival, coming to terms with uncertainties, and locating a basis for hope (Thorne et al., 2006). But from the patients’ perspective, healthcare providers operated under a different set of assumptions. Patients perceived that healthcare providers used statistical numbers simply to fulfill professional obligations to inform patients, to govern their decision-making, to act as buffers to prevent unrealistic expectations, and to actively restrict the hope of patients (Thorne et al.). How individuals employed numerical information in their understanding of disease also shifted during the course of illness. Although patients largely accepted statistical information as an accurate reference point in the early stages of their disease, the progression of disease forced individuals to renegotiate a more complicated relationship with statistical figures. Many came to realize the limitations of medical scientific information when applied to their own circumstances (Thorne et al.).

In a grounded theory study (n = 10), Duggleby and Wright (2005) explored the process of how individuals with advanced cancer lived with the notion of hope. Participants often defined hope in terms of their own expectations and goals, such as eliminating suffering and achieving a peaceful death. Individuals often described the process of transforming hope, which involved acknowledging “life the way it is”, searching for meaning, and positive reappraisal (Duggleby & Wright, 2005). Respondents described their concern with wanting to live with hope in spite of
their loss of function, independence, relationships, goals, and the possibility for a long life (Duggleby & Wright). Participants employed motivating catch phrases in order to harness their abilities to locate hope, such as “‘live life,’ ‘keep on going,’ and ‘live day by day.’” (Duggleby & Wright, p. 75). Generating certain social expectations to maintain hope, some individuals identified the consequences of having a diminished sense of hope. For instance, one participant noted, “If you don’t have any hope, then you have nothing for the future, or even for the present” (Duggleby & Wright, p. 75). Through the process of transforming hope, individuals often developed new patterns of understanding that positively reappraised what they wanted for the future. For example, some participants described their hope in terms of not suffering, hope for a better life for their family in the future, and “living life to the fullest in the time they have left” (Duggleby & Wright, p. 76).

10.5 Patients Needs Regarding Care in Advanced Cancer

Although my study is focused on the search for treatment, previous studies suggest that individuals with advanced cancer have multiple needs beyond receiving cancer treatments. In an Australian study of 418 cancer patients who were estimated to have a life expectancy of less than two years, Rainbird, Perking, Sanson-Fisher, Role, and Anseline (2009) identified the perceived care needs of individuals in relation to their everyday functioning. Participants identified needing help to cope with a lack of energy and tiredness, the fears about the cancer spreading, and the frustrations of not being able to do everyday activities that they could do before (Rainbird et al., 2009). Heyland et al. (2006) examined the types of care considered important to individuals with advanced disease (n = 440) and immediate family members (n = 160). The facets of care rated most important to participants were trust and confidence in healthcare providers (55.8 percent), not being kept on life support (55.7 percent), honest communication of information (44.1 percent), and the opportunity to review one’s life and say goodbye (43.9 percent) (Heyland et al.). Interestingly, both the study sampled from both Rainbird et al and Heyland et al. did not identify curative treatment as a priority in their care, which differs from the findings by Pardon et al. (2009) that was discussed earlier in this chapter.
The literature also describes the needs of individuals with progressive disease to work towards a “good death”, which is often considered the conclusion to effective palliative care practices (McNamara, 2004). Hughes, Schumacher, Jacobs-Lawson, and Arnold (2008) asked advanced lung cancer patients (n = 100) open-ended questions about the attributes that lead to a good death. By examining the frequency of key terms, Hughes et al. (2008) located certain themes related to a good death: being asleep (84), pain-free (74), peaceful (27), quick (16), with family around or cared for (12), with God (6), free of regret (4), and at home (3). Using similar data collection methods to Hughes et al., Vig, Davenport, and Pearlman (2002) concluded that a good death was an individualized process and that each study participant voiced a unique combination of themes. Although respondents identified painlessness, dying in their sleep, and a quick death as a component of a good death (Vig et al.), which echoed the findings by Hugh et al., other participants identified not have any prior knowledge of impending death as a characteristic of a good death. For instance, one participant remarked, “Good death? Well, an ideal death to me would be to go bed at night and not wake up in the morning… You don’t have any knowledge of it; you’re asleep”. (Vig et al., p. 1544).

10.6 Suffering and Advanced Cancer

To certain clinicians, there is a concern that the provision of invasive forms of cancer therapies might lead to unnecessary suffering in individuals that may already be suffering from metastatic disease. Several empirical studies have characterized the nature of suffering in advanced cancer, although not necessarily about suffering related to receiving treatment. In a well cited mixed method study of 381 patients, Wilson et al. (2007) examined the physical, social, psychological, and existential dimension of suffering from incurable disease. Even though almost half of respondents (49.3 percent) did not consider themselves to be suffering and 24.9 percent felt that they suffered only mildly, about 25.7 percent were suffering at a moderate to high level (Wilson et al.). Of the group who experienced the highest level of suffering, the highest correlated symptoms were general malaise, weakness, pain, and depression (Wilson et al.). In qualitative narratives, physical problems accounted for most of individuals’ reports of suffering (49.5 percent), psychological (14 percent), existential (17.7 percent), and social (18.8 percent).
Social concerns that led to suffering included dependence, isolation, being a burden to others, and leaving loved ones behind. (Wilson et al.) Facets of existential suffering included the lack of control, the loss of identity, the uncertainty of the future, and the inability to escape one’s circumstances (Wilson et al.). Similarly, in an extensive systematic review of the literature on existential suffering, Boston, Bruce, and Schreiber (2011) located the loss of autonomy and the uncertain negotiation of one’s previous identity as a central feature of suffering. The loss of autonomy was further divided into the loss of independence, control over the future, and continuity of self (Boston et al.). Additional descriptors of existential suffering included the loss of purpose in a life afflicted by advanced cancer and the crisis to locate meaning in the larger question of “why am I here?” (Boston et al., p. 606).

In another key qualitative study of existential suffering, Bruce, Schreiber, Petrovskaya, and Boston (2011) conducted a series of semi-structured interviews with cancer patients, family members, and physicians. Through a grounded theory analysis, Bruce et al. (2011) conceptualized a process of how individuals both experience and address existential suffering. Leading to uncomfortable and anxiety-provoking emotions, this suffering often began with experiences of feeling lost, out of control, and ungrounded (Bruce et al.). Individuals then sought a way out by turning away from the discomfort, attempting to limit uncertainty by clinging to familiar habits, and learning to live with the flux of instability (Bruce et al.). Unlike the portrayal of existential distress as a uniform and static concept in many other studies, Bruce et al. conceptualized the fluid and dynamic nature of existential suffering.

With the open public debate about euthanasia in the Western context, recent studies have linked the suffering of those at the end of life with this controversial act. To some, the end of intolerable suffering is sometimes used to morally justify the role of euthanasia as a humane practice. Karlsson, Milberg, and Strang (2012) conducted in-depth interviews with 66 individuals receiving palliative care about their attitudes toward dying. Those advocating for euthanasia, though not for themselves per se, did so because they viewed suffering as meaningless, the anticipatory fear that suffering could multiply and take on unforeseen dimensions, and doubts about receiving adequate help to alleviate suffering (Karlsson et al.). Those that opposed euthanasia did so because of the perceptions that life, despite suffering, had meaning, trust in the
bodily and emotional adaptations to suffering, and by placing faith in healthcare services to alleviate suffering (Karlsson et al.).

Similar to the link between existential suffering and the loss of control, other scholars have pointed to the possible interrelationships between euthanasia and the desire for control in advanced disease. Karlsson, Milberg, and Strang (2011) examined patient perspectives on the link between euthanasia and autonomy. By promoting patient empowerment and control over one’s personal decisions about mortality, the possible legalization of euthanasia was perceived by some as increasing patient autonomy (Karlsson et al., 2011). For certain individuals, euthanasia was positively referred to as a fundamental human right that should be supported to promote control over one’s death, similar to personal control over one’s life. Conversely, a different set of participants felt that euthanasia could decrease autonomy in a troubling way, by increasing the authority of clinicians to decide over life or death (Karlsson et al., 2011). Many participants who were strongly opposed to euthanasia also reported a deeper sense of mistrust in other social relationship and felt that the power to decide who should live or die was too complicated for healthcare staff to decide (Karlsson et al., 2011).

10.7 Positive Thinking and Advanced Cancer

In addition to the literature that examines suffering, there is another group of studies that examines the expectations for individuals with cancer to think positively. In one of the few poststructural studies on this topic, Youll and Meekosha (2013) examined the perspectives of seven family caregivers about how positive thinking impacted their experiences of cancer. Some participants felt that overt expressions of sadness, pain, or fear could weaken one’s ability to fight cancer, whereas adopting a positive attitude helped their family members to cope with illness. Many felt it was their role to facilitate this way of thinking in day-to-day interactions (Youll & Meekosha). Yet, in hindsight, most participants wished that they could have shared more intimacy and become more emotionally engaged with their family member, unrestrained by the obligation to always “be strong” (Youll & Meekosha). Positive thinking often became a culturally endorsed way to govern the interpersonal dynamics between patients and family members, restricting the way individuals spoke about the encroachment of death (Youll &
Some family members employed positive thinking as a form of resistance against a medicalised understanding of cancer. Family members were often highly sceptical of the medical care provided to their loved ones, with many describing their impressions of slow responses, inappropriate treatment, the second guessing of treatment decisions, and incorrect diagnoses (Youll & Meekosha). Intertwined with feelings of medical mistrust, positive thinking became a defiant way to substitute one’s own perception of the outcome of cancer as a form of resistance to the prognosis claims of oncologists (Youll & Meekosha).

In a grounded theory study of family caregivers and haematological patients receiving stem cell transplants, McGrath, Montgomery, White, and Kerridge (2006) examined the relationships between positive thinking and discussions about death and dying. Even though all participants identified positive thinking as a useful method of coping that was similar to Youll and Meekosha (2013), McGrath et al. found that positive thinking interfered with important conversations and planning about the end of life because of the obligations to always remain positive. At the same time, positive thinking had a range of meanings and consequences. Although it was sometimes difficult to mediate, certain participants were able hold a limited amount of positive thinking to gain strength in challenging times, yet not let this way of thinking impede the planning and preparation for death (McGrath et al.).

11 Relational Influences on the Search for Life-Extension

In the final section of this chapter, I explore some of the relational influences that may lead individuals with advanced cancer to seek life-extension. I first examine the literature on the relational dynamics between patients and family members. Next, I consider the studies that map out certain social tensions between patients and healthcare providers that are generated by the search for treatment. In particular, I consider the growing number of studies that have explored the trust and mistrust of physicians.
11.1 Cancer Treatment and Familial Responsibility

In addition to the anxiety that results from facing one’s own mortality, the possibility of death may generate feelings of guilt for leaving behind family members. In a key phenomenological study of 15 advanced cancer patients, McPherson, Wilson, and Murray (2007) explored patients’ perceptions of being a burden to their family at the end of life. Participants referred to physical, social, and emotional burdens that they were imposing on family members because of their illness (McPherson et al., 2007). Participants were particularly concerned with burdening relatives about choices regarding advanced measures and the decision to transition from the home to institutionalized care (McPherson et al.). Individuals also expressed a sense of failure at being unable to complete important social roles, particularly for participants with young children. As a result of these pressures, individuals struggled with the idea that they were responsible for their own limited function, or in some cases, having developed cancer in the first place. Even if responsibility was attributed to external factors, such as genetic susceptibility, this did not lessen patients’ sense of burden and feelings of accountability (McPherson et al.). Individuals reported a variety of strategies to cope with their family’s sense of burden: being active in their own care, concealing their needs, prioritizing the needs of others, and helping family plan for a future without them (McPherson et al.).

In a grounded theory study, Elmberger, Bolund and Lutzen (2005) used focus groups and interviews to explore how women with breast cancer dealt with their moral concerns related to parenthood. Participants felt pressure about not being able to live up to their own perceived self-image as an ideal mother (Elmberger et al. 2005). The reactions of their children to their altered appearance (i.e. fear, aggression, shame) further intensified their sense of failure about not being a model parent. By pushing aside illness or pretending that they were well in front of their children, participants tried to deal with the realization that this parental ideal could not be achieved in advanced disease. Individuals alleviated their moral responsibilities of motherhood by arranging for extended family and friends to be “extra parents”. Although themes around the pressure to survive were evident in the study by Elmberger et al., few women overtly described the association between surviving cancer and meeting their parental responsibilities.
In one of the few studies that examined the link between parenthood and potentially life-extending treatment, Nilsson et al. (2009) examined the treatment choices of advanced cancer individuals with and without children (n = 668). Researchers asked participants to pick between the options of (1) “a course of treatment that focused on extending life as much as possible, even if it meant more pain and discomfort” (Nilsson et al., 2009, p. 401), or (2) receiving care that relieved pain and discomfort, even though it means not living as long. After adjusting for other variables, individuals who had dependent children were more likely to prefer invasive, non-palliative cancer treatments and also exhibit symptoms of anxiety (odds ratio = 1.77) (Nilsson et al.). Individuals with dependent children were also less likely to engage in advanced care planning for a “do not resuscitate” order (odds ratio = 0.44) and had a lower quality of life in the last week of life (Nilsson et al.).

11.2 Family Members as Advocates for Treatment

When individuals are not able to self-advocate as the disease worsens, patients may relinquish the control over treatment choices to family members (Winter & Parks, 2008). Similar to patients’ preferences for curative therapies (Slevin et al., 1990; Donovan et al., 2002; Sahm et al., 2005; Hirose et al., 2005), many studies suggest that family members favour the use of more invasive therapies late in the cancer trajectory. Surveying family members of individuals with advanced cancer, Oh et al. (2004) found that only 69 percent of family members could discern whether their loved ones had metastatic versus non-metastatic cancer. Compared to the acceptance rate of 41 percent for their primary physician, approximately 60 percent of family members approved of additional rounds of curative chemotherapy, despite the limited treatment efficacy of these therapies (Oh et al.). In a similar longitudinal study, Burns, Dixon, Broom, Smith, and Craft (2003) found that most caregivers understood that the cancer of their loved one was life threatening (92 percent). Yet, when loved ones were provided palliative treatments, only 48 percent of family members understood that the treatment was non-curative, and 25 believed that treatment would provide a cure (Burns et. al, 2003). Similar to patients, family members may have overly optimistic perceptions of cancer therapy, although more research is needed.
A sense of conflict often arises when the perspectives of family members differs from patients. Kramer, Kavanaugh, Trentham-Dietz, Walsh and Yonker (2009) conducted a cross-sectional study of the predictors of conflict reported by family members of lung cancer patients (n = 150). Twenty-nine percent of participants reported disagreements among family, 19 percent felt anger, and 12 percent insulted or yelled at another family member (Kramer et al., 2009). Kramer et al. suggest that a higher level of family discord was associated with stronger preferences for life-prolonging treatments. Yun et al. (2006) examined the disparity in aggressive care preferences, (ICU admission and CPR usage) between advanced cancer patients and their families (n = 240 pairs). Sixty-eight percent of patients and their family members were in agreement regarding admission to the ICU and 71 percent were in agreement regarding CPR (Yun et al., 2006). Individuals with advanced cancer who were younger, unmarried, preferred to die in hospital, and had previous disagreements with their families were more likely to have a different treatment preference from their family caregivers (Yun et al.).

11.3 Communication about Prognosis and Treatment Options with Physicians

Some studies suggest that the relational dynamics between patients and providers in the disclosure of prognosis plays a pivotal role in influencing whether individuals search for life-extension. In a key qualitative study, Gordon and Daugherty (2003) explored oncologists’ attitudes about communicating prognostic information to individuals with metastatic disease. As opposed to using percentages and figures to convey the outcome of cancer, oncologists disclosed prognosis in terms such as “not being curable” (Gordon & Daugherty, p. 142), which was perceived as a neutral statement. Oncologists often discussed their reluctance, the obligation to protect patients, remorse, and guilt at having to disclose a poor prognosis. Gordon and Daugherty found that oncologists often conveyed these feelings through the use of metaphors, such as “hit someone in the face” (p. 155) or “force it down their throat” (p. 155), in order to depict the perceived impact of such information on patients.

Gordon and Daugherty (2003) suggest that oncologists felt that patients often expected to be cured and to live longer than estimated. Many individuals expressed these hopeful expectations
of survival in terms of attending a life event in the distant future; for example, attending their grandchildren’s high school graduation (Gordon & Daugherty). Participants also exhibited a different frame of prognostic understanding than physicians, as evidenced by their belief in a cure after a mild response to treatment or their surprise when their cancer relapses. Although physicians tempered unrealistic hope by offering a “dose of reality” (Gordon & Daugherty, p. 160) through discussing individuals’ expectations of therapy, they also used hope to smooth through their own anxieties around disclosure. Oncologists accomplished this by being positive about curative therapies, telling patients that scientists are “working on new therapies all the time” (Gordon & Daugherty, p. 159). One oncologist commented, “I think just by offering therapy…. is offering hope” (Gordon & Daugherty, p. 159). DelVecchio Good et al. (1990) also found that oncologists expressed their care of the patient through offering biomedical care. At the same time, the findings by Gordon and Daugherty point to how physicians may provide contradictory messages to individuals: be realistic about your poor chances of survival, yet here are other curative treatment options.

Although several studies have examined the interpersonal dynamics between physicians and patients in the context of treatment choices in advanced cancer (Clayton et al., 2005; Gleason, Harper, Eggly, Ruckdeschel, & Albrecht, 2009; Lamont & Christakis, 2001; Hagerty et al., 2005), fewer studies have explored the role of the nurse. In an interview study (n = 13), McCullough, McKinlay, Barthow, Moss, and Wise (2010) examined how nurses report their contribution to prognostic communication when individuals have advanced cancer. Nurses described being present with patients in treatment consultations and offering clarification to patients later when asked. When patients were unable to discriminate against the different treatment options, nurses attributed this to how physicians presented curative therapies in meetings (McCullough et al., 2010).

As with physicians, nurses found it challenging to balance hope versus realism in their interactions with patients. Although nurses acknowledged dealing with the stress of individuals within the complexity of treatment options and the unpredictability of its effectiveness, McCullough et al. (2010) did not explore how nurses might relate to patients in a way that either mitigated or intensified this anxiety. Deferring responsibility to other members of the team, nurses attributed the tensions surrounding treatment to the dynamic between physicians and
patients, and often perceived physicians as ultimately controlling this process. Because of the fear that physicians might withdraw treatments, nurses believed that patients were often hesitant to question physicians about the extent of treatment side effects (McCullough et al., 2010).

11.4 Trust and Mistrust of Physicians

The mistrust of physicians may influence patients’ search for life-extension because of the perception that physicians may withhold certain curative options or do not always have their best therapeutic interests in mind. Several empirical studies have examined the role of trust in advanced cancer. In an extensive literature review of the literature from 1998 to 2008, Hillen, de Haes, and Smets (2011) found that patients’ trust in cancer care physicians was generally strong. Trust was enhanced by the perceptions of physicians’ technical competence, biomedical knowledge, and honesty about prognosis and treatment (Hillen et al.). Having a trusting bond with physicians was associated with certain medical outcomes. A trusting relationship led to better communication, improved treatment adherence, and a decrease in negative emotions like fear (Hillen et al.). Although the relationship between trust and the willingness of individuals to forgo the search for biomedical therapies was not described in the literature, a sense of trust was related to patients’ willingness to accept and adhere to medical advice throughout diagnosis and treatment (Hillen et al.). In a qualitative study of advanced lung cancer patients that refused diagnosis or treatment (n = 9), Sharf, Stelljes, and Gordon (2005) found that the mistrust of medical authority impacted the decision to not seek treatment. Mistrust was defined by participants as the widespread suspicions of both the information provided to them and also the physicians themselves (Sharf et al.). In many cases, mistrust was based on previous negative experiences with physicians or episodes where family members or friends had become incapacitated by cancer treatments (Sharf et al.).

In a similar thematic review of the trust literature from 1980 to 2006, Seetharamu, Iqbal, and Weiner (2007) located certain factors that influenced patients’ trust of oncologists. Oncologists often engendered trust through how they navigated the suffering of individuals, such as minimizing the potential for humiliation during medical consultations and demonstrating a genuine appreciation for the discomfort of patients (Seetharamu et al.). A sense of trust was also
engendered when oncologists mediated the power imbalances with patients, were sensitive to the vulnerabilities of emotional and physical intrusions, and by recognizing the social privilege of physicians (Seetharamu et al.). Trust was also fostered when patients were allowed to retain a sense of control over their treatment options, medication, and the day-to-day managing of their cancer (Seetharamu et al.).

In a qualitative study on trust, Hillen et al. (2012) conducted semi-structured interviews with 29 cancer patients in the Netherlands. Similar to the findings of the earlier studies by Hillen et al. (2011) and Seetharamu et al. (2007), fidelity, respect, honesty, and competence were often viewed as important to trust. Hillen et al. (2012), however, discovered that the need to trust one’s oncologist was central to participants’ descriptions because of the severe and life-threatening nature of their cancer. Even though a deeper bond of trust was developed after repeated interactions, individuals felt compelled to quickly establish a trust alliance with their oncologist (Hillen et al., 2012). Even though the study sample had participants with both advanced and non-advanced disease, the study analysis did not take into account how disease status might influence the perception of trust. Few studies have considered, how the inability of certain cancer treatments to generate a response, which is often the case in the trajectory of advanced cancer, might color patients’ sense of trust.

A recent trend, particularly in studies from the US, the trust literature has shown an increasing concern with how the different social locations of cancer patients might impact their sense of trust during cancer screening (Bynum et al., 2012; Sheppard et al., 2013), diagnosis, and treatment (Guadagnolo et al., 2009; Halbert et al., 2006). Much of this research is focused on how various ethnic and racial groups experience the mistrust of medical authority (Bynum et al.; Sheppard et al.; Guadagnolo et al.; Halbert et al.). At the same time, few studies have considered the effects of additional social locations (for example, educational level, occupation, financial status, or disease acuity) on cultivating trust in the medical encounter.
Discussion of The Literature Review

In this final section of this chapter, I discuss the overall results of this literature review and place these broader findings within the empirical and theoretical concerns of the present study. Although the epidemiological evidence regarding the search for life-extension in advanced cancer was difficult to obtain because this topic is difficult to conceptualize, the magnitude of this phenomenon can be inferred based on the larger population based studies that were reviewed. Approximately 16 to 32 percent of individuals with incurable disease continue to receive therapies intended to eradicate cancer close to death (Barbera et al., 2006; Earle et al., 2008; Murillo & Koeller, 2006). Because these kinds of treatments may lead to further interventions like intensive care, and are sometimes provided regardless of their effectiveness, the clinical appropriateness of curative therapies in advanced cancer has been questioned in the literature (Weeks et al., 1998; Emanuel et al., 2003).

This literature review highlighted the shifting clinical contexts that currently surround the search for life-extension. A relatively new model to support care of the dying, the integration of palliative care within curative oncological protocols has been shown to lead to better short-term survival (Temel et al., 2010) and improved quality of life (Meyers et al. 2011; Bakitas et al., 2009). Although several studies have highlighted beneficial outcomes of early palliative integration, not much is known about how these two seemingly divergent approaches to care impact on how patients, family members, and health professionals negotiate the search for treatment intended to extend life. Through my study, I consider the social tensions and social effects on the self that result from simultaneously dealing with the likelihood of death yet searching for life-extension and, by extension, pursuing a cure for advanced cancer.

Although clinicians have informally labelled curative treatment in advanced cancer as “futile” or medically unnecessary, there was a lack of health science research to corroborate with some of these assumptions. Similarly, although invasive treatment in advanced disease was labelled as “aggressive” in certain studies (Earle et al., 2004; Braga et al., 2007; Temel et al., 2010), the literature did not provide a uniform and empirically informed definition of which therapeutic interventions constitute aggressive treatment and why. Yet, some empirical evidence does suggest that healthcare professionals, in particular nurses, find these therapies ethically
problematic because advanced cancer patients may not be fully informed about their poor prognosis (McLennon et al., 2013; Demrosch et al., 1993; Kuuppelomäki & Lauri, 1998).

Despite being labeled by certain clinicians as futile or aggressive, the search for potentially life-extending treatment is also framed by the emerging scientific possibilities to cure incurable cancer. Some literature has considered the wider cultural view that biomedical science will eventually piece together the puzzle in order to win the long-term war on cancer (Camus, 2009; DelVecchio Good et al., 1990). One of the implications of this perception is the sense that care of the individual with advanced cancer should be focused on providing biomedical intervention, as opposed to addressing other dimensions of their personhood (DelVecchio Good et al., 1990). As evidenced by the numerous studies on experimental clinical trials, many of which consider how to expand this treatment option to an even wider population (Jenkins et al., 2013; Ford et al., 2011), the encroachment of bio-scientific rationality in the treatment of incurable cancer forms an important backdrop to this phenomenon. While previous research has examined how individuals have an optimistically skewed view of clinical trials as a curative venture (Kass et al., 2010; Sulmasy et al., 2010; Meropol et al., 2003), less is known about how individuals who are searching for life-extension might accesses experimental interventions as an alternative to standard treatments. Moreover, few studies have explored how individuals who seek life-extension utilize their understanding of bio-scientific discourse, particularly given the recent increase in public awareness about cancer research (Camus). My study opens up a new understanding of the utilization of bio-scientific knowledge from the perspectives of individuals with late-stage cancer and their family.

This literature review examined several studies that considered the unique rationales of patients toward treatment and cancer. I divided the literature into three larger categories. As individuals may pursue curative therapies if they believe in certain prognostic benefits, the first group of studies suggests that cancer patients are often willing to receive more invasive forms of cancer therapy in exchange for relatively small gains in the length of survival (Slevin et al., 1990; Donovan et al., 2002; Sahm et al., 2005; Hirose et al., 2005; Voogt et al., 2005). The second group of studies suggests that individuals with advanced disease sometimes overestimate the curative value of a wide spectrum of biomedical treatments such as chemotherapy, radiation, and clinical trials (Chen et al., 2013; Chow et al., 2001; Penson et al., 2004; Weeks et al., 1998; Kass
et al., 2010; Meropol et al., 2003; Sulmasy et al., 2010; Godksesen et al., 2013). Focusing on the informational deficits of individuals, the third category suggests that individuals who seek life-extension may not fully understand disease, treatment, and the possibilities of dying from their disease (Tattersall et al., 2002; Chochinov et al., 2000; Hancock et al., 2007; Quirt et al., 1999).

Based on certain assumptions, the current research on patients’ perceptions of their disease and treatment provides only a partial understanding of the search for life-extension. From a neoliberal perspective, individuals are regarded as competent and self-directed individuals, who are supported by healthcare systems to make intelligent and informed choices about disease when they maximize their own curative potentials through different practices of the body (Eliott & Olver, 2005; Shelton, 1998). Supported by a realist position that views seemingly uncontrollable events such as late-stage cancer as controllable (Vahabi & Gastaldo, 2003), understanding the biomedical details of one’s disease status is now a key responsibility for patients. The “correct” knowledge about disease may motivate individuals to either take up curative practices, or when biomedicine concludes that one’s cancer is incurable, let go of the search for life-extension. Suggesting that individuals who search for life-extension may understand their disease and treatment in a way that is considered “irrational”, many of these previous studies on the rationalities of patients have focused on the “deficiencies” of these individuals in not meeting these expectations and responsibilities.

Despite the neoliberal demand to take self-directed responsibility about disease (Moore, 2004), these studies may suggest that individuals who search for life-extension are seemingly passive recipients in the negotiation of treatment. Under this perspective, patients are not fully able to effectively utilize biomedical scientific knowledge, the valued currency needed to make informed treatment choices, in the pursuit of life-extension. The current literature thus places individuals in a powerless position – patients are overly reliant on healthcare providers to accurately disclose prognosis and offer interventions. In this view, these kinds of individuals are depicted as one-dimensional, rationalistic, and medically constructed individuals (Marta, 1998). A simplistic binary categorization of “rational” or “irrational” binds patients and healthcare providers, emphasizing the disconnectedness in locating treatment options, while viewing the emotional, linguistic, and socio-cultural dimensions of choice as less significant in their choices (Marta).
Since the current literature has often focused on individuals’ apparent irrationality, not much is known about the search for life-extension within the complexities of individuals’ lives, social relationships, and understandings of their own identities. Although many studies have explored how patients are often willing to receive more invasive forms of therapy and overestimate the curative potential of treatment, few studies have critically problematized these research claims. As if the search for life-extension exists in a social and historical vacuum, few studies have explored how it came to be that individuals who have advanced disease understand their treatment in these ways given broader social forces.

On one hand, one group of research studies suggested that patients are often uninformed about treatment and advanced disease. On the other hand, another group of research suggested that individuals with cancer often seek out information in an active way. Studies reviewed in this chapter have examined how cancer patients with late-stage disease still request knowledge about treatment, and often want this information to be optimistic (Hagerty et al., 2005; Pardon et al., 2009; Kutner et al., 1999). Moreover, a growing body of literature has suggested that individuals often seek knowledge about cancer treatment outside of the authority of healthcare professionals (Rutten et al., 2005; Carlsson, 2000; The et al., 2001; Walsh et al., 2010; Muusses et al., 2012; Smith-McLallen et al., 2011). The tensions between the uninformed and information seeking individual described in this review generate interesting research possibilities. Few studies have considered how individuals with late-stage cancer who are seeking treatment might locate knowledge and how they might use this knowledge to advocate for themselves in the medical encounter.

In my search of the literature, I could not locate any study that interrogated the search for life-extension in advanced cancer though a poststructural theoretical framework. As a result, few studies have considered how individuals might use their knowledge of disease to more assertively exercise power relations with healthcare providers, rather than become exclusively reliant on biomedicine. Given the increased duration of living with advanced cancer in the current state of biomedicine, where individuals repeatedly encounter the cancer care system for months to years, and the more open public discourses about cancer (Willig, 2011), the assumed powerless of patients because they are uninformed or unaware of dying may be problematic. In this study, I seek to examine how individuals might actively generate their own curative
possibilities that potentially lie outside the dominance of biomedicine. As evidenced by the literature on positive thinking and alternative medicine (Youll & Meekosha, 2013; McGrath et al., 2006; Molassiotis et al., 2005; Shen et al., 2002; Mercurio & Ardath Eliott, 2011), individuals with late-stage cancer may be seeking life-extension from more dispersed influences that lie beyond biomedicine at this point in time.

Leading to existential distress that may delay death and in turn sustain the search for life-extension, death anxiety (Grumann & Speigal, 2003; Sand & Strang, 2006) and the denial of death (Zimmermann, 2004) in advanced cancer was also examined in this literature review. The possible interrelations between death anxiety, denial, and the search for life-extension is not well understood in the literature. Once again, the current chronicity of advanced cancer, where the experience of disease is typically characterised by repeated and unresponsive treatment attempts, problematizes whether patients who seek life-extension are necessarily in denial of their death.

In this literature review, I considered the emotional or psychosocial factors that may influence individuals’ search for life-extension. In particular, I examined the literature on the meaning of illness (Luoma & Hakamines-Blomqvist, 2004; La Cour et al., 2009; Lee et al., 2004), end of life transitions (Reinke et al., 2008), hope (Duggleby, 2000; Eliott & Olver, 2009; Luoma & Hakamines-Blomqvist, 2004; Helf et al., 2003; Thorne et al., 2006; Duggleby & Wright, 2005), the needs of late-stage cancer patients outside of treatment (Rainbird et al., 2009; Heyland et al., 2006), and suffering (Wilson et al., 2007; Boston et al., 2011; Bruce et al., 2011; Karlsson et al., 2012). Emphasizing the subjective experience of individuals, as opposed to considering how the self is shaped by social, political, and historical contexts (Fraser, 1985), many of these studies are framed using humanistic perspectives. Although I do not dispute the importance of psychosocial or emotional influences in the search for life-extension, I suggest that this approach offers a limited view of this complicated phenomenon. Rather, by considering how wider political and social forces beyond the subjective experience of advanced cancer might mould the search for life-extension, I generate richer and unexpected ways to understand this important phenomenon.

Finally, I explored some of the studies that considered the relational factors that influence the search for life-extension in this literature review. First, I examined the effects of familial relationships in the search for life-extension, such as burdening family members with treatment
choices at the end of life (McPherson et al., 2007) and the concerns about one’s ability to fulfil parental obligations (Nilsson et al., 2009; Elmberger et al. 2005). Similar to patients’ preferences for curative therapies (Slevin et al., 1990; Donovan et al., 2002; Sahm et al., 2005; Hirose et al., 2005), the literature also suggests that family members favour the use of more invasive medical therapies late in the cancer trajectory (Oh et al., 2004; Burns et. al, 2003). Although the study by Yun et al., 2006 found that family conflicts often led to receiving more invasive therapies at the end of life, few studies have critically examined how the relational dynamics with family might shape the search for life-extension. Moreover, few studies have considered the effects on family members when patients active participate in the search for biomedical treatment, rather than prepare for the possibilities of dying.

While several studies have examined the unwillingness of physicians to openly disclose information about cancer prognosis and treatment options (Gordon & Daugherty, 2003; Clayton et al., 2005; Gleason, Harper et al., 2009; Lamont & Christakis, 2001; Hagerty et al., 2005), few studies have examined the further relational tensions, power imbalances, and the social dynamics around how knowledge is exchanged in the negotiation of treatment. Furthermore, less is understood about how relationships with healthcare professionals and their actual care practices might lead late-stage cancer patients to search for life-extension. Even though the current literature suggests that individuals’ generally trust their oncologists (Hillen et al., 2011; Hillen et al., 2012; Seetharamu et al., 2007), less knowledge is known about how the limitations of biomedicine to generate long-term life-extension might lead to a sense of mistrust for some individuals with metastatic disease. By considering how power relations are exercised in the negotiation of treatment at the end of life, this study provides new insights into the search for life-extension.

13 Conclusion to Literature Review

In this chapter, I situated the aims of this study within the body of literature that has previously focused on the search for life-extension in advanced cancer. This chapter was divided into six main sections. I first described the epidemiological distribution of this phenomenon, by considering the studies that have examined the prevalence and contributing factors to the
provision of curative biomedical treatment late in the disease trajectory. I then reviewed the studies that examined the clinical contexts that surround the search for life-extension. In particular, I considered how this phenomenon is often problematized by the literature as “aggressive” or “futile” care. I also reviewed studies that have considered the cultural role of biomedical science in the treatment of incurable disease, as well as the emergence of complementary and alternative medicine. In the third section, I reviewed the biomedical studies that have examined the kinds of rationales cancer patients might employ to drive their pursuit for life-extension. I then moved on from reviewing individuals’ understanding of disease prognosis and treatment, to consider the psychosocial factors that may impact this type of treatment practice. In particular, I reviewed studies on the meaning of illness, end of life transitions, the hope for survival, patients’ needs beyond treatment, suffering, and positive thinking. In the fifth section, I explored some of the relational factors that may lead individuals to search for potentially life-extending treatment. After considering the dynamics between patients and family members, I then focused my review on the studies that examine the social tensions between patients and healthcare providers that are generated by the search for biomedical treatment. To conclude this chapter, I discussed the overall results of this literature review and placed these broader findings within the empirical and theoretical concerns of the present study.
Chapter 3
Theoretical Framework

14 Introduction to Chapter

In this chapter I describe the theoretical framework that I use to examine the discourses in operation and the kinds of subjectivities constituted by these discourses when individuals with advanced cancer seek life-extension through biomedical treatment and beyond. This chapter is organized in four sections. In the first section, I introduce the work of Michel Foucault and poststructuralism as a philosophical approach. In the second section, I describe key concepts such as power/knowledge, governmentality, biopower, and neoliberalism. In the third section, I outline the two central theoretical concepts that guide this study: discourse and subjectivities. Within the notion of subjectivities I also develop an understanding of care of the self. In the final section, I justify the use of a Foucauldian theoretical perspective to achieve the aims of this study and for researching life-threatening cancer in the 21st century.

15 An Introduction to Foucault and Poststructuralism

Michel Foucault, a late 20th century French philosopher, was influential in developing poststructuralist theory as a challenge to the assumptions of structuralism. By viewing language and culture as a closed system of signs and other elements, structuralism is an analytical approach that explained human phenomena in terms of its underlying structures (Piaget, 1970). According to structuralist theory, everything has a structure below the level of meaning, and this essential structure constitutes the reality of that object or idea (Gutting, 2005; Blackburn, 1996). Certain schools of structuralism were concerned with the centrality of distinct social structures, such as socioeconomic class, to provide a framework for the analysis of social life. Opening up the rigidity of structuralism, Foucault (1966) became concerned with a genealogical understanding of the world, which examines power relationships and the historical “conditions of possibility” that allowed forms of knowledge to emerge or conversely to be suppressed. Whereas structuralism viewed knowledge as universal, essential, and inherent, poststructuralism viewed knowledge as haphazardly arranged, fragile, transitory, and full of contradictions (Foucault;
Cooter, 2007). Poststructuralism argues that objects, individuals, and relationships have multiple meanings that shift with various contexts or different historical locations.

Although there are other philosophers that are categorized under this theoretical framework, Foucault is the most prominent thinker in poststructuralism. A Foucauldian approach forms the theoretical perspective of this study. For the purposes of this study, I use the term “Foucauldian” interchangeably with the term “poststructuralism”.

16 Key Theoretical Concepts

In this section, I outline some of the key theoretical concepts that provide the foundation for understanding a poststructural framework. Significantly informing the research analysis and findings of this study, these concepts include: power/knowledge, governmentality, biopower, neoliberalism, and autonomy.

16.1 Power/Knowledge

Foucault made significant theoretical contributions to the notions of power and knowledge. These ideas are so aligned in poststructuralism that they are collapsed into the single term power/knowledge (Foucault, 1976; Mansfield, 2000). Knowledge is enmeshed in relations of power to Foucault; it regulates the social conduct of individuals and their bodies through various practices. Power/knowledge operates through multiple technologies (techniques) and numerous institutional apparatuses such as morals, laws, philosophical approaches, and scientific statements (Foucault).

Rejecting the idea that power is enforced from above, Foucault (1976) suggests that power is relational; people exercise power from innumerable points and power is located everywhere because it “comes from everywhere” (p. 93). Power is not something that is acquired, seized, or dispensed, but rather is something that one exercises from innumerable points through one’s relationships with others. As one always exists within power relations, one is never outside of
power. Power relations are not in a position of exteriority to other types of relationships such as economic, sexual, or political, but rather power is inscribed through how individuals interact with others (Foucault, 1976). Power produces more than knowledge, but also produces the actual form of the subject (Yates & Hiles, 2010). The individual is not a nucleus onto which power fastens itself and the individual does not exist as an outsider that stands as an antithesis of power (Foucault, 1980; Yates & Hiles). Rather, through power/knowledge relations, certain “bodies, certain gestures, certain discourses, certain desires, come to be identified and constituted as individuals” (p. 98).

Power relations form a dense web that passes through various societal apparatuses and institutions (Foucault, 1976). At the same time, “where there is power, there is resistance” (Foucault, p. 95) and this resistance is never in a position of exteriority in relation to power. As opposed to a single locus, one exercises resistance at multiple points throughout the web of power relations in an irregular fashion at various densities (Foucault). The effects of resistance on individuals and society are multiple, diverse, and often difficult to locate. Resistance to power relations has occasionally led to broad political movements, cleavages in society, and the mobilization of individuals. But more often resistance is mobile and transitory, moving through apparatuses and institutions without necessarily being localized in them (Foucault).

16.2 Governmentality and the Government of Individuals

In my discussion of how cancer treatment practices generate a particular relationship to the self, governmentality, and in particular self-government, becomes an important theoretical idea. Foucault (1979) argues that governmentality is the common ground for all modern forms of political thought, action, and authority (Rose, O’Malley, & Valverde, 2006). Governmentality is defined as an “ensemble formed by the institutions, procedures, analyses and reflections, the calculations and tactics” (Foucault, p.20) that constitutes different forms of power. The shift from the authority of sovereign rule to governmentality began in early 19th century Western Europe. Governmentality evolved as the art of government to regulate a population that could not be controlled by the aristocracy or the family alone (Rose, 2006). Rather than the repressive forms of maintaining power in the sovereign model of rule, the “art of government” involved a
shift towards how to govern (Foucault). To maintain civil rule, governmentality as a concept had to act on relations that were subject to natural processes and external pressures. A new type of power arose that was invested in systems of social administration such as prisons, schools, factories, and hospitals (Mansfield, 2000; Foucault). Rather than forming an authoritative body, government became a collection of practices and activities that were implicated in directing and shaping the conduct of individuals and populations (Rose, 1996; Burchell, 1996). Developing ways to govern through the regulation of the “conduct of conduct” (Gordon, 1991, p. 2), governmentality employed a multitude of technologies, including domination, disciplinary techniques, and self-governing ethics (Holmes & Gastaldo, 2002).

Individuals and groups are governed in numerous ways and on multiple levels: as nations, citizens, and self-governing subjects (Gordon, 1991). As a result, governmentality is connected to the politics of the self and self-government (Oksala, 2007). Since it involves practices that try to shape individuals through governing their choices, desires, and aspirations, governmentality is concerned with practices of the self (Rose & Miller, 1992; Holmes & Gastaldo, 2002). The government of individuals occurs when individuals are made subjects of particular discourses (i.e. the process of subjectification) that often generate norms and expectations of behaviours. For instance, biomedicine produces professionally defined truths that function as norms like the parameters of what is acceptable weight and blood pressure. As opposed to the fear of punitive punishments, the subjectification of individuals operates through the internalization of these normative regulations (Foucault, 1977a). Becoming particular kinds of governed subjects, individuals modify their behaviour in an attempt to approximate normal parameters (Frank & Jones, 2003; Oksala). As a result, normalizing techniques of self-government often inscribe a way of living that conforms with a collection of social rules and ways of conceiving of oneself and others (Holmes & Gastaldo).

16.3 Biopower or Life as a Political Object

The control of biological life for political aims, biopower is an important theoretical concept used to examine how the bodies of individuals with advanced cancer became political objects in the health sciences (Packer, 2011). Beginning in 18th century Western Europe, the government of
individuals and populations began to be exercised through biopower or the calculated management of life (Foucault, 2003). Biopower exerted its political influence through the management of the vital characteristics of human life: health, reproduction, sanitation, birth rate, and longevity (Foucault, 1997). The rise of biopower was coupled with the rise of capitalism in Western Europe (Foucault, 1997). Through various social institutions such as hospital, schools, armies, and factories, individual bodies were transformed and trained to be economically and politically useful (Foucault, 1977a). Institutions used disciplinary techniques such as hierarchical observation, surveillance, examination, and normalizing judgements to build the capacities of individuals towards productive ends (Foucault, 1977a). These practices produced “docile bodies” that were simultaneously subjected and transformed into useful objects for governing bodies such as biomedicine (Foucault, 1977a).

Foucault proposes two poles of biopower: anatamo-politics and biopolitics (Rabinow & Rose, 2006; Foucault, 1976). Anatamo-politics is concerned with integrating the body in efficient systems of production, whereas biopolitics is concerned with the numerous disciplinary techniques that distribute bodies in time and space (Foucault, 2003). Groups and individuals often exercise biopower through practices that come to measure, categorise, shape, and construct the “biopolitical” body (Rabinow & Rose; Genel, 2006). The body then is not stable or static within biopower, but is in flux with the various political structures and systems of knowledge that constitute this form of power (Foucault, 2003).

16.4 Biomedicine in Poststructural Thought

For Foucault, medicine was an important “science of humanity” under which individuals came to be constituted as objects of knowledge (Packer, 2011). Medicine is not simply a series of interventions, relying on remedies and cures to combat illness. Patients are both objects and subjects of the gaze of healthcare professionals (Foucault, 1963). In addition to the manipulation of the body as an object, patients are often governed through becoming the subjects of the health sciences (Foucault, 1963). Health science employs various widespread techniques to constitute patients as subjects: developing diagnostic categories, enforcing disease risk parameters, and outlining health promotion strategies. In the form of a body of knowledge, medicine defines a
way of living, a reflective mode of relation to oneself, to one’s body, to food, and to sleep (Murray, 2006). For instance, Foucault (2003) viewed ancient Greek medicine as a “technology of life” because it offered a novel aesthetic on how to live a good life, a way to break free of past modes of subjection. Acting as a “technology of the self”, modern medicine in the West, in contrast, instructs individuals how to be the good self rather than how to live the good life (Foucault, 2003).

As a result, contemporary biomedicine does not liberate the self, but appropriates the self to its own ends. A notion healthcare discourse conceals and systematically obscures, medicine has become part of the contemporary problem of the self and simultaneously is constructed as an answer to the problem of the self (Murray, 2006). The 21st century self is constrained by demands set forth by the morality of medicine. Life is deemed troublesome if one fails to submit to examinations, to professional recommendations, and by refusing to meet the responsibilities set forth by the dominant discourses of health established by biomedicine (Murray).

16.5 Neoliberalism and Health

Neoliberalism in health is a useful theoretical concept to help interrogate the conditions of possibilities for the various discourses of cancer treatment. Advanced neoliberalism has evolved as a widespread formula of rule that informs how governance is practiced in late modernity (Gordon, 1991; Rose & Miller, 1992). Whereas classical liberalism emphasized the responsibilities of the state to care for its citizen, neoliberalism has evolved into a rationality in which citizens are responsible for their own care (Moore, 2004). Neoliberalism was developed as a response to the concern with the modern oppressive forces of control, and thus advocated for choice and freedom of the individual. An influential force, particularly in the Western world, neoliberalism focuses on the most efficient and least costly means to achieve its governing effects (Foucault, 1997). Contemporary healthcare manifests this approach through the move to lower healthcare costs, de-institutionalize healthcare, the promotion of active citizenship, and the emphasis on responsibility of the self for one’s own health (Moore).
16.6 Autonomy

Autonomy becomes an important idea in my discussion of the discourses and subjectivities around neoliberalism and health at this point in history. Although Foucault suggests that individuals have a certain amount of agency, the notion of autonomy in poststructuralism is problematic. Embedded in neoliberalism as a theoretical concept, the traditional view of autonomy has connotations of self-ownership, sovereignty, and individual control over decisions (Marshall, 1996). Foucault views the pursuit of personal autonomy as a social construction, which is constituted by historical, social, and political locations (Olssen, 2005). Autonomy is very challenging to obtain from a poststructural perspective. According to Foucault, the conception of individuals as completely free agents is highly problematic, as modern power and the technologies of governmentality have produced individuals who are governable (Bevir, 1999; Marshall). Autonomy is also a model for personal health that is employed and promoted by contemporary medicine. Although the physical body may be ill, the production of a political identity of autonomy by healthcare professionals allows patients to sometimes feel that they are in control of situations that may not be controllable (Marshall). Individuals are sometimes made to feel that they are in control of the care of their own diseased bodies and their subjective experience of disease. The production of a free subject by the neoliberal discourse of autonomous patient choice creates different forms of socialisation and social control. The guise of freedom constitutes a more nuanced form of conduct in which a belief in one’s own control constitutes a political identity that makes individuals more governable (Olssen).

17 Discourse and Subjectivity

17.1 Historical Ruptures and the Human Sciences

In this section, I briefly trace the evolution of Foucault’s early scholarly work that led to the development of discourse and subjectivity as central concepts in poststructuralism. In his early scholarly writing that lead to his ideas on discourse, Foucault (1972) critiques the traditional notion of history as a linear progression or a gradual evolution of ideas across time. Under this traditional view, the most current form of knowledge is often viewed as the historical product of
the accumulation of wisdom over time and thus is often considered the highest form of knowledge. Foucault also problematizes the notion that one can trace the historical origins of knowledge in a unified and linear way. From a poststructural perspective, breaks, ruptures, and discontinuities in ways of thinking define a system of knowledge as much as unified and coherent themes. To Foucault, knowledge is often the product of historical tensions, transformations, disjunctures, and interruptions. By recognizing the role of discontinuity in the development of knowledge, one is then freed up to describe the complexity of knowledge formation and the “interplay of relations within it and outside it” (Foucault, p. 29).

Foucault was interested in the “sciences of humanity” of Western Europe, such as medicine, psychiatry, public health, law and punishment, and human sexuality. He sought to develop a history of how human beings in Western culture came to be constituted as objects of knowledge (Packer, 2011). Foucault developed an archaeological method to examine how systems of knowledge form human objects. An archaeological approach involves a “critical investigation that aims to discover the social and historical conditions for the possibility of specific forms of knowledge” (Packer, p. 345). Although the informational content of the human sciences is significant, the conditions that make this knowledge possible are more of a concern to a poststructural perspective. For example, understanding the social, political, and scientific conditions that make the discourse of psychiatry possible is more of a focus than a pure description of psychiatric knowledge. As a result, Foucault (1972)’s early scholarly work was primarily focused on “the history of ideas, or of thought, or of science, or of knowledge” (p. 21).

Foucault first became concerned with archaeology, but moved on to develop a genealogical understanding of knowledge. An archaeology of knowledge compared how previous historical eras had written and spoke about a particular system of thought in different ways, but did not explore the transition of this knowledge to its current state (Packer, 2011). Disclosing the accidents, coincidences, surprises, and struggles that lead to contemporary ways of thinking (Packer), Foucault gradually developed a genealogical approach to trace the pedigree of contemporary systems of thought. A genealogy involves developing “histories of the present” with a focus on “the unstable ensemble of faults, fissures, and heterogeneous layers that threaten the fragile inheritor from within and from underneath” (Foucault, 1984a, p. 82).
17.2 Discourse

The focus of the first research question in this study, discourse is a central theoretical tenet in poststructuralism. Foucault (1972) defines discourse as a system of thought composed of different courses of action, practices, ideas, beliefs, and attitudes that systematically construct the objects of which they speak. Although they involve certain statements of “truth” that provide knowledge about a topic (Hall, 2001), discourses do not only simply describe knowledge, but also function to constitute, produce, and generate particular systems of understanding (Foucault).

A group of statements that provide a way of representing knowledge about a topic at a particular historical moment (Foucault), discourses are concerned with the historical “conditions necessary for the appearance of an object of discourse” (p.44)

Discourses exist under what Foucault (1972) calls “positive conditions of a complex group of relations”. (p. 45). Foucault uses the term “discursive relationship” (p. 46) to denote the group of relations that discourse must establish, “in order to speak of this or that object, in order to deal with them, name them, analyse them, classify them, explain them”. (p. 46). Establishing one discourse in relation to another, these discursive relations are often established between “institutions, economics and social processes, behavioural patterns, systems of norms, techniques, types of classification, and modes of characterization” (p. 45).

Power and knowledge are joined together through discourse (Foucault, 1966). Moving beyond an archaeological approach that was concerned with historical systems of thought, Foucault’s concern with power and knowledge was also coupled with his shift towards a genealogical approach (Packer, 2011). Each discursive situation has its own politics of “truth” that distinguish what some consider to be true and false knowledge (Foucault, 1980). At the same time, the creation of discourses exposes the fragility of existing power relations. By establishing unique ways of thinking about the world or developing new rules of conduct, the generation of new and emergent discourses makes it possible to destabilize existing power relations (Foucault, 1976).

Power produces more than discourse and knowledge, but also produces the actual form of the subject (Yates & Hiles, 2010). The individual is not a nucleus onto which power fastens itself and the individual does not exists as an outsider that stands as an antithesis of power (Foucault, 1980; Yates & Hiles). Rather, through power/knowledge relations certain “bodies, certain
gestures, certain discourses, certain desires, come to be identified and constituted as individuals” (p. 98).

On the surface, discourses are an elusive theoretical concept in poststructuralism. A discourse does not necessarily refer to a common object, exclusive style, shared concept, or central theme (Foucault, 1972). Rather, there are “systems of dispersion” (Foucault, p. 37) or dispersed elements of discourse. Foucault uses the term, discursive formation to describe a “truth game” that unites and dictates what is considered to be “true” knowledge (Packer, 2011). A discursive formation describes, “a sense of order, correlations, positions, functioning, and transformations between statements, objects, and thematic choices” (Foucault, p. 38). Not necessarily a form of knowledge itself, a discursive formation is neither true nor false, but rather defines which statements are considered to be true or false knowledge.

Discourses involve rules of formation that both prescribe and exclude ways to discuss certain topics of knowledge. Forming the conditions under which a type of discourse is subjected to, the rules of formation are the conditions that set forth the existence, maintenance, and modification, of a particular set of discourses (Foucault, 1972). The rules of formation generate the conditions for discourses to emerge or conversely generate the conditions to restrict discourses from appearing (Foucault). In order to analyze discourses in poststructural thought, Foucault described the importance of considering the rules under which a particular statement can be made and consequently, “according to what rules could other similar statements be made?” (p. 27). As discourses are often in flux, these rules of formation govern what can and cannot be said about a topic at a particular era (Hall, 2001). As different discourses arise at different historical moments and supplant the existing and dominant ones, discourse often open up new possibilities to conceive of knowledge (Hall).

Although he does not deny that things can have a real and material existence in the world, Foucault (1972) argues that both things and actions often take on their meanings as objects of knowledge within discourse, as opposed to the things and actions in themselves (Hall, 2001). Foucault’s constructivist approach suggests that that objects of knowledge are rarely conceived outside of discourse (Yates & Hiles, 2010). For example, topics such as deviance, punishment, and sexuality are given meaning as objects of inquiry through the particular discourses that
disciplines such as biomedicine and the penal system define (Hall). Genealogy in poststructuralism is concerned with how these objects of knowledge emerge, are organized, selected, transformed, and classified in discourse (Yates & Hiles).

Foucault (1972) asks the challenging question: what defines the unity of a discourse? In other words, what characterizes one type of discourse as separate from another type of discourse? Foucault uses the term “the field of discursive events” (p. 27) to describe the constitutive elements of a discourse. The field of discursive events is comprised of “the totality of all effective statements in their dispersions as events and in the occurrence that is proper to them” (Foucault, p. 27). Although seemingly vast, the field of discursive events is typically finite and can be determined in a poststructural analysis. The field of discursive events is defined by the collective rules of a discourse where similar statements of knowledge can be made (Foucault). The analysis of the discursive field involves grasping this knowledge, determining its conditions of existence, establishing the correlations with other connected statements, and examining what other forms of understanding are excluded by this knowledge (Foucault). As previously discussed, understanding the actual knowledge embedded in a discourse is not necessarily central to a Foucauldian approach, but rather understanding the discourse that constitutes this knowledge (Foucault). One of the central questions Foucault asks is, “What was being said in what was said” (p. 28)? In other words, understanding the social, political, or historical conditions that permit or restrict this knowledge is as significant to a poststructural analysis as understanding the actual content of the discourse.

17.3 Discourses and Practices

Although the employment of language is vital, a Foucauldian understanding of discourse is not purely a linguistic one (Hall, 2011). For instance, Foucault (1972) claims, “discourse is not a slender surface of contact, or confrontation, between a reality and a language” (p. 48). Rather, in addition to the language that moulds them, discourses exist as various practices that Foucault claims, “systematically form the objects of which they speak” (p. 49). According to Schubert (1995), “discourse does not exist outside of practical activity” (p. 1013). Through discourse as a theoretical concept, Foucault attempts to “overcome the traditional distinction between what one
says (language) and what one does (practice)” (Hall, 2001, p. 72). Under this conceptual view, individuals enact these ideas in their everyday practices, course of action, ideas, beliefs, and attitudes that that systematically construct the discursive objects of which they refer to (Foucault). Foucault was particularly interested in the numerous practices that institutions use to regulate the conduct of subjects. For instance, Foucault was well renowned for his studies of the rehabilitation practices that were deployed on prisoners in the penal system and the practices of moral discipline used on the so-called sexually deviant in psychiatry.

Certain individuals or groups come to personify a particular discourse (Hall, 2001). These individuals are both the objects of study and the subjects of interventions from governing bodies. For instance, three prominent subjects (and objects) from Foucault’s exploration of discourses are the psychiatric patient, the sexual deviant, and the reformed prisoner. By constructing forms of knowledge, discourse defines and produces these individuals as objects of knowledge. Influencing the way that a topic can be discussed, the creation of discourses determines what can be said, by whom, and when (Hook, 2001). By shaping our conduct and influencing how one understands oneself, discourses initially influence how ideas are put into practice (Hall). Discourses often employ various ways to establish credibility, authority, and the sense that a particular type of knowledge is the “truth” at a given historical moment (Hall; Packer, 2010).

17.4 Types of Discourses

There are several types of discourses, such as dominant, emergent, and residual. As knowledge is mobile and depends on historical and political locations, some discourses move in the background, whereas other discourses emerge as new and accepted knowledge (Hall, 2001). Legitimatized by the social prestige of certain institutions like biomedicine and science, dominant discourses are often considered important, relevant, and “true” knowledge by mainstream society (Manias & Street, 2000). According to Epstein and Johnson (1998), dominant discourses are often identified as “common sense, almost incontrovertible” (p. 191) and organize one’s practices, conduct, attitudes, and beliefs in taken for granted ways. For example, Epstein and Johnson refer to the dominant discourse of the nuclear family in a North American cultural context as the almost “natural” way to organize reproduction and childcare.
Emergent discourses are systems of knowledge that are “new, almost waiting to happen”. (Epstein & Johnson, 1998, p. 192). Epstein and Johnson make the clear distinction between discourses that are “merely novel” (p. 192) that arise within existing dominant discourses and discourses that are emergent “in the strict sense” (p. 192) that develop patterns, elements, and ways of understanding that are become alternative or oppositional to dominant social discourses. Conditions of exclusion that distinguish an emergent discourse from a dominant discourse are often formulated from the margins of accepted knowledge and practices. When emergent discourses start to oppose the established order, a discontinuity is produced, leading to a new type of order (Epstein & Johnson). According to Schubert (1995), the process of transgression becomes, “a way of opening space in which alterative discourse can flourish”. (p. 1013).

Foucault (1977b) defines transgression as, “an action that which involves the limit, that narrow zone of a line where it displays that flash on its passage, but perhaps also its entire trajectory, even its origin”. (p. 33). The limits that Foucault refers to in this quote are the limits imposed by a particular discourse (Schubert). An emergent discourse often supports a transgression, overturning the limits of established ways of knowing and thus allowing other possibilities to emerge.

Epstein and Johnson (1998) suggest that established discourses are not necessarily completely eliminated in the emergence of new discourses, but rather traces of these older discourses exist and often come to the surface in different ways. In other words, residual discourses are often incorporated into the dominant. Residual discourses have, in some respects, expired or have “had their day”, but still have left traces and influence the everyday courses of action, ideas, beliefs, and attitudes of individuals (Epstein & Johnson).

18 Subjectivities

18.1 Subjectivity and the Self

Foucault disputes the unifying nature of a single and essentialist self in place of the dispersion of multiple subjectivities (Foucault, 1969; Packer, 2011). As opposed to a universal identity, multiple subjectivities exist concomitantly within one individual and shift with changing social
locations (Foucault; Holmes, O’Byrne, & Gastaldo, 2006). Rather than a complete rejection of the essentialist human subject, Foucault insists that humans are not necessarily the origin of or the centre of the practices in which they participate (Packer). In other words, “subjectivity is not the source of meaning” (Packer, p. 349). Selfhood does not exist outside of being subjected, as there is no self without being a subject (Frank & Jones). As a result there is no “pure” consciousness because the self is always constituted by the production of discursive systems (Mansfield, 2000). Persons are subjects because they know themselves and others through socially preferred, enforced, and contested modes of knowledge (Frank & Jones, 2003).

Power/knowledge also constitutes our subjectivities. The self is socially constructed through the interplay of multiple forms of power/knowledge in multiple locations (Foucault, 1976). Both the individual subject and the elements that make up our individuality, such as our gestures and use of language, are an effect of power (Mansfield, 2000). Since the effects of power on subjectivity are experienced through the body, “questions of subjectivity are inseparable from questions of the body” (McLaren, 2002, p. 82). The subject is rarely self-determining in this poststructural view, but rather is the crystallization of multiple power/knowledge tactics (Frank & Jones, 2003). Subjectivities are not the antagonists of power, standing outside or vis-à-vis power, but rather are the very material of power (Mansfield). Through the process of subjectification, one becomes a subject that is produced by the crystallization of several discursive forces (Mansfield, 2000).

18.2 Subjectivity and Care of the Self

For certain critics in philosophy, the notion of human agency and the abilities of individuals to shape their own lives is missing from a Foucauldian perspective (Packer, 2011). Foucault’s view of subjectivity; however, allows for the possibility of human agency to a certain extent. Foucault’s rejection of the ahistorical subject coexists with his “deeper concern for the constitution of forms of subjectivity as actually experienced” (Yates & Hiles, 2010, p. 57). In his later scholarly work, Foucault came to focus on self-constitution and how the human subject becomes an object to him or herself as a “domain of possible knowledge” (Packer, p. 368). In this sense, subjectivity as a concept is associated with the ways in which the subject develops self-knowledge through the relationship to oneself (Foucault, 1988; Packer).
Through his study of the history of sexuality, Foucault became concerned with developing a study of the “forms of moral subjectification” (Packer, p. 368). In particular, Foucault (1988) used the phrase “technologies of the self” (p. 18) to describe self-constitution. This notion refers to techniques that 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” (Foucault, 1988, p. 18). Individuals employ such techniques to transform themselves “in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality” (Foucault, 1988, p. 18). From a historical perspective, Foucault compares the technologies of the self in ancient Greece and Rome to Christian practices of asceticism. He applauds the ancient Greeks for moulding themselves on the aesthetically determined rules of beauty and style, rather than referring to the “good” or “bad” self (Flaming, 2006). Aesthetics are important to Foucault because he believed that self-creation ultimately is an artistic and creative endeavour (Foucault, 2001).

The notion of subjectivity of as an aesthetical undertaking opens up the possibilities of certain subjectivities to be viewed as ugly, unappealing, undesired, or problematic. In Foucault’s (1977a) work on the systems of disciplinary action, he describes how certain subjectivities are distributed along a continuum of good and bad, positive and negative, in relation to one another. Through a hierarchical system of credits and debits, authoritative bodies often classify individuals as “normal” or “abnormal”, thus making what is considered to be normal the normative (Ransom, 1997). To Foucault, this “micro-economy of perpetual penalty” (p. 181) operates as a normative differentiation, not necessarily of the acts itself, but of the “individuals themselves, of their nature, their potentialities, their level or their value” (p.181). Discipline, and the various practices that are intended to discipline others, is then integrated into the “cycle of knowledge of individuals” (Foucault, p. 181).

These personal maxims of aestheticism transform people and makes their life into an œuvre (work) that carries certain stylistic values (Foucault, 2001). As opposed to uplifting the self, technologies of Christian doctrines enforced particular metaphysical standards of asceticism or a renunciation of the self (Foucault, 2001; Flaming, 2006). Foucault (1976) argues that modern individuals are the inheritors of the Christian morality of asceticism, which generates its own forms of subjectification. Individuals also inherit secular traditions that view the external law as
the basis for morality and are concerned with the regulations for acceptable behaviour in relations with others (Foucault, 2001). As a result, it is often difficult to see respect and care for oneself as part of the contemporary moral imperative, yet concern for the self is central to ethics in poststructuralism (Foucault, 2001).

Mainstream constructions of “self care” are often concerned with the self as a free agent (Murray, 2007). This approach is favoured by traditional bioethics with its focus on autonomy and informed consent (Murray). In care of the self or practices of the self, Foucault (1984a) proposes a different view of caring for the self. In caring for the self, individuals develop maxims or rules of conduct called ethos, a particular way of being and behaving (Flaming, 2006). Ethos is a Greek term meaning nature or disposition (Packer, 2011). Care of the self is synonymous with living an ethical life, but does not involve discovering the transcendental or essential self through the Socratic admonition to “know thyself” (Foucault, 2001). Rather, care of the self is a task (McNeill, 1998). Care of the self questions the historical and cultural milieus that shape a person as an individual human being (Foucault, 1984a).

18.3 Subjectivity and Ethics of the Self

Traditional ethics examines how individuals behave with respect to established moral regulations and normative codes in society. To Foucault, the notion of ethics does not refer to a theoretical system or a metaphysical reflection on moral principles, or the pursuit of theoretical knowledge that is then applied to practice (McNeill, 1998). Rather ethics is a practice that is concerned with the relationship to the self. Unlike mainstream ethics, which is about obligations to others, one’s self’s relation to one’s self is the “prime ethical practice” (Flaming, 2006, p. 221). Foucault’s (1977a) ethics are about how an individual turns him or herself into a particular subject.

Poststructural ethics are how individuals transform and modify themselves “to attain a certain state of perfection” (Foucault, 2001, p. 177). Individuals accomplish this not only through conforming to a moral code, but also by shaping themselves into persons who instantiate certain values (Prado, 2003). Being ethical consists of the ability to transgress the limits of the self within certain power/knowledge relations (Lamb, 1995). The ethics of the self as a practice
describes particular techniques for resisting normalizing social forces and the imbalanced power relations that result from them (Holmes, O’Byrne, & Gastaldo, 2006). Ethical transformation involves values that are aesthetic as well as moral, which is why Foucault describes the transformation of one’s self as “close to the aesthetic experience” (O’Leary, 2002, p.3). As the self is never a permanent self-identity, the ethical self is a particular way of being, a relationship to the self. The ethical transformation of the self is situated, historical, and finite. There is no way of being ethical that is not a response to historical and social forces. The self is constituted as a response not only to a given situation, but also to our conditioned interpretations of the world and the ethical, political, and institutional practices of power (McNeill, 1998).

The task of remaking oneself according to Foucauldian ethics presupposes a high degree of self-knowledge: one must know who and what one is, and what to do to change (Prado, 2003). At the same time, because ontological knowledge of the self is not always attainable, care of the self is a never-ending and elusive task (McNeill, 1998). The end result of ethics is not the creation of a final or foundational self, but rather is concerned with the work or process of exploring the self in particular historical and cultural contexts (Flaming, 2006).

Foucault’s conceptualization of ethics differs from traditional normative ethics (for instance, the ethical expectation to do “good”). The principle task in Foucauldian ethics is not a final, foundational “good” individual, as traditional ideas about the ontology of the self suggests, but rather it is the critical interrogation of how we have come to understand ourselves (Flaming, 2006). As the self is aesthetically self-creative, to be ethical, one should not be guided by the timeless, rigid, and metaphysical principles of good and bad, moral and immoral, that some schools of normative ethics uphold as fundamental ethical principles (Flaming). Foucault was sceptical of the universal criterion of moral judgement that stemmed from the doctrine of humanism in the Enlightenment. Leading to moral categorization, humanism often established certain ethical expectations that “good” individuals adhere to. One of the limiting effects of ethical normalization is a restricting of the self or what Bernauer and Mahon (1994) call a “narrowing and impoverishment of human possibilities” (p. 143). Foucauldian ethics, as opposed to normative ethics, opens up new possibilities of understanding and different kinds of ethical questions. For instance, how do individuals apply different techniques onto themselves to enable them to recognize themselves as ethical subjects (Bernauer & Mahon)? What type of activities
do people engage in and how do they moderate their behaviour in order to be ethical subjects (Bernauer & Mahon)? How do individuals establish the relationship between themselves and the rule of conduct in order to be an ethical subject (Bernauer & Mahon)? In order to be ethical, what type of human being is one attempting to become (Bernauer & Mahon)?

18.4 Historical Ontology of the Self

Framing his overall theoretical project, the “historical ontology of ourselves” (Foucault 1984b, p. 49) was developed by Foucault as a way to conduct an analysis of the self. In this line of inquiry, human beings are analyzed as historically determined or a “series of historical inquires” (Foucault, p. 43). This approach does not only ask for a description of the various qualities or characteristics of a person, but also interrogates, “the more fundamental ontological question of how we become a person” (Packer, 2011, p. 370). In other words, the different ways of becoming a subject or the process of subjectification can be examined as a contingent and historical process.

Foucault (1984b) asks three central questions that describe the process of historical ontology: “How are we constituted as subjects of our own knowledge? How are we constituted as subjects who exercise or submit to power relations? How are we constituted as moral subjects of our own actions” (Foucault, p. 49)? In doing so he identifies three domains of historical ontology or how the human subject is constituted. The first domain of truth describes how individuals are constituted as both objects and subjects of knowledge (Yates & Hiles, 2010; Packer, 2011). The second domain of power relations explores how subjects are constituted through their actions on others and by being acted upon by others (Yates & Hiles). The third domain of ethics describes how individuals constitute themselves as particular types of subjects (Yates & Hiles). In the historical ontology of ourselves, Foucault is concerned with the study of practices to discover how the social world is ordered: “the ordering of objects in knowledge, of subjects in power, and of ourselves (as orderers) in ethics” (Packer, p. 372). How we act as orders in Foucauldian ethics is related to the relationship we have with ourselves.
18.5 Subjectivities and the Body

Moving beyond the biological sciences of the body and the study of its functioning, the body occupies a central place in poststructuralism through the “political technology of the body” (Foucault 1977a, p. 26). Invested in relations of power and domination, the body becomes a political instrument that is, “meticulously prepared, calculated, and used” (Foucault, 1977a, p. 26) in order for it to become a productive and subjected body. As a result, the body becomes the locus of multiple practices of subjectification and objectification (Packer). A location with a surface and a volume, the body also become articulated and inscribed by discourse (Packer). The body is the inscribed surface of discursive events (Foucault, 1984c). The task of genealogy, as an analysis of historical descent, is to expose the body as a political object that is imprinted by discourse and history (Foucault, 1984c).

18.6 Death in a Poststructural Perspective

Death and the possibility of dying is a significant theme in the study of individuals with advanced cancer. In order to ground my wider discussion of death in this study, I briefly situate death and dying in a poststructural perspective.

Foucault (1976) examined the link between the power of the sovereign (i.e. the king or aristocracy) and the role of death. The sovereign power over life and death was grounded in the right to take life through execution or the right to let live by forging execution (Tierney, 1998). With the advent of modernism, subjects (i.e. the peasantry) shifted from being the property of the king to an economically engaged labour force. Death came to be viewed as something that was harmful to the labour supply (Tierney). By the end of the 18\textsuperscript{th} century, medicine and public health systems evolved to protect society from diseases routinely prevalent in the population. Death came to be viewed as a permanent threat that perpetually disrupted a productive, well functioning, and economically viable society (Foucault, 1963). The concern with preventing death was transformed into an instrument of governmental power that gained knowledge of illness and administered a calculated solution to the problem of death (Tierney).
By the end of the 18th century, individuals at the end of life became pivotal tools in the development of modern medical knowledge (Foucault, 1963). The practice of post-mortem examination in 18th century Europe increasingly shaped the dead and dying body as a site of scientific inquiry. Autopsies on the dead allowed physicians to observe, display, and describe pathological events that had previously remained concealed, hidden, and inexpressible (Long 1992). With the emergence of the age of the enlightenment, its emphasis on progress, and the concern with the extension of scientific possibilities (Peerson, 1995), advancing medical knowledge outweighed previous moral objections to dissection.

Foucault (1963) suggests that the 18th century transformation of death initiated a concern with the individual as the object of science, which is arguably continued in contemporary practices of death and dying. Foucault notes, “from the integration of death into medical thought is born a medicine that is given as a science of the individual” (p. 243). In other words, biomedicine’s concerns with death led to the preoccupation with understanding the dying individual in multiple ways, developing the scientific study of the dying body, but increasingly developing a more complete understanding of the “lived experience” of death. As it became an a priori condition for medical knowledge, modern individuality is bound up with death and death became “embodied in the living bodies of individuals” (Foucault, p. 243). Medical discourses of death and dying are important as the “constitution of the sciences of man” (Foucault, p. 244) not only methodologically, but also ontologically as they concern the move to viewing individuals as objects of substantive knowledge.

19  A Foucauldian Framework and the Search for Life-Extension

In this section, I justify the utilization of a poststructural framework in order to achieve the aims of this study. I discuss how a poststructuralism facilitates an exploration of how discourses constitute the search for life-extension and the kinds of subjectivities that are produced by the discourses in operation.
19.1 The Notion of Discourse and the Aims of this Study

In this study, I lend empirical data from the perspectives of patients, family members, and healthcare providers to critically explore the multiple discourses in operation that constitute the search for life-extension in advanced cancer. As previously discussed, the broader conditions that permit or restrict a particular discourse to exist are a central concern to poststructuralism, as opposed to merely understanding the content of the actual discourse (Foucault, 1972). By using discourse as a theoretical concept, this study examines the broader political, social, and historical conditions that allow this practice to exist in the current historical time and place. As discourses exist as practices that constitute the objects of which they speak (Foucault), I also interrogate how discourses shape the modes of conduct, behaviours, attitudes, and beliefs of the different social actors involved in this phenomenon.

Using a poststructural perspective, this study considers several important questions: how is it that individuals with severe and incurable disease, who have likely been previously unsuccessful in treating their cancer, are able to search for life-extension through biomedical therapies and other therapeutic ventures that lie beyond biomedicine? Despite the vulnerabilities of having advanced disease and the risks of certain invasive forms of treatment, how is it that individuals are able to actively navigate the healthcare system and exercise certain power/knowledge relations within this system in order to advocate for treatment? In addition, given the lay position of patients and family members, how do individuals draw upon knowledge of their own disease status and a lay understanding of bio-scientific understanding in their search for life-extension?

There are multiple social and clinically related factors that may influence the search for life-extension. There is an extensive body of health science literature that has focused on the deficiencies of patients and family members to comprehend their prognosis, understand the efficacy of treatment, or to accept the possibilities of dying from cancer (Sahm et al., 2005; Hirose et al., 2005; Donovan et al., 2002; Slevin et al., 1990; Chow et al., 2001; Pension et al., 2004; Weeks et al., 1998). Based on the particular assumptions of this literature, individuals seek life-extension because they may not be “capable” of making rational and informed decisions about their treatment (Marta, 1998). Some in the clinical world have also framed the provision of invasive forms of treatment in incurable cancer as overly aggressive and medically futile care,
(Murillo & Koeller, 2006; McLennon et al., 2013; Demrosch et al., 1993; Kuuppelomäki & Lauri, 1998), thereby calling into question the appropriateness of this practice – and also placing a normative judgement onto those who seek treatment. The widespread belief in the emerging scientific possibilities to cure incurable cancer (Camus, 2009), often leads to the perception that care of the individual with advanced cancer should be focused on providing biomedical intervention, as opposed to addressing other facets of their personhood (Good et al., 1990). Moving away passive recipients of biomedicine towards active consumers with the capacity for rational health choices (Moore, 2004; Rose, 2007), individuals who search for treatment may also exist within a larger project of self-improvement that is part of the 21st century self afflicted with disease (Lupton, 1997). In this new mode of conduct, individuals with advanced cancer may emphasize investments in themselves to generate life-extension, leading to certain forms of mistrust of healthcare providers (Hillen et al., 2011; Sharf et al., 2005).

In light of these multiple contexts, few studies have considered how the different discourses in circulation might be either interrelated or antagonistic in relation to one another. By categorizing the different discourses in operation as dominant, emergent, or residual, I consider the relationships between the different discourses in operation that shape the search for life-extension as a discursive practice. Poststructuralism does not locate power/knowledge relations within a single governing institution, such as medicine or other regulatory bodies (Rose & Valverde, 1998). Foucault’s (1972) conceptualization of discourse also questions the linear, progressive, and straightforward view of knowledge that is sometimes taken for granted in scholarly disciplines like evidence-based healthcare. Although biomedicine may still enact a powerful force in the search for life-extension, discourse as a theoretical concept encourages an exploration of how unforeseen discourses combine together in order to constitute a particular group of practices. Treatment practices in advanced cancer are not determined by a single unified influence, but rather are shaped by the complex interrelation of numerous discourses in fractured, uneven, and occasionally antagonistic ways (Foucault). In this study, I locate and explore the multiple and dispersed discursive locations where our rules, standards, values, and interactions shapes the thoughts, behaviours, attitudes, and modes of conduct about the biomedical treatment of advanced cancer (Rose & Valverde). By employing discourse, I work with the contradictions, tensions, and fragilities in how the search for life-extension are understood and constructed.
19.2 Subjectivity and the Aims of this Study

As the personal is political to Foucault (Oksala, 2007), subjectivity as a theoretical assumption facilitates a deeper understanding of the search for life-extension by placing the individual subject within broader discourses (Marta, 1998). By situating patients, family members, and healthcare providers within wider social understandings about biomedicine, resisting medical authority, death and dying, and generating one’s own possibilities for a cure, I lend empirical data to the examination of how one becomes a subject in advanced cancer (Foucault 1976). As the uniformity of any single subject is contested in poststructuralism (for example, the subject that may be unwilling to face), this study generates a new understanding of how the search for biomedical treatment generates multiple types of subjects that intertwine and conflict when individuals pursue life-extension (Foucault). While the current research on the provision of life-extending therapies in incurable cancer has often emphasized the individual and autonomous self (Marta), I consider the multiple selves that come from numerous discursive locations, thereby speaking to the complicated nature of this phenomenon.

In addition to conducting a typology of the different types of subjects, I also consider the numerous social effects of these subjectivities in the search for life-extension. For instance, how is it that certain authoritative institutions, such as the cancer care system, punish certain forms of subjectivity, whereas other forms of subjectivity remain immune to punishment? As the constitution of the self in poststructuralism is in part an aesthetical process (Foucault, 2001), I consider how certain types of subjectivities come to be viewed by some as ugly, unappealing, undesired, or problematic (Foucault, 2001).

Although governing and disciplinary discourses often constitute the self (Foucault, 1976), the notion of subjectivities generates other possibilities for understanding. Subjectivity is not just the outcome of the forces of social control, but provides a forum for individuals to think through their circumstances and to work through the contradictions in their lives (Biehl, Good, & Kleinman, 2007). Subjectivities allow individuals to, “inwardly endure experiences that would otherwise be outwardly unbearable” (Biehl et al., p. 14). Life threatening cancer may unsettle one’s relationship to the self in an irrevocable and almost overwhelming way. Using care of the self as a poststructural concept (Foucault, 1998), I consider how cancer treatment practices might
reshape or renegotiate the relationship individuals have with themselves in the disruptive context of advanced cancer. In this study, I articulate how the search for life-extension involves more than procuring regimes of cancer therapy, but also might constitute a process of self-formation in order to become a kind of subject that can defy the biological destiny of advanced cancer. Employing Foucault’s (1997) notion of ethics as the relationship one has with one’s self, I investigate how individuals apply different techniques of the self onto themselves (for instance, the moderation of behaviour) in order to be shaped as an ethical subject (Bernauer & Mahon, 1994). Moreover, I also explore how individuals establish the relationships with themselves in the context of broader governing forces.

19.3 An Overall Foucauldian Approach and the Aims of this Study

Because power/knowledge relations are discontinuous, unstable, and transitory (Foucault, 1980), some scholars have labelled Foucault’s work as “nihilistic” because his ideas preclude the possibility of judging one form of truth as better than another (Taylor, 1984). Others have suggested that his theoretical perspective obscures the reality of oppression in people’s everyday lives, undermining the possibility of social change (Hartsock, 1990). While some see a Foucauldian approach as pessimistic, others see it as liberating because it allows for other possibilities and points to alternative ways to view healthcare practices. A poststructural perspective opens up a new consideration of how receiving biomedical treatment in incurable disease may have certain productive effects. By challenging taken for granted understandings, a Foucauldian perspective has the potential to resist and call into question unchallenged assumptions about healthcare and how dying from cancer is viewed socially.

It is important to note that I do not seek to supplant, remove, or exclude existing health science discourses, but rather I examine them as discourses that are often utilized by healthcare providers to produce and maintain their own status in power/knowledge relationships. At the same time these seemingly dominant discourses are vulnerable and I expose their fragility in certain social contexts. I do not argue that certain healthcare practices should be dismantled or abandoned in this study, but rather I explore how they generate particular subjectivities that may lead to the search for further cancer treatment. Unlike a traditional bioethics study or an emancipatory
theoretical approach, I do not attribute or point out a form of “blame” to a particular group like physicians or the mass media, but argue that each social actor in this phenomenon is constrained by their unique locations within certain discourses in circulation. Used in this way, a Foucauldian perspective is actually sympathetic to the constraints of many of the social actors in this phenomenon.

My theoretical approach positions this study somewhat at odds with the traditional concept of nursing. Nursing often regards itself as a socially progressive project, where nurses attempt to improve the health status of individuals and populations (Manias & Street, 2001). However, the goal of pure social progression is often hard to defend in a poststructural perspective, where few are exempt from being implicated in the governance of individuals (Manias & Street). Also, the effects of progressive, well-intended policies and practices may lead to unforeseen negative consequences for some social actors, but not others.

19.4 Conclusion to Theoretical Framework

In this chapter I describe the theoretical framework that I use to guide my study of the search for life-extension through biomedical treatments and beyond in advanced cancer. I first described key theoretical concepts in poststructuralism. I began by describing how knowledge is enmeshed in relations of power (knowledge/power) through regulating the social conduct of individuals (Foucault, 1976). Employed through disciplinary techniques, governmentality was defined as the art of government used to regulate a population (Foucault, 1979). Self-government was outlined as the process by which individuals are made subjects of numerous discourses (i.e. subjectification) that generate normative behavioural expectations. Next, I described how the bodies of individuals become controllable political objects through biopower. I briefly outlined how biomedicine currently exists as a collection of techniques by which patients are constituted as subjects in order to be good selves (Foucault, 2003). Emphasising self-responsibility, neoliberalism was framed as a formula of rule based on the most efficient means to achieve certain disciplinary effects (Foucault, 1997).
In the second section of this chapter, I outlined discourse and subjectivity as the main theoretical concepts in this study. Discourse is a group of statements that provide a way of representing knowledge at a given historical moment, but also exist as practices that constitute the objects of which they speak (Foucault, 1972). The process of subjectification, or how one becomes a subject, results from the crystallization of multiple discourses (Mansfield, 2000) and the interplay of multiple power/knowledge relations (Foucault, 1976). In my description of subjectivity, I examined care of the self as a form of self-constitution according to certain aesthetic principles (Foucault, 1988). I also described ethics of the self as a practice that is concerned with the relationship to the self in order to become particular ethical subjects (Foucault, 1997). To conclude this chapter, I justified the use of poststructuralism in order to achieve the aims of this study. I considered how a Foucauldian framework facilitates a deeper understanding of how this issue came to be in the current climate of the treatment of advanced cancer and also the multiple effects of this practice on shaping the self.
Chapter 4
Methodological Approach

20 Introduction to Chapter

In this chapter, I outline the methodological approach that guided this study. I first examine the fit between case study methodology and the poststructural examination of the search for life-extension. Next, I describe how the research process unfolded in the collection of case data. I also outline how Foucauldian discourse analysis was used as an analytical framework. I then discuss some of the ethical considerations that influenced this study. By considering the trustworthiness, authenticity, and the role of reflexivity, I conclude this chapter by discussing the quality of the study results.

21 Case Study in the Research of Life-Extension

21.1 Case Study and the Concerns of this Study

In order to examine discourses and subjectivities, this study employed case study as a methodological approach (Creswell, 2009; Yin, 2012; Flyvberg, 2011). There is a long-standing tradition between poststructural thought and the study of cases (Flyvberg, 2006). Foucault (1977a) often looked to historical cases, such as his examination of the prison system in Western Europe or the psychiatric management of mental illness, as a way to develop his ideas about politics, power/knowledge, and the body. In a similar way, case study was a helpful methodological approach in this study because it facilitated an investigation of the search for life-extension within its numerous real-life social circumstances and contextual influences (Yin, 2009; Stake, 1995). Because this study was concerned with the interactions between several types of discourses and subjectivities, as opposed to a predetermined few, case study was the best methodological approach to interrogate the dense and multiple relationships within the search for life-extension (Dooley, 2002).
21.2 Description of the Cases

Leading to a deeper examination of how discourses generate the possibilities for participants to pursue biomedical treatment (Flyvberg, 2006), I focused this study on a fewer number of cases constructed around participants with advanced cancer (Sandelowski, 2011). In the interest of building richer and more developed cases, seven cases were compiled. Yin (2009) suggests that approximately five or more cases should be studied in order to provide a balance between case variation and analytical depth. In total, the data collected for the cases included: 20 interviews (including multiple interviews with participants), 30 documents, and five hours of field observations. Study participants included seven patients, five family members, seven healthcare providers, and one natural healer. Participants who were healthcare providers included two oncologists, three palliative care physicians, and two oncology nurses. A summary of the data collected in the cases is found in Table 2.

Case study methodology focuses on a relatively bounded phenomenon (Yin, 2002; Stake, 2000; Gerring, 2004; Hentz, 2007; Sandelowski, 2011). As a result, cases were focused on data related to the search for treatment in the later stages of cancer treatment, as opposed to the overall experience of illness. Although there was a general composition to all cases (see Figure 1), cases varied in their composition. For instance, Krishna’s case (Case Six) consisted of one interview and three hours of observation, whereas Todd’s case (Case Three) consisted of five interviews with multiple participants and numerous documents. Each case began with a particular participant with advanced cancer and then moved outwards to include interviews with other social actors, documents, and observable moments that individuals identified as central in their search. Documents included websites, online articles, books, pamphlets, and written texts provided to me by participants (for example, typed personal responses to interview questions). As most participants did not attend events related to treatment (for example, information sessions about cancer) or were unwilling to be observed at clinic appointments, less field observation data was collected.
The cases in this study are classified as *radical* (or atypical) case studies (Flyvberg, 2006; Baxter & Jack, 2008; Stake, 2000) in the sense that participants search for life-extension is often viewed in clinical practice as a problematic activity because it may call attention to patients’ discontentment with their care, challenging relationships with healthcare professionals, and barriers to acknowledging the closeness of death. Although this study will demonstrate that the search for life-extension in advanced cancer is an emergent issue, the cases are also radical in the sense that they study a patient population that may be distinctive from other populations in several ways. This particular study population may able to draw on certain health resources, understand the cancer care system in a sophisticated way, verbalize their displeasure with their care, demand more attention, and may be more assertive than individuals who do not search for treatment in advanced cancer. Because they involve social actors that are not obvious to an
outside viewer and activate deeper mechanisms in the phenomenon under study (Flyvberg, 2011), radical cases reveal more information than representative cases in that they extend beyond the confines of the actual cases (Baxter & Jack, 2008).

22 Inclusion Criteria

Inclusion criteria for participants included: (1) advanced cancer that was recurrent, late stage (stage 3 or stage 4), or metastatic; (2) a Palliative Performance Scale (PPS) score of 50 to 100 percent; (3) a Short Orientation Memory Concentration Test (SOMC) score of 10 or above. Exclusion criteria included: (1) newly diagnosed individuals receiving medical treatment for the first time; (2) individuals who were not able to speak English; (3) individuals who were mentally incapable of providing informed consent.

23 Case Selection

Selecting the most fitting case to study is a vital component of case study methodology (Yin, 2009). I therefore utilized purposeful sampling to select interesting and information rich cases (Patton, 1990; Coyne, 1997; Kuzel, 1999). I selected cases using two criteria: (1) To maximize variation in terms of cancer-related criteria (for example, type of cancer, mode of treatment); and (2) To promote variation across various demographic criteria (for example, gender, cultural background). I sometimes selected the cases by the social repercussions they seemed to provoke in clinic staff. For instance, I selected Isabel’s case (Case One) because she was sometimes portrayed as a problematic patient by the healthcare team, but I also selected Achmed’s case (Case Five) because the same clinical team seemed to idealize him as a well-behaved patient.

24 Description of the Study Setting

This study occurred in multiple settings such an ambulatory care clinic, a tertiary cancer institution, public spaces like a coffee shop, and participants’ homes in different cities.
Participants were recruited from an outpatient palliative care clinic that was located within an tertiary cancer hospital. Although this clinic offers palliative services such as end of life planning, the majority of the patients are seen at this clinic for the control of cancer related pain late in the disease trajectory. Many individuals were concurrently receiving palliative care alongside medical treatments traditionally associated with the eradication of cancer. The waiting room of the clinic was typically bustling, with approximately ten patients attending this clinic per day. Patients typically have follow up visits approximately every two to three weeks. This clinic employs a multidisciplinary team approach: palliative care nurses, physicians, pharmacists, and social workers collaborate to manage patients’ cases.

Because I had no previous relationships with the team, generating buy-in from the clinic staff initially was difficult. I first introduced the study to the team by conducting a presentation at a monthly staff meeting. Protective of patients and family members, some team members expressed concerns about the time commitment involved in participating, burdening vulnerable individuals, and causing emotional distress. Although it was not overtly stated, some seemed uncomfortable with nature of the research topic. The first two patient cases were recruited with the help of the senior clinical leader. During a staff meeting three months later, I summarized the general experiences of these early participants in order to reassure the team about my skills as an interviewer. Following this, I communicated with referring staff members about potential participants via email and telephone. Although prolonging recruitment by making it more difficult to connect with potential participants, the clinical leader recommended that I not be present on site because of the busyness of the clinic.

25 Recruitment

To locate participants with advanced cancer that would fit the inclusion criteria, I collaborated with clinic physicians to review their most current patient caseload based on prognosis, current treatment regimes, medical history, and demographic information. Cases were discussed in a general sense to ensure that the personal identities of participants were not revealed during recruitment. In order to promote a heterogeneous sample, physicians were provided with an information sheet outlining the types of patients sought in recruitment (see Appendix A). Using a
predefined script (see Appendix B), physicians made the initial contact with participants to briefly explain the study and to ask for permission for me to contact them. Although I prepared an approved email to recruit patients and family members (Appendix C and D), individuals preferred to be contacted via telephone. Of the twenty individuals that were introduced to the study at the clinic site, thirteen individuals agreed to be contacted. Of this group of thirteen patients, two individuals were excluded because they met the exclusion criteria: one was receiving biomedical treatment for the first time and another did not speak English. Four individuals that I contacted did not return my communication because they had become gravely sick or had died.

With the exception of Cases Two, Six and Seven, participants asked if a spouse or sibling could be interviewed along with them, thus recruiting family members to the study. Mark was interviewed immediately after his wife’s Krystal’s (Case Seven) interview. Using snowball sampling (Browne, 2005), I asked participants to refer additional family members, other caregivers, and healthcare professionals that they identified as key figures in their search for life-extension. For Cases Two and Six, I was not able to recruit additional family members. For instance, Daniel (Case Two) asked his wife in person, but she was not interested because of her concern with becoming emotionally distraught during the interview. With the exception of Krishna (Case Six), who was hesitant to refer anyone to the study, participants referred oncology nurses and physicians involved in their treatment. I contacted these healthcare professionals via email (see Appendix E). Of the healthcare providers contacted, all participated in the study, except for two physicians who did not return my email and two nurses who stated that they were unable to participate.

Recruitment and data collection took place between July 2011 and August 2012, a slower rate than anticipated. I recruited one case approximately every one and a half months. Physicians often had to wait two or three weeks for patients to attend their follow up clinic appointment in order to recruit them to the study. Delaying data collection, the workflow of oncology nursing was being reorganized at the time of recruitment. It often took several follow up contacts emails and telephone calls with healthcare professionals to schedule interviews. Figure 2 provides an overall summary of how this study was operationalized.
26 Screening Participants

Because of a concern with the functional abilities and cognitive status of participants, I administered two quantitative measures before the start of the interview to screen out individuals who may not have been suitable for participation. (1) The Palliative Performance Scale (PPS) measures the functional status (i.e. ambulation, activity level, etc.) and general burden of disease at the end of life (Victoria Hospice Society, 2006; Anderson, Downing, Hill, Casorso, & Lerch, 1996). A score of 100 percent represents an ambulatory patient with limited physical symptoms, whereas a score of zero signifies a patient who has died (Anderson et al., 1996). A PPS score of
50 percent to 100 percent was used to screen participants for inclusion (see Appendix F). The Short Orientation Memory Concentration Test (SOMC) is a cognitive screen test that was used to exclude participants with cognitive impairments (Katzman et al., 1983). A cut off SOMC score of 10/11 (see Appendix G) suggests that participants have sufficient cognitive abilities to particulate in the study (Davous et al., 1987). The first study participant preferred not to complete the screening measures before the start of the interview, but was still included in the study because she were assessed by myself as an experienced oncology nurse to be cognitively stable and not in distress. Following this, a notification was submitted to the research ethics board. Three additional participants preferred not complete the screening measures.

27 Research Participants

The study sample of individuals with cancer exhibited demographic diversity, including gender, age, racial background, and cultural background. Of the female participants, two had breast cancer and one had pancreatic cancer. Of the male participants, two had prostate cancer, one had leukemia, and one had multiple myeloma, a haematological cancer of the white blood cells. The duration of having cancer ranged from less than a year (Krystal) to a second reoccurrence following a long remission (Eva). Participants were currently seeking life-extension through a variety of biomedical treatments: oral chemotherapy, hormone replacement, experimental drug trials, bone marrow transplant, and experimental radiation therapies.

The participants’ ages ranged from late thirties (Isabel) to seventies (Eva). With the exception of Eva, who was divorced, each patient had a spouse. Except for Eva, they each had one to three children that ranged in age from teenaged to adult. Participants had a wide variety of occupations that were largely professional in nature. For instance, Todd held a management position in a food-processing factory, Krishna owned a manufacturing business, and Daniel was a life insurance agent. Each participant was educated at college or university. The most educated participant was Achmed who possessed a graduate degree and worked in a scientific field. The sample was ethnically diverse and included individuals from Korea, Canada, Belgium, Iran, and Nepal. The diversity of the sample is summarized in Table 1.
Table 1: Diversity with the Sample

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Diversity within the Sample</th>
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<tbody>
<tr>
<td>Age</td>
<td>Late thirties to early seventies.</td>
</tr>
<tr>
<td>Marital Status/Children</td>
<td>Divorced to married, no children to three children.</td>
</tr>
<tr>
<td>Profession/Educational status</td>
<td>College educated to university educated with graduate degree.</td>
</tr>
<tr>
<td></td>
<td>Information technology professional, Insurance agent, Factory manager, Business owner, Professional in scientific field, Part time sales clerk.</td>
</tr>
<tr>
<td>Cultural Background</td>
<td>Korea, Canada, Belgium, Iran, Nepal.</td>
</tr>
<tr>
<td>Cancer type</td>
<td>Breast, Prostate, Pancreas, Leukemia, Multiple Myeloma.</td>
</tr>
<tr>
<td></td>
<td>Metastases to bone, liver, brain, bone marrow, lymph nodes.</td>
</tr>
<tr>
<td>Treatment type</td>
<td>Hormonal therapy, oral chemotherapy, alternative and complementary therapy, radiation therapy, stem cell transplant, experimental clinical trial.</td>
</tr>
</tbody>
</table>

Of the family members who participated in this study, all were spouses except Magda, Eva’s sister. Isabel identified the natural healer recruited to this study as her mentor and friend. This natural healer disclosed that she was not a licensed naturopath and thus was not labeled a healthcare professional. The sample of clinicians included radiation and medical oncologists, palliative care physicians, and oncology nurses. Healthcare professionals had clinical experience in oncology that ranged from five to fifteen years. Reflecting the academic focus of the tertiary institution they worked in, many reported that they had either previously conducted their own study or participated in other research studies about cancer. For a more detailed description of both the participants and the cases see Appendix H.
27.1 Data Collection

27.2 Interviews

In total, twenty interviews were conducted across the different cases. The interviews ranged in duration from half an hour (Oncologist, Case Three) to two hours (Interview One, Achmed). Although most interviews were conducted with a single interviewee, some interviews were conducted with two participants within a single case. For example, the interview with Isabel, Todd, Eva, and Achmed was conducted with their spouse or family member. Although I conducted the initial interviews with two participants, the follow up interviews in these cases were conducted with only one interviewee. This tactic was helpful because it allowed me to develop trust with the interviewee, introduce topics from the first interview, and allowed participants time to reflect on the interview questions. Although I attempted to conduct the follow up interview about one week later, participants’ scheduling conflicts often pushed the second interview up to one month after. Interviews took place at the clinic, a coffee shop, an office at the university, and the home. With the exception of the telephone interview with the clinic nurse from Case Five, interviews with healthcare providers took place in their office or a meeting room at the hospital.

One week before the interview, all participants were given the consent form and the interview guideline. Written consent was obtained before the start of data collection. The interviews were guided by a semi-structured approach for individuals with cancer (see Appendix I), healthcare workers (see Appendix J), and family members and the natural healer (see Appendix K). In order to facilitate an in depth discussion of subjectivity during the interview, patients and family members were asked before hand to bring in a symbol, an image, slogan, physical artefact, or document that expressed their approach to treatment (see Appendix L). Individuals brought a range of items to the interviews such as self-help books (Todd), typed lists of cancer research articles that they accessed (Isabel), and a thick binder of personal health records (Achmed). I also asked participants about objects in their vicinity (for example, a box of tiles in Todd’s kitchen) or the objects they had incidentally brought with them (for example, a stack of newspapers brought by Daniel) in order get a richer sense of their subjectivities.
In order to locate the search for life-extension within the contexts of participants’ lives, I began the interviews with a brief discussion of their initial diagnosis. I employed the interview scheme only as a loose guide to make sure certain topics were covered (Kvale, 1996). Rather than view the interview process as a rigid way to access the “pure information” of respondents (Holstein & Gubrium, 2003), I instead collaborated with interviewees in the co-creation of knowledge. I was continually conscious about how my own identity (male, person of colour, registered nurse etc.), attitudes, assumptions, and preconceptions influenced the dynamics and power relations of the interview process (Hewitt, 2007). To facilitate a dynamic and creative process, I often brought different orientations to the interview, making linkages between themes and reflecting back my interpretations to interviewees (Holstein & Gubrium). With the exception of Daniel, Krishna, and Krystal, other participants with cancer wanted to have a follow up interview.

Following each interview, I made detailed field notes to record my impressions, questions that generated useful discussion, barriers to the interaction, preliminary thoughts about analysis, and topics to focus on in follow up interviews (Warren et al., 2000). To provide a rich account of each case study, I also documented participants’ appearance, mannerisms, and demeanour. In total, I generated approximately 30 pages of field notes following the interviews.

The interviews were tape-recorded and transcribed verbatim. The transcripts were generated with attention to the changing characteristics of speech (for example, intonation and pauses) and different emotions not captured in text (for example, crying or laughing). Incorporating these nuances of speech into my analysis, I viewed these emotional characteristics as expressions of subjectivity and thus carried them over in the use of quotations in later chapters. To develop familiarity with the interview data, I transcribed half of the interviews myself. A reputable professional transcription service transcribed the other half of the tapes. Approximately 600 pages of interview transcripts were generated.

**27.3 Documents**

Since case study methodology often involves multiple sources of data (Yin, 2009), approximately 30 documents were collected across the seven cases in order to augment the
interview data. As documents often record a “full state technology of power” (Hodder, 2000, p. 703), the analysis of documents facilitated a deeper examination of the discourses in operation and the formation of subjectivities. Identified through the interview process, documents from participants included: websites, self-help books, pamphlets, magazine articles, self-made graphs of personal medical records, and cancer summaries written by participants. To store and manipulate the document data, I transcribed key texts from books, electronically scanned certain diagrams, and used the “web capture” function of NVivo 10 that converted website screens into usable pdf forms. As the document data were vast, I focused on selections of the documents that participants openly discussed during interviews. Some of the documents discussed by participants (for example, talk-show programs, radio shows) were not considered because they could be located. With healthcare providers, I sometimes asked if they drew on certain ethics protocols, clinical practice guidelines, or institutional policies when working with patients that seek life-extension. Interestingly, clinicians could not name documents specifically but only discussed these items and how they employed them in general terms.

### 27.4 Field Observations

Because case study often examines research phenomenon within its real life contexts (Yin, 2009), I conducted approximately five hours of field observation. As previously discussed, participants did not give me permission to attend any formal appointments with healthcare professionals. With the exception of Daniel, participants did not discuss any observable events (for example lectures or information sessions) related to cancer treatment that they were planning to attend. Although he had to cancel at the last minute because of acute pain, Daniel invited me to attend a public lecture ran by his peer support group about decision making in advanced cancer. I observed approximately two hours of this event. The other three hours of field observations were spent with Krishna (Case Six) while waiting for his various clinic appointments in the study institution. During these observations, I focused on how power relationships might be enacted in different social settings, such as the sharing of language or the bodily posturing of individuals relative to others (Yin). Recognizing that my own subjectivities shaped my observations (Hamilton & Manias, 2007), I did not cast myself as an objective and
neutral observer. I did not tape or video record observations, but made detailed field notes following the events.

28 Analytical Strategies

Following a case study approach, data analysis was grounded in a poststructural perspective (Yin, 2009). In order to examine how discourses constitute the search for life-extension, and the subjectivities that are shaped by these discourses, I employed Foucauldian discourse analysis as the analytical framework (Yates & Hiles, 2010). Although some methodologists have suggested the use of prescribed steps in discourse analysis, I adopted a more flexible and iterative approach that Frost et al. (201) proposes embodies the “spirit of poststructural inquiry” (p. 444). In this section I outline the different strategies of data analysis.

28.1 Coding and Other Analytical Strategies

To begin my analysis, I undertook multiple and close readings of the transcripts, documents, and field notes, highlighted key passages, and wrote memos of my initial analytical impressions (Strauss & Corbin, 1990; Dierckx de Casterle et al., 2012). This was an important analytical technique that I repeatedly drew on. In this early phase, I focused on increasing the conceptual understandings of the research data as a whole, retaining the integrity of each individual case, but also developing a feel for the conceptual differences between cases (Dierckx de Casterle, et al.). I kept an ongoing journal of my initial analytical impressions.

Although the data was coded, coding was not necessarily central to my analysis. Coding often assumes that decontextualized units such as categories, themes, or other general structures in the data are more objective than the context-laden words and meanings that constitute an individual’s subjectivity (Packer, 2010). By providing so-called objective knowledge, an over reliance on coding may limit the rich interrogation of subjectivity in the data: both the subjectivities of the participants and the researcher (Packer). Rather than over emphasize coding, my own subjectivities as the co-creator of the knowledge were a central analytical concern.
Coding did help me to digest the data into analyzable units, to link different segments in the data, and to generate emergent conceptual categories (Morse & Richard, 2002; Coffey & Atkinson, 1996). To facilitate coding, I utilized the qualitative data management software NVivo (Version 10). Moving through several rounds of coding, I approached this process as a dialogical process that moved between the empirical data and emerging analytical concepts. The first rounds of coding moved in an inductive fashion, starting with local categories and terms used by informants themselves (Coffey & Atkinson; Strauss, 1987). These early rounds of coding approached the data at a more general level and considered broader units of analysis. Later rounds of coding involved a deductive approach to open up and think creatively about the data (Coffey & Atkinson). Codes and categories were combined to generate emerging analytical ideas. The analytical ideas developed from the coding process were intertwined with the concepts developed through the multiple readings and memoing of the data. In addition, I met regularly with my research committee to engage in conversations about the data that often led to new analytical directions.

A primary of concern of case study research is to understand the relationships, complexities, and problems within an individual case (Stake, 1995). Although I examined cases as separate entities, I also synthesized the findings across the seven cases in order to promote a more robust analysis (Yin, 2009). In doing so, I looked for emergent patterns and different ways to categorize the cases, a primary feature of this methodology (Stake). Although I attempted to classify the cases according to type of subjectivity, I found this analytical approach too restrictive. As multiple subjectivities exist simultaneously within one individual and different subjectivities shift with changing social locations (Foucault, 1969), participants (and cases) in this study could not be neatly categorized. Rather than simply look across cases to locate common themes, I also probed the data for inconsistencies, fragilities, and conflicts (Braun & Clarke, 2006). I did not necessarily search for central “truths” in my analysis, but considered the fluidity and inconsistency of meanings (Manias & Street, 2001).
28.2 Locating Discourse and Subjectivity in the Analysis

I was not only concerned with characterizing the different discourses that constitute the search for life-extension, but also with describing the conditions of possibility that permit these discourses to exist (Foucault, 1972). To locate discourses in the data, I closely examined the different practices that different participants used to either locate treatment or restrict this practice (Frost et al., 2010). These practices included different techniques to obtain knowledge, negotiation strategies, assertive communication styles, and different techniques to shape the self. Examining how discourses are enacted in different types of practices was crucial in order to move beyond analytical reduction of discourses in the data to narratives, forms of representation, or the text alone (Hook, 2001).

Attending to the numerous mechanisms of power/knowledge in the data (Arribas-Ayllon & Wakerdine, 2008), my analysis of discourse did not privilege a textual analysis, but considered how individuals enacted various discourses through different practices of agency and resistance (Hook, 2001). I was interested in how the various systems of knowledge about cancer treatment were legitimized or discredited depending on the different subject positions of participants (Frost et al.). For example, I scrutinized the documents for the different strategies that the authors employed to establish positions of authority (Hodder, 2000). Illuminating new discursive patterns, I considered how the effects of power relations normalized, disciplined, or corrected individuals who disrupted traditional patient-healthcare provider hierarchies (Yates & Hiles). I also looked for how certain discourses operated as “truthful” depending on the social contexts and the perspectives of who was asked (Hook, 2001). Throughout my analysis, I was conscious not to depict discourses in an overly linear and continuous way. Rather than grant a privileged status to the content and structure of discourses, I called attention to the destabilization of such meanings, attempted to undermine their authority, and called attention to the discontinuities developed in my analysis (Hook).

In order to answer my second research question, my analytical focus turned to a concern with the process of subjectification, or how participants become subjects through the crystallization of the discourses (Mansfield, 2000). As poststructuralism rejects the ahistorical subject, my analysis focused on examining discursively situated forms of subjectivities that were “actually
experienced” (Yates & Hiles, 2010, p. 57) by participants. Another analytical challenge was to be sensitive to how participants are both subjectified subjects, constituted by a set of forces and structures not of their own making, and agentive subjects, who have agency to shape themselves in response to certain discursive forces (Yates & Hiles). I worked through this challenge by considering how participants shaped the self within certain governing social forces.

I did not consider interview content exclusively as “an expression of the inner subjectivity of the interviewee” (Packer, 2011, p. 56) waiting to be unearthed in analysis. I instead considered how individuals illustrated their subjectivities as a dynamic and fluid social performance for me as the researcher (Atkinson & Delamont, 2005). To locate subjectivity, I considered how individuals described themselves and their perceived rights, obligations, responsibilities, and needs with regards to their treatment and disease. I also considered how participants acted upon themselves to shape their own lives, their own conduct, and the rationalities that they employed to describe this process of shaping the self (Yates & Hiles, 2010). As with my analysis of discourses, I considered how participants’ gestures, perceptions, and use of language reflect different forms of power/knowledge in different contexts (Foucault, 1976).

29 Ethical Considerations

This study was reviewed and approved by the Health Science Research Ethics Board at the University of Toronto (see Appendix M) and the site of recruitment. Highlights of the ethical considerations are described below.

29.1 Risks and Benefits

As with all qualitative research, there was risk that individuals could be identified through participation in the study, although measures were taken to ensure privacy and confidentiality. For patients and family members, there was a potential risk of becoming emotionally distressed during the interview related to the recounting of past cancer experiences and discussing the possibility of death. Drawing on eight years of nursing patients who were often acutely ill, my
own clinical background helped me to navigate the emotional distress of participants. For instance, Todd and his wife Nancy became distraught when they brought up the topic of funeral planning during their first interview. Despite their crying, they were determined to keep the interview going as illustrated by their statement: “Ask us anything. We can take it!” In this instance, I paused the interview to provide support and then respectfully asked for their permission to continue. I later reported my assessment of their distress to their palliative care physician, who informed me that they were being followed by a social worker. I also followed up with both Todd and Nancy a few days after the interview.

The potential benefit to participants was that interviews provided a confidential, non-judgemental, and safe environment to speak about their experiences, frustrations, and fears regarding the search for life-extension. Individuals may have derived a therapeutic benefit or may have experienced a catharsis by discussing their experiences. For instance, despite Nancy’s obvious distress, she invited me back to her home for a follow up interview because she felt she had more to share about experimental drug trials. The benefits of this study to the scientific and clinical community will be discussed further in the conclusion chapter. By understanding the discourses and subjectivities in operation, this study can point to better ways to help patients and family members navigate treatment in the context of life threatening disease.

29.2 Compensation

I reimbursed participants’ transportation costs, such parking or public transit, of up to $20. If the interview or observation was in the participant’s home, I did not reimburse the transportation costs. Following the interview, participants received a $30 gift card to a popular drug store chain. The honorarium was reasonable in that it provided gratitude to participants for their time, but was not coercive. Healthcare professional participants also received a $30 gift card to a well-known bookstore chain.
29.3 Informed Consent Process

As previously discussed, participants were provided a copy of the informed consent form at least one week before the interview. I obtained signed consent before the start of the interview or observations. Before written consent was obtained, participants were verbally informed about the nature of this study, the components of data collection, and the process of withdrawal from the study. No participants that were recruited withdrew from the study. The informed consent for patient participants is in Appendix N. The consent form for family members and healthcare providers are similar in format.

29.4 Privacy and Confidentiality

Personal information that could potentially identify participants was either not recorded in this study or removed after data collection. Confidentiality with regard to the data collected was ensured by means of pseudonyms that were retained through data collection, storage, and analysis. Names chosen, however, reflected their gender and assigned ethnic background. During the writings of study findings, direct quotations from interviews were described using the same pseudonyms and details of the study settings were referred to only in generalities. When describing the details of patient cases, which are essential in case study research, I obscured the details of the case to prevent the identification of the participants, but attempted preserve to the flavour of individuals’ demographic profiles. For example, I assigned participants a different country of origin, but from the same region of the world. When describing the details of participants’ medical history, for example, I obscured the number of months or years. In addition, I obscured the gender and other identifying details of healthcare professionals that participated in this study.

To maintain privacy, only my doctoral research committee had access to the data. To properly secure electronic data files were stored on: 1. The electronic data server of the Lawrence S. Bloomberg Faculty of Nursing, which is backed up daily, 2. An encrypted external jump hard drive. All electronic data have been secured under password-protected files on the server and will be kept for seven years. After seven years of storage following the completion date of this
study, the electronic data files will be erased. Interview audiotapes were erased once each tape was transcribed.

30 Study Limitations

The major limitation of this study was that the sample did not represent participants from a wider range of social locations. Although the patient sample was heterogeneous in terms of demographic criteria such as gender, ethnic background, and the type of cancer, individuals were educated, had supportive social networks, largely professional, had access to a computer, well spoken, articulate, and able to advocate for themselves in English. With the exception of Isabel (Case One), who was the only participant to describe the financial consequences of having advanced disease for a prolonged period, participants appeared to be economically stable. In fact, based on my field observations of the home environment during interviews, certain participants seemed economically affluent.

Another limitation of this study was the site of participant recruitment. As this study was conducted in the publically funded Canada healthcare system in a large urban cancer centre, the possibilities of obtaining a number of treatment options are perhaps greater than a smaller institution in a rural area or a resource limited country. Healthcare institutions with austere conditions may not have been able to offer its patients the resources that characterized the search for life-extension in this study: the electronic charting system, access to experimental treatments, specialized palliative care teams, and clinicians that also engage in clinical research. Moreover, participants were recruited from an outpatient palliative care clinic, which may have influenced how they viewed their disease and treatment. For instance, individuals recruited from an inpatient unit may have different perspectives about this phenomenon.

The perspectives of nurses in this study was based on their work in an ambulatory clinic, where nurses would see numerous patients in one shift, interact with the patient briefly, and often focus on the administration of care (for instance, booking diagnostic tests and other appointments). As nursing practice on an inpatient unit is typically focused on a lower number of patients over a longer period and on the direct communication biomedical data (for example, reporting on daily
blood work), these nurses may have different social arrangements with patients and families than the nurses interviewed in this study. The different relations dynamics of nurses who work on an inpatient unit may shape their professional role in the search for life-extension in an altogether different way.

31 The Quality of The Research

In a general sense, the quality of constructivist research is determined by whether the research findings can be traced back to the theoretical framework and the strategies of data analysis (Manning, 1997). Conducting the research in a rigorous fashion is a means to promote integrity, competence, and legitimacy of the research process (Patton, 1999; Tobin & Begley, 2004). In this study, I drew upon on three sets of criteria to achieve methodological rigour: trustworthiness, authenticity, and reflexivity (Patton, 2002, 1999, 1990).

31.1 Trustworthiness

Promoting the grounding of the research findings in the actual data, trustworthiness refers to being attuned to the interrelationships between the viewpoints of the participants and the researcher’s interpretations of them (Hamber, Johansson, Lindgren, & Westman, 1994; Tobin & Begley, 2004; Guba & Lincoln, 1989). Although I positioned this study as a creative endeavour, I closely followed the data collection strategies, ethical guidelines, and analytical procedures as outlined in this chapter in order to help promote trustworthiness (Patton, 2002). In addition to these procedures, I regularly met with my thesis committee to discuss the quality of my data analysis. I also conducted an ongoing audit trail to track my methodological decisions and kept a critical self-account of the systematic research process (Sandelowski, 1986; Tobin & Begley, 2004).
31.2 Authenticity

Authenticity involves a set of criteria that commits the researcher to a set of actions, such as having a balance of perspectives, shared knowledge, and the possibilities of social action that result from the research findings (Manning, 1997). Although there are several types of criteria that outline authenticity, I choose to focus on ontological and catalytic authenticity in this study. Bolstered by reflexivity, ontological authenticity addresses the question of whether the experience of the research process improved the respondents’ sense of developing a new meaning or different perspectives about the subject matter (Manning). Several patients and family members often engaged in dialogical conversations (Manning) during the interview that was often characterized by an open, collaborative, and dynamic process.

Because they wanted to express their concerns about the cancer care system, respondents such as Isabel and Eva, described how participating in this study was very meaningful to them. Isabel, in particular, viewed her participation in this study as an important political act in her larger personal project to resist the dominance of biomedicine. Other participants, such as Daniel and Achmed (Case Five), reported the willingness to share the skills (for instance, keeping detailed medical records) they had proudly developed. Despite my challenges of collecting data on Krishna, I developed caring and trustful researcher-respondent relationships with most participants, an additional criterion of ontological authenticity (Manning).

Catalytic authenticity focuses on mobilizing the insights and interpretations developed by the study inquiry into actions that have social or political value to others (Manning, 1997). The implications of this study to clinical practice, education, policy, and future areas of research will be discussed in the conclusion chapter. Future action will focus on translating the new knowledge generated in this study into improving the lives of both individuals who seek life-extension. As it highlights the interconnected subjectivities between healthcare providers and patients, this study will also have multiple implications for healthcare providers that care for these types of individuals.
31.3 The Use of Reflexivity in this Study

A critical theoretical framework often considers how the subjectivities of the researcher impact the research process, thereby resulting in a concern with speaking for others and an attendance to the power relations inherent in knowledge production (Packer, 2011; Choi, 2006; Fine, 2005; Patton, 1999). As it deconstructs the authority of the researcher, reflexivity assists in disclosing how power/knowledge relations and dominant ideologies operate through the research process (Choi). In this section, I describe how I utilized reflexivity in order to contribute to the authenticity of this work (Patton, 2002). I worked from the poststructural position that views the researcher as the primary instrument for data collection. The awareness of my own subjectivities was an important facet of promoting methodological rigour (Manias & Street, 2001; Patton, 1999).

In order to bring more openness and sensitivity to the research process, I had to consider my previous personal relationships with people who have advanced cancer within two contexts: my familial history with cancer and my clinical work as an oncology nurse. Considering the effects of my own positionality was the beginning of the reflexive process. For instance, I had to continually reflect on my previous positions as “nurse” or “caregiver” with the emerging positions as “researcher” and “producer of knowledge”. I had to reflexively consider how the boundaries between these positions became blurred and what this blurring meant to the study process. For example, when witnessing the suffering of participants, I had to carefully consider how my instincts as a clinician to intervene in a therapeutic sense affected the interview process. My concern with protecting and “saving” cancer patients, a role oncology nurses are often socialized to take up, occasionally led to my hesitancy to probe deeper about certain emotionally laden topics (for example, funeral preparations), despite wanting to discuss these topics during the interview. Through continual reflection and debriefing with my doctoral committee, I developed a better clarification of my role as a researcher.

As a researcher using a critical perspective, I developed an awareness of my location within the very discourses (for example, biomedicine and palliative care) that I aimed to investigate and problematize. McCabe and Holmes (2009) argue that reflexivity in poststructural inquiry is more than promoting research validity, but is also about acknowledging the “nature and function of
power” (p. 1524) of participants and researchers. As a result, I was cognizant of how my authoritative expertise as a clinician and researcher vested me with a sense of power, which could have either liberating or repressive effective (McCabe & Holmes). The interview could become repressive in that participants could find themselves in a discursive field where they could see themselves as deviant or bad (McCabe & Holmes). To limit this, I attempted to cultivate an open and respectful research environment where participants would feel free to disclose their perspectives without judgement. The research interview can be a liberating experience because it isolates the individual from the judgement of society (and the healthcare team) and provides a space where one can explore different and often controversial perspectives (McCabe & Holmes).

In the interest of being open and transparent, I shared my identity as an oncology nurse with participants and sometimes discussed with them how this might have affected the research relationship. Yet, this raised concerns about whether participants modified the information they were willing to share. Concerned with unsettling the existing social arrangements that support their ability to access treatment, certain participants may have been hesitant to bring up certain subjects because of my professional background. For instance, some interviewees avoided naming particular healthcare professionals when critiquing their care. For other participants, my own subjectivity as a nurse did not stop them from expressing their frustrations and thoughts about challenging healthcare professionals. According to McCabe and Holmes (2009), these individuals were able to utilize the interview as “a vehicle for reflexive thought and action” (p. 1523) in order to examine their own stance against normative values. Through reflexive engagement with me as the researcher, these individuals were able to explore particular power structures and dominating discourses that greatly impacted their search for treatment (McCabe & Holmes).

In order to promote reflexivity, I also had to continually review the multiple assumptions that I bought to the research process. In particular, I had to reflexively examine how my previous assumptions about physicians, which were generated by my own clinical work, might have coloured my examination of the power dynamics between patients and physicians. When participants described their concerns about physicians’ inabilitys to be attentive, I could empathize with the challenges of exercise power with relationship with physicians. When I
reflected back, I wondered whether I was reverting back to being resentful of the power of physicians, which nurses are sometimes socialized to do in the clinical world. This tendency resurfaced again during my interview an oncologist. Because this oncologist seemed rushed and unwilling to engage in a deeper conversation about practice, the interview provoked a sense of annoyance and fed into my assumptions that physicians are often dismissive, a claim supported by certain participants. As my doctoral committee pointed out, this way of thinking sometimes came out in the tone of my early drafts of writing. Judging physicians and rendering individuals powerless is in fact antithetical to my poststructural approach. Through a reflexive process, I became more attuned to seeing how constrained physicians were in their clinical role, how participants exercised their own practices of resistance to counter biomedicine, and the discursive interrelationships that constitute the dynamic between these two groups.

My familial experience of losing a close family member to cancer also influenced my relationship to participants. Examining my subjectivity around death due to cancer was crucial because it helped me understand how I might have shaped my own self through the research process, an important facet of reflexivity (Patton, 2002). I occasionally found myself mesmerized by participants’ sense of confidence and dedication to life-extension, which was likely a social performance of their faith in their own curative abilities. As I developed meaningful research relationships with most of the participants in this study, I did want them to die of their disease.

Similar to the patients and family members that I interviewed, I found myself caught up in the wider culturally endorsed assumptions that one could transcend death by adopting certain subjectivities. Shaped by my own discomforts towards death, I often obscured the possibilities of dying in earlier rounds of data analysis and writing. Reflexively considering my assumptions about death helped me better engage with the actual possibilities of dying in this work, which was a prevalent theme in the findings. At the same time, the sense of discomfort with mortality was never fully obliterated, but rather remained an ongoing dimension of the research process. For instance, after the data was collected I became preoccupied with preserving the experiences of participants in the writing after they had died. This shaped my particular relationship to the data. To help me work through the reflexive concerns with death and dying, I often debriefed with my supervisor and kept an ongoing journal of my responses and reflections.
32 Conclusion to Methodology Chapter

In this chapter, I outlined the methodological framework that guided this study, in particular the fit between case study methodology and the poststructural examination of the search for life-extension in advanced cancer. I also describe how the research process unfolded in the collection of case data and also how Foucauldian discourse analysis was utilized as an analytical framework.

In the next chapter, I answer the first research question of this study concerning the discourses in operation by presenting the results of data analysis.
Chapter 5
Results Chapter: Discourses

33 Introduction to Chapter

In this chapter, I present the results of the data analysis in order to answer the first research question: How do discourses constitute the search for life-extension through biomedical treatments for those with advanced cancer? This chapter is organized in three sections. In the first section, I briefly reiterate Foucauldian assumptions about discourse and outline how discourse as a theoretical idea is utilized in this chapter. In the second section, I describe the current biomedical field in advanced cancer that provides some of the contextual backdrop for the discourses in circulation. In the third section, the main focus of this chapter on results, I discuss the multiple discourses that are in operation in this phenomenon (see Figure Three). Rather than constituting a smooth and continuous body of knowledge, I describe how discourses often compete with and disrupt each other, which is a key finding in this study.

To answer the research question, I consider four types of discourses that constitute the research phenomenon.

1. A dominant discourse in this study, the *discourse of biomedicine* monopolizes key elements of cancer knowledge about disease status and treatment options, and also manages the gatekeeping of medical treatments like chemotherapy and experimental trials. The discourse of biomedicine is currently manifested through key informational practices intended to educate patients about their current disease status through institutionally driven technologies, such as the open access to the electronic medical chart. Seeding the conditions for individuals to move beyond being merely informed about disease and treatment, these practices produce certain expectations for patients to manage complex disease information in a highly sophisticated manner. Although the discourse of biomedicine still holds a dominant position, I highlight its fragility within the treatment of advanced cancer. I consider how the perceived limitations of biomedicine from patients and family members threaten to displace the prestige of this discourse, and by extension, the mainstream cancer care system. In particular, I outline
how the limited medical possibilities in treating advanced cancer leads to a rise in medical uncertainty from the perspectives of participants.

2. Although the move to encourage individuals to take ownership over their diseases has already been initiated since the late 20th century, I characterize the discourse of self-care within the context of the search for life-extension. Originating in response to the dominance of the discourse of biomedicine and its therapeutic restrictions, this emergent discourse shaped certain modes of conduct, attitudes, beliefs, and everyday practices that individuals take up in order to generate their own curative possibilities despite having late-stage disease. In this section, I describe individuals’ active utilization of bio-scientific knowledge and individuals’ manipulation of how treatment is administered in the cancer care system as emergent practices of the discourse of self-care. I also describe how the discourse of self-care threatens to dislocate the traditional hierarchical arrangements of bio-scientific knowledge and other treatment practices set forth by the discourse of biomedicine. Despite the antagonism between these this discourse and the discourse of biomedicine, I map out how the cancer care system is itself implicated in the production of the discourse of self-care.

3. I examine the discourse of palliative care as a dominant discourse that is derived from the discourse of biomedicine. A particular way of approaching the care of dying, the discourse of palliative care is sometimes idealized by healthcare professionals, yet is viewed with certain reservations by patients and family members because of its close associations with death and dying. In doing so, I describe the perceived passivity of the palliative approach from the perspective of participants, and its seeming incompatibility with the discourse of self-care that encourages the active search for life-extension.

4. Arising in response to biomedicine’s limited capacity to eradicate certain forms of advanced cancer, the emergent discourse of self-healing is shaped by the growing social expectation that individuals cultivate their own curative and life-extending potential, despite the vulnerabilities of their disease. In particular, I discuss how the discourse of self-healing shapes the different self-therapeutic techniques that participants employed in their everyday practices of the self and how they frame their overall search for life-
extension. To conclude this final section, I examine the discourse of positive thinking as an increasingly appropriate technique to extend one’s life and even eliminate cancer in the 21st century.
Figure 3: The Discourses in Operation

The Social World

The Discourse of Biomedicine

The Discourse of Palliative Care

The Discourse of Self-Care

The Chronicity of Dying

The mistrust of biomedicine

Power/Knowledge Relations

The Utilization of Bio-Scientific Knowledge

Neoliberalism

Self-governance

Forms of Resistance

Care of the Self (Shaping the Self)

Care of the Self

The mistrust of biomedicine

Neoliberalism

The Utilization of Bio-Scientific Knowledge

The Discourse of Palliative Care

The Discourse of Self-Care

The Chronicity of Dying

Forms of Resistance

Care of the Self (Shaping the Self)
34 The Use of Discourse in this Chapter

In this brief section, I revisit the poststructural framework about discourse that was previously discussed in the theoretical chapter. I also briefly outline some considerations about how discourses are employed in this results chapter.

Discourse was defined as a group of statements that provide a way of representing knowledge at a given historical moment (Foucault, 1972; Hall, 2001). There are certain types of discourses that I categorize as dominant, emergent, or residual (Epstein & Johnson, 2006). Discourses are constituted by the rules of formation, a set of principles or the conditions of possibility that allow a particular discourses to either emerge or fade (Foucault). As a result, I report on the conditions of discursive possibilities as important study findings in this chapter. Shaping the conduct of social actors and influencing how individuals understand themselves (Hall), discourses exist as practices that constitute the objects of which they speak (Foucault). As a result, I examine the behaviours, actions, understandings, and perspectives of research participants in order to locate the multiple discourses in operation. I also explore how particular individuals come to personify discourses as simultaneous objects and subjects of discourse (Hall).

In this chapter, I employed cohesive, logical, and linear descriptions of discourses and their associated practices when articulating the results. This chapter was written in this manner to satisfy the conventions of formal academic writing and to make the ideas more understandable to the reader. Yet, it does not discount the poststructural assumption that breaks and ruptures in ways of thinking define discourses as much as coherent themes. Discourses are continually in flux; some move in the background, whereas others emerge as accepted knowledge (Hall, 2001). Consequently, I describe the interrelationships, movement, incoherence, disruption, and tensions amongst the multiple discourses.
35 A Description of the Field in Advanced Cancer Treatment

In this section, I describe the current biomedical field of cancer care that was taken from the perspectives of study participants, observations in the field, and my own analytical voice. Although these findings are the products of different systems of knowledge, I do not situate this biomedical field within any one of the four discourses in operation. Rather, I position this field as forming the contextual background for the major discourses at play that are later described in this chapter. To characterize this field, I discuss advanced cancer as an ambiguous terrain that includes participants’ desperation to receive treatment and participants’ recognition of the closeness of their death.

35.1 Living yet Dying: Advanced Cancer as an Ambiguous Terrain

The diagnosis of life-threatening cancer positioned participants within an ambiguous terrain. Individuals with cancer were situated between many uncertain locations: between life and death, the possibilities of life-extension and letting go, and suffering and continuing on in the everyday. Although at different levels of intensity, each patient in this study articulated the severity of his or her cancer during the research process. For instance, before the start of his first interview, Todd (Case Three) looked me in the eye very seriously. He then motioned to his left elbow down to his hand and then his right calf down to his ankle and said, “Here’s where I don’t have cancer”. Each patient reported debilitating cancer related pain, various impairments to everyday bodily functions, nausea, and severe fatigue related to the side effects of treatment. In the face of this physical suffering, individuals were still able to live at home, were well enough to participate in the study, and often told their stories in interviewers with a sense of vigour. In fact, the colourful and energetic way that certain individuals recounted their stories was unexpected.

Forming an important background, the ability of participants to survive with extensive disease is a manifestation of the current state of oncological medicine. With the exception of Krystal (Case Seven), who was diagnosed with metastatic pancreatic cancer a few months prior to her interview, most had endured a long encounter with disease that ranged from several months to a
second reoccurrence after many years of remission. For most participants, the search for life-extension came late in the disease trajectory. Previously, participants had gone through several rounds of chemotherapy, radiation, hormonal treatments, and surgical procedures that often did not slow down or reverse the metastases of their current disease. For some individuals, the accumulated experiences and first hand knowledge of the cancer care institution and its various social actors informed how they currently sought life-extension in the cancer care system.

For certain participants, the prolonged exposure to advanced cancer amplified the intensity with which they pursued potentially life-prolonging interventions. Recognizing the duration between their first attempts with curative treatment and the more progressive stages of their present disease, participants often highlighted the significant stakes at play in their current line of treatment. The possibility of not responding to their current treatment regime signified a leap closer to death. For instance, Daniel (Case Two) shared his rationale for enrolling in a clinical drug trial for his metastatic prostate cancer:

“So far, so good. Yeah, but reaching the end of my life. I’m the only one left, so eventually I have to move onto another trial. Otherwise you die [laughs].

I – You have anything in mind?

I don’t know. I do the research. I show it to my, ah… hard to tell. It depends on the oncologist, what they decide. So many different types of drugs, so it’s not necessary this one or that one. So it’s up to them in that time… if I can go on another trial, very simple, as I see it. When you have to be put on compassionate relief, there’s nothing you can do. Before that, do as many trials as you can get. It’s a very simple logic, isn’t it [laughs]? So I welcome, different kinds. I welcome to being a guinea pig forever”.

(Daniel, Case Two, Interview One)

Daniel mentions that he is the “only one left” from his peer support group of men with advanced prostate cancer. Although he concedes he is reaching the end of life, experimental treatments are perceived as a viable way to prolong his life. He is willing to move onto the next trial (and the next and the next) in order to sustain his existence. In contrast to “compassionate relief”
(Daniel’s term for palliative care), where the known end is death, clinical drug trials leave open the uncertain but hopeful possibilities for the future. The actual anti-cancer drug that Daniel takes is not as important as accessing the next trial. Through experimental chemotherapy, biomedical science determines the temporal frame for the remainder of his life. He welcomes the opportunity to be a “guinea pig forever”, to be scientifically manipulated in order to stop his aggressive disease. Despite downplaying the severity of his situation through the use of humour and suggesting “a very simple logic”, he positions himself on an uncertain manifestation of life that exists from trial to trial in order to survive. Disrupting the continuity of his previous self, the search for treatment establishes a new ambiguous form of his identity. Daniel is willing to exchange elements of his old self in exchange for a new self, the “guinea pig” self.

As evidenced by the increasing opportunity for participants to learn about and participate in bio-scientific research, the more open social dialogue about clinical trials created the conditions of possibility for individuals to move from trial to trial. With the exception of Eva (Case Four), who was reluctant to receive harsher forms of treatment because of her older age, participants located trial information on the Internet, newspaper articles, and other mass media sources. Reflecting the academic focus of the study setting, trials were often introduced by oncologists as a further therapeutic option when standard treatments were exhausted. Following his first unsuccessful round of standard hormonal and radiation therapy, Daniel joined a local peer run support group for men with prostate cancer. This support group had informational resources (for example, a website and public lectures) to encourage individuals to enrol in clinical trials. Although peer moderated, the website of this organization was linked to clinical trial registries. The monthly electronic newsletter of this institution also provided an updated list of scientific studies that individuals can bring forward to their oncologist. Rather than become limited by what one’s local physician and the cancer care system offers, the more widespread awareness of experimental trials opened up new medical frontiers in the treatment of late-stage cancer that some participants viewed as expansive.
35.2 The Desperation for Treatment

The current cancer care field was further characterized by an intense sense of desperation to access treatment. Because of their dire physical symptoms and the extent metastatic disease had spread across their bodies, participants were desperate to receive cancer therapies. Whereas all participants with cancer viewed their current treatment regime as a way to extend their lives, certain individuals (in particular, Isabel and Daniel) also hoped to cure themselves of advanced cancer. Although each patient articulated his or her own sense of personal desperation, the drive to achieve a cure was shared and occasionally amplified by the influence of local social networks. For instance, James (Case One) described his determination to exhaust every therapeutic option in order to prolong his wife’s life. His wife Isabel was currently being treated for metastatic breast cancer.

“Make no mistake about it, if a witch doctor danced a circle on a bunch of bones is going to cure her, I’m all for that. I don’t care if it’s the conventional or whether it’s holistic or whether it’s death rays from Mars that can get transferred into health rays. I don’t care what it is, as long as it works. I have no prejudice. We have an open mind. Actually, we have the diligence to explore every single option and to find out about it”.

(James, Case One, Interview One)

By entertaining the possibilities of exaggerated therapies, James conveys his sense of desperation. The actual treatment and its associated costs become secondary to prolonging Isabel’s life. Mirroring James’ sense of desperation, Isabel’s ambition for treatment for distinguishes her from other individuals in similar situations. In her second interview she claimed, “I don’t want to get sick again, and a lot of people don’t think that way. They’re not prepared to do what it takes to get better” (Isabel, Case One, Interview Two). Isabel, like many participants in this study, was willing to push for life-extension in an intense way. Bringing this intensity to the healthcare system, patients and family members advocated for themselves in increasingly desperate ways.
35.3 The Recognition of Death

The current cancer care field was characterized by the recognition of death by participants with late-stage cancer. The desperation to survive and to self-advocate for biomedical treatment coexisted alongside participants’ understanding of the severity of their disease, their poor prognosis, and their understanding that they would likely die of their cancer. At the same time, participants’ recognition of their death was often concealed; individuals rarely engaged in an open dialogue about death. For instance, Isabel (Case One) admitted to cashing in her death benefit from her insurance company to help pay for her expensive alternative anti-cancer treatments. A sculptor in his spare time, Daniel (Case Two) was working on a clay bust self-portrait, depicting himself as a Chinese emperor that is historically found in ancient tombs. A religiously devout person, Krishna (Case Six) lamented that could not visit Nepal, his country of origin, and pray in important sites of Hindu pilgrimage before his death. Interestingly, Eva (Case Four) was the only participant who openly discussed planning for her hospice care, will preparation, and funeral arrangements. In her seventies, Eva was significantly older than other participants, was experiencing her second disease reoccurrence, and had been living with breast cancer for many years.

Although not as forthcoming as Eva, Krystal was the only other participant who engaged in a more candid and prolonged discussion about the possibility of dying. Krystal openly admitted her desire to relinquish the search for biomedical treatment, yet also described the relational implications of letting go of this search. In particular, she described her challenges of dealing with her family when she decided to stop receiving a harsh round of folfirinox, a type of chemotherapy often used to treat metastatic pancreatic cancer.

“Going off of folfirinox was very easy for me. My family was very upset and they thought that they understood why I was doing it because I said I just couldn’t function and they saw me declining. I was really sick and I am after quality of life, as they are for me. So I said I wasn’t going to take it anymore. So after the initial shock to the family and the fact that there was another chemo that we could look at made them feel better…”

(Krystal, Case Seven, Interview One)
Krystal reveals some of the social implications that result from relinquishing treatment and from the more open recognition of death. By satisfying her family’s wish to keep her alive, the search for biomedical cancer treatment kept Krystal socially entangled in a particular way; the pursuit of chemotherapy makes her family feel better about the likelihood of a cure. Later in the interview, Krystal discussed the ambitions of her husband Mark to locate experimental radiation treatment only offered in the United States: “He’s just not willing to give up. So, as far as he can see a 50 percent chance means more months and maybe more treatments” (Case Seven, Interview One). As with Daniel, Mark articulates his willingness to experience time as a moving from treatment to treatment in order to generate life-extension for Krystal. Mark’s treatment practices highlights the sense of discontinuity between what individuals understood about mortality and what they were willing to undertake to achieve treatment.

36 The Multiple Discourses in Operation

In the third section of this chapter, I build on my characterization of the biomedical field to consider key findings about discourses in this study. I interrogate the multiple and competing discourses that are in operation when individuals with life-threatening cancer actively seek life-extension through biomedical treatments. In my discussion, I group these various discourses within four broad classifications: (1) The Discourse of Biomedicine, (2) The Discourse of Self-Care, (3) The Discourse of Palliative Care, and (4) The Discourse of Self-Healing.

36.1 Discourse One: The Discourse of Biomedicine

36.1.1 Introduction to the Discourse of Biomedicine

Within the study setting, the authority and prestige of the discourse of biomedicine was constituted in multiple ways. Biomedical discourse retained its dominance by shaping the privileged social location of professionals relative to patients. For instance, healthcare providers reported specialized and prolonged formal training in oncology, palliative care, and oncology nursing. The discourse of biomedicine also moulded the types of knowledge that were valued in
clinical practice. For example, oncology practice in the clinic worked from the premise of evidenced based healthcare. A social performance of their expertise, clinicians often referred to peer-reviewed articles during interviews to illustrate that their current treatment practices were based on the latest bio-scientific research.

Physicians were also the principle gatekeepers that determined if treatment was obtained or not. Recruited from a palliative care medical clinic, each patient was medically managed in one form or another. Although some resisted medical authority, participants could not discount that conventional biomedicine had somehow kept them alive up to this point. Through their privileged position in the cancer care system, physicians had the authority to define current therapeutic regiments, as well as the capacity to constrict or open up future therapeutic endeavours.

Physicians regulated bio-scientific data about the status of individuals’ cancer and knowledge about possible treatment. The discourse of biomedicine provided fairly rigid guidelines about which types of disease knowledge were either legitimized or discredited. For instance, Todd’s (Case Three) palliative care physician described the information that patients and families employed when seeking cancer treatment.

“I find that most of the patients what I hear from them is, ‘Oh you know, I had this neighbour who had chemo and he died the next day.’ {Laughter} Or negative stories that they’ve heard first or second hand that affects their decision making: ‘I don’t want to do chemo because my cousin went through it or I don’t want to get morphine for pain because you know, morphine kills.’ Or they say, ‘Oh we heard on the news or the newspaper that there is this new study or this new med, or should we go to Mexico because we heard there is a clinic there.’ It’s more that… I don’t find that it’s as much scientific information. It’s a more, ‘who said what’ kind of thing”.

(Palliative Care Physician, Case Seven, Interview One)

In addition to clinic appointments, patients and family members gathered medical treatment knowledge from multiple sources: previous illness experiences, family members, informal social networks, and the mass media. By calling attention to the seemingly incorrect medical beliefs of
individuals with cancer, this physician places a sense of doubt on certain folk understandings about biomedical therapies. In fact, certain misconceptions about treatments seem to amuse this particular physician. Compared to the solid, scientific, and more formal types of knowledge from the discourse of biomedicine, the diffuse array of lay information sources should be approached with certain reservations in this professionalized view.

Later in the interview, this physician discusses some of the challenges of working with patients who bring self-obtained disease knowledge into the medical encounter.

“I always tell my own students, never underestimate a patient’s intelligence. People are smart. People are smart, but don’t overestimate their medical knowledge. So in the sense that they do a lot of reading on the Internet. But sometimes a little knowledge is dangerous because you don’t know where to put it. You read all this stuff and you don’t know how to put it into context. So it’s helpful that patients are proactive and look at [electronic charting system] or go on the Internet and they ask questions. Um, but sometimes you do spend a lot more time re-educating them. {Laughter} Yeah, re-educating that knowledge and you know, sort of redirecting that knowledge”.

(Palliative Care Physician, Case Seven, Interview One)

According to this physician, certain forms of lay obtained knowledge are “dangerous” because they can misdirect individuals. Although patients are intelligent, this physician still believes that an important part of the professional role is to re-educate, redirect, and re-contextualize the information that patients bring forward in clinical consultations. The discourse of biomedicine establishes certain expectations for physicians to regulate patients’ usage of knowledge and ultimately provides them with the institutional authority to discredit certain forms of disease knowledge. Although patients may have particular beliefs and understandings, medical knowledge is often privileged in determining whether a cancer treatment is provided or not. Given the sophisticated formal training and advanced clinical skills needed to work in the clinical setting, the appropriation of legitimized knowledge may be understandable from the perspective of physicians. This particular physician seems concerned that patients may adsorb inaccurate disease knowledge without a proper understanding of the contexts of their disease. In
this instance, the intention is to redirect knowledge so that patients are properly informed and are able to make the most appropriate treatment choices.

For participants that were intensely advocating for life-extension, it sometimes became difficult to recognize and appreciate the good intentions of physicians. The dominance of the discourse of biomedicine generated certain tensions for participants who attempted to exercise their own control and power over knowledge in the medical encounter. Isabel (Case One) described some of the conflicts she experienced when she tried to bring self-researched information to her oncologist.

“...Its encouraged that whatever I am doing I should present to my oncologist, whether they agree with it or not, just so they know, and if they can find any conflict with what I’m taking with what they’re giving me. So I thought okay, ‘Well I’ll do that.’ Um, at first I wasn’t comfortable with that. I’m not comfortable with her period. Her communication is not very good. For one, sometimes she looks at you, she bats her eyes or she looks down at the floor. And she has this silly kind of smile of her face. It’s hard. I just find the communication with her very difficult. But anyway I give some of this information. She said she researched it. She says, ‘Oh that’s just done on animal studies.’ Well, you didn’t it research it then. It wasn’t just on animal studies. So I could tell, when you’re an expert at something, you know when someone is lying to you”.

(Isabel, Case One, Interview One)

As a result of her oncologist’s behaviour, Isabel recognizes her inability to exercise power in this situation. Although the cancer care system encourages patients to openly discuss their own research and self-directed therapies, the oncologist, and by extension the discourse of biomedicine, reasserts its monopolization over legitimized knowledge during the consultation. Isabel provided several scientific studies about a new and experimental form of cancer treatment, yet her oncologist quickly discredits this information as not translatable to humans. Whereas patients can only propose cures loosely based on a lay and non-legitimized understanding of science, the power of the discourse of biomedicine lies in its ability to translate clinical research into actual evidence-based interventions. In an effort to rebalance power relations, Isabel provides a harsh critique of her oncologist’s communication style: it is insensitive, harsh, and
untruthful. She challenges her physician’s credibility and claim to knowledge by suggesting that she did not even properly research the treatment. In her first interview, Isabel summarizes her overall perspective of how oncologists often view themselves relative to James and herself: “I’m God, holier than thou, kind of walking on water” (Isabel, Interview One). Her unique and sometimes confrontational approach towards seeking treatment is largely shaped by her deep resentment of the dominance of the discourse of biomedicine.

36.1.2 The Biomedically Informed Patient as a Discursive Practice

The discourse of biomedicine shaped certain knowledge practices that encouraged patients to develop a deeper understanding of their disease status. Creating the conditions of possibility for individuals to advocate for increasingly sophisticated knowledge about life-extending therapy, these practices encouraged a more open access to personal health information for those with advanced cancer, rather than keep cancer knowledge isolated in the healthcare system. Given the current emphasis on consumer satisfaction, quality assurance, transparency, and openness in 21st century medicine, clinicians in the study setting had to ensure that patients had a strong biomedical understanding of cancer in order to effectively conduct the work of biomedicine. For instance, in order to obtain consent for a clinical trial, Todd (Case Three) discussed several consultations with his oncologist to ensure he had sufficient knowledge about his disease status. Through this process of becoming informed and regularly accessing his medical recording on the electronic chart system, Todd developed a clear understanding of the severity of his disease and recognized that this trial was estimated to extend his life a couple of months. At the same time, my analysis found that there were certain unforeseen social effects of this practice that extended beyond keeping individuals merely informed.

An innovative technological system that was unique to the research setting, the open availability of online medical charts was an intriguing example of how the discourse of biomedicine shaped patient’s access to knowledge. Under this arrangement, patients were given full entry to their personal medical information, including access to their most current lab values, biopsy results, imagining scans of their cancer, consultation reports from specialists, and clinic notes from healthcare providers. Designed to be interactive, individuals could graph the progression of
cancer-associated results over time (for example, tumour burden or white blood cell count). Access to this knowledge was unfiltered in the sense that the electronic chart that patients and family members could access at home was virtually identical to the electronic chart used by clinicians in their day-to-day work.

With the exception of Eva, each patient in this study utilized the electronic chart system when researching treatment, often cross-referencing the disease knowledge they self-researched with the numerical values from the chart. Todd was the most illustrative patient example. The uncensored availability of the medical chart allowed individuals to have a more complete biomedical understanding of their disease than perhaps ever before. Through the open availability of diagnostic imaging, participants could visualize the internal structures of their cancers in new ways. Todd explained, “…You can actually go in and I can see my bone scan and then actually see on the body the highlighted areas where the cancer is…” (Case Three, Interview Two). Although he can feel the inner bodily discomfort from bone metastases, the chart data externally confirms this understanding. Todd and his wife Nancy used this chart data to monitor his day-to-day progression at home between medical appointments. By logging onto the system with their teenaged children, they could also teach them about the nature of their father’s disease. Interestingly, Todd was somewhat surprised that patients have unrestricted access to the medical chart. He later said, “…You think the doctors kind of keep stuff to themselves and they have their own opinions and are you really finding out exactly what’s going on. This makes everything just as clear as day” (Case Three, Interview Two).

Unlike other participants who openly used this type of knowledge to advocate for additional treatment, Todd had some reservations about introducing chart data to physicians in the clinical encounter.

“Little bit hesitant to do that just because, you know, we’ve mentioned a couple of times on [electronic chart system], ‘We saw, you know. We saw this and that, and you know.’ Just because you don’t want to get their backs up in any way right?”

(Todd, Case Three, Interview Two)
This quote highlights certain tensions that result from the institutional practices of the biomedically informed patient. Although Todd has open access to medical data, traditional conceptualizations of patient-provider relationships restrict his ability to utilize this knowledge in face-to-face encounters with oncologists, particularly if there is a discrepancy between information obtained in person and the online chart. In Todd’s case, his recognition of the hierarchical position of physicians allows his doctors to become somewhat immune from challenges by informed patients. By avoiding certain conflicts, Todd is being strategic in preserving the traditional power and knowledge relations between physicians and patients. As described in the following results chapter, healthcare providers often idealized Todd as a model and obedient patient. These strategies allowed him to both receive daily care that was beyond the standard (for instance, special follow up phone calls at home) and to ultimately become enrolled in a clinical trial.

Physicians discussed how the online charting system complicated the everyday relational work with patients, particularly around the medical work of educating individuals about the signs and symptoms of progressive cancer. The Prostate Specific Antigen (PSA) test highlighted how power relations shifted as a result of open chart access. A general indicator of disease status, the PSA test measures the amount of serum antigen that develops in response to the prostate tumour. For Todd, the online chart became an important means to track his current PSA result, “right up to the minute” (Case Three, Interview Two) in between clinic appointments, which would indicate for him, “how aggressive my disease is” (Case Three, Interview Two). Todd’s oncologist initially described how having access to up to date data might alleviate the anxiety of patients waiting for pivotal biopsy results. Later in the interview, however, this oncologist warned of the negative consequences when patients interpret biomedical knowledge without professional guidance.

“This is something about prostate cancer specifically, most patients are very fixed about. PSA reading and a PSA that goes from five to six for me has a completely different meaning, as opposed to a PSA that goes from a 150 to 156 okay. For a patient though it might have a completely different meaning”.

(Oncologist One, Case Three, Interview One)
According to this oncologist, some patients translate their fixation on certain lab results into this assertively questioning physician about their progress in clinical appointments. This fixation sometimes arises when patients access this information from the medical chart without any formal medical guidance. Although the incremental difference in PSA between 150 and 156 might not be as clinically significant as the difference between five and six, some patients may view any increase in this result as harmful. Similar to the palliative care physician from Case Three, this oncologist feels that it is his role to help patients reinterpret and re-contextualize medical data.

Despite the benefits of the online chart in alleviating patients’ anxieties, certain physicians expressed annoyance with this practice because it opened up an appraisal of their therapeutic abilities from patients and family members. For instance, Todd’s oncologist admits, “I see my notes to a certain extent as my private view of things that I am happy to share within professionals, but I am not sure whether I necessarily would like to share that with patients” (Oncologist One, Case Three, Interview One). This particular oncologist resents that the textual constructions of the patient must now be openly shared, where it could potentially offend patients or feed individuals’ suspicions that medical care has not gone smoothly.

Even though clinicians continually attempted to reassert their authority, they could not discount that open access charting had changed the power relations with participants. For instance, Todd’s oncologist felt it was necessary to put constrains on certain charting practices in order to accommodate these shifts.

“This is by far more challenging. So we have to wait to write every single word because if you use the wrong word, you can make an elephant out of a mouse for a patient. You can create a lot of uh, {Long pause} how can I say, a lot of... anxiety”.

(Oncologist One, Case Three, Interview One)

Irrespective of the influence and esteem of the clinical position of physicians, this oncologist is forced to write his medical notes with considerable self-discipline, restraint, and with a sense of consideration for the other. If unburdened by the social implications of language, the oncologist would be able to write medical notes in a freer way. This clinician is acutely aware of the power
that certain patients exercise in the medical consultation when they come armed with personal health knowledge. As a protective strategy, this oncologist wants to limit confrontation by depicting patients and family members in a conservative and constrained way.

Although the practice of keeping patient biomedically informed may generate certain conflicts for professionals, it may simultaneously relieve them of other tensions in oncological practice. For individuals with worsening metastatic cancer, the online chart reinforces the poor prognosis at a distance that is first introduced in person by the oncologist. Todd recounted how reading key oncology notes reconfirmed his advanced disease status.

“It depends on the news right? If the PSA is down or up, or if the doctors are writing, I would say generally there’s something in there that’s upsetting. Only because of my status you know. We know the chemotherapy is not working. So again I think if there’s anything negative about [electronic chart system], what happens is that it’s reconfirmed your sort of worst fear. Or the discussions that you have with the doctor that the chemo is not working and we’ve got some problems and this and that. Well then you’re reading it again, so naturally that makes you a little bit upset I guess, to see it again on paper”.

(Todd, Case Three, Interview Two)

Every time Todd rereads the medical notes, he revisits the realization that his cancer is incurable. Although his oncologist regularly reminds him in person, the electronic chart formalizes and concretely displays Todd’s poor prognosis in different ways. In case he leaves with a sense of disbelief about what is said in person after each appointment, Todd can log onto the system at any time to confirm and reconfirm. As opposed to the face-to-face meetings, where the discussion may be focused on the most current diagnostic test, the online chart also allows for a historical and cross-sectional view of illness. The practice of disclosing a poor cancer prognosis and reinforcing the likelihood of death may be one of the most emotionally and ethically charged facets of the practice of oncology. Although the online chart does not eliminate face-to-face disclosures, this practice may alleviate healthcare professionals from reconfirming poor clinical results by encouraging patients to revisit this information on their own. Todd downplays these tensions by claiming that it only makes him “a little bit upset”. Nonetheless, this new
institutional practice highlights the ambiguity of his circumstances: living in the everyday with the knowledge of his impending death.

36.1.3 The Effects of Medical Uncertainty

As certain aspects of life-threatening cancer occasionally evaded a biomedical understanding, the experience of having advanced disease often diminished the prestige of the discourse of biomedicine from the perspective of patients and family members. In particular, individuals identified two pieces of vital knowledge that were difficult to obtain from professionals: how to properly treat their advanced cancer and an accurate estimate of the time left to live. As a result of this threat to the dominance of the discourse of biomedicine, medical uncertainty emerged in the data as an influential theme in the data with important social effects.

Although healthcare professionals were able to keep them alive and able to live at home, certain participants were deeply disappointed that their advanced disease had not yet been cured. Isabel (Case One) described her disappointment with chemotherapy in treating her cancer:

“When we talk, they’ll say to me, ‘Are you doing chemotherapy?’ And I said, ‘No.’ I ask them, ‘Do you have any idea how effective chemotherapy is?’ Everybody just does what the doctor says. ‘Oh, it’s standard. We’ve been doing this for years. We’ve been doing it for eighty years, offering chemotherapy and radiation. So it must have at least like 50 percent success rate,’ that’s what most people think. ‘Or at least at 30 percent or something.’ It must be worth it. Ah, no… not true”.

(Isabel, Case One, Interview Two)

Dispelling some of these myths in this statement, Isabel suggests that patients often overestimate the curative potential of biomedical treatment. Although certain individuals may anticipate a cure, Isabel is savvy enough to recognize that the actual treatment often does not quite meet one’s expectations. Often based on the most current scientific research and their association with medical expertise, biomedical treatments often are assumed to be the most effective way to deal with serious forms of cancer. By implying that chemotherapy and radiation are actually
antiquated forms of therapy, Isabel problematizes this assumption. Because of its socially privileged position, biomedicine is sometimes viewed as inherently trustworthy, particularly when it focuses on curing cancer as a moral enterprise. Patients often assume that a particular regime of treatment is sufficient to cure disease, particularly when it is labelled as “standard” by the cancer care system. Cautioning against this approach, Isabel instead suggests that one should view biomedicine’s therapeutic claims with a sense of caution.

Another reservation that participants had about the prestige of biomedicine is its lack of precision in treating progressive disease.

“Even my doctor, thank you for being honest. My oncologist said, ‘We’re only guessing. It’s trial and error.’ Oh Jesus, you know. In this day and age, you’re still guessing. I kind of knew they were, but they’re even admitting that they are guessing when it comes to chemotherapy. They don’t know what’s gonna work for people, so it’s trial and error. Um, I started looking up the drugs because I said, ‘Well what would you be recommending for me if I was to take chemotherapy.’ So I wrote down some of the names of the drugs and I’ll look them up. Then I thought there’s no effing way that I’m taking these drugs”.

(Isabel, Case One, Interview Two)

Despite the wide arsenal of diagnostic and therapeutic tools available at their disposal, oncologists could not determine a precise course of action for effectively treating Isabel’s disease. Given the seriousness of Isabel’s dire situation, the trial and error approach of biomedicine seems far too haphazard for her liking. Her comment highlights the difficult position that physicians are sometimes forced into when individuals seek life-extension. Although certain aggressive forms of cancer simply do not respond well to any form of treatment, physicians still gets harshly blamed for their therapeutic shortcomings. In response to this uncertainty, Isabel feels the need to take personal ownership over her treatment.

One of the residual effects of the sense of medical uncertainty is the expectation to take personal ownership over one’s disease and the emergence of self-care discourses, which will be discussed later in this chapter. Under this view, in order to compensate for biomedicine’s shortcomings,
one must take personal responsibility to both understand and treat cancer oneself. As described by Isabel, the consequences of not taking responsibility for advanced disease may be harsh.

“And one of my problems, and the reason why, you wonder why I do all this research, is because doctors don’t quite often. They don’t get together and they don’t consider everything, all the drugs that you’re taking. And if you don’t educate yourself on it, you could be dead. And I’m not exaggerating. A lot of people die from neglect, you know. Um, complications they might call it”.

(Isabel, Case One, Interview Two)

Despite its social prestige, biomedicine is failing Isabel by not effectively managing her cancer treatment. As opposed to the term “complications”, which attributes the blame to the treatment itself, Isabel uses the harsher term “neglect”, which focuses her anger and frustration towards the therapeutic shortcomings of certain oncologists. According to her perspective, death is the ultimate consequence for not taking personal ownership over one’s treatment.

Krystal’s (Case Seven) husband Mark also expresses his frustrations with biomedicine’s lack of specificity about his wife’s treatment for advanced pancreatic cancer. In response to his perception of biomedicine’s lack of therapeutic certainty, Mark also describes some of the knowledge seeking strategies that he employs to access vital pieces of disease information.

“I think the big problem is that either they don’t know or they don’t want to give you an answer and be wrong. Because if you don’t ask specific questions you don’t get specific answers. And my guess is because it’s such a complex disease you can’t. You don’t know what’s going to happen, you know, you really don’t”.

(Mark, Case Seven, Interview One)

Mark recognizes the medical complexity of advanced cancer and the difficulties that physicians have when providing specific information. Similar to Isabel, he expresses fear and frustration at medicine’s inability to be precise about certain key pieces of information. At the same time, Mark seems more accepting of the perceived shortcomings of clinicians than Isabel and has learned to sharpen his line of questioning in response. Mark also conveys the challenges of
enduring the uncertainty of advanced cancer; one really cannot know what will happen in the future with this serious disease.

Medical uncertainty was further characterized by the challenges of physicians to accurately estimate how long individuals have long left to live. From the perspectives of patients and family members, biomedicine was also limited in its ability to accurately predict the time left to survive from advanced cancer. Mark described the uncertain estimates of how long his wife Krystal has left to live from her disease.

“The surgical oncologist said that was insane, the doctor shouldn’t have said so. You’re an individual. He said, ‘I’ve got people like you with similar diagnosis and they have been in my clinic for five years.’ So we went from three to six months to five years, and then a week later we meet with the oncologist we’re dealing with now and said, ‘She’s a year to a year and a half.’ So, you know, three to six months, to five, to one and a half years. {Long pause} Pretty diverse perspectives…”

(Mark, Case Seven, Interview One)

According to Mark, it was often difficult to get a clear answer about prognosis from physicians. Estimates of prognosis varied greatly depending on the particular clinician and timing of when the question was asked. For certain participants, the knowledge of time left was significant because it shaped the intensity with which they advocated for treatment: less time meant a more desperate search. As a result, patients and family members often demanded a definite estimate about prognosis, yet healthcare providers were not willing to provide a definite answer. Because of the sophistication needed to understand cancer, it may be very challenging for physicians to provide an accurate estimate of prognosis. Yet, patients still have assumptions about the abilities of biomedicine that are challenging to meet and may lead to the general mistrust of physicians.
36.2 Discourse Two: The Discourse of Self-Care

36.2.1 Introduction to the Discourse of Self-Care

In response to the perceived therapeutic inadequacies of biomedicine and its tendency to privilege its own forms of disease knowledge, the discourse of self-care emerged as a way for participants to actively generate their own curative possibilities. The findings of this study suggest that self-care discourses threaten to dislocate the traditional hierarchical arrangement of healthcare practice and disease knowledge established by the discourse of biomedicine. From the perspectives of patients and family members, the discourse of self-care was characterized by the belief that one had to subvert the confines of biomedicine in order to both gather cancer knowledge, in some cases, access the actual treatment. Although physicians were trusted (or mistrusted) at different strengths and depending on the context, the discourse of self-care was characterized by the perception that one had to actively rely on one’s own knowledge, abilities, and skills when seeking life-extension. In this section I describe the various practices that are shaped by the discourse of self-care, such as the manipulation of the cancer care system and patients’ active utilization of bio-scientific knowledge. Moreover, I describe how patients and family members’ understandings of seeking life-extension are presently constituted by the discourse of self-care.

36.2.2 Challenging the Authority of Physicians

Given the high stakes involved and the intensity with which individuals sought life-extension, patient described how challenging the authority of physicians was at times necessary in order to access treatment. Shaped by the emerging discourse of patient self-care, challenging certain clinicians was considered an essential practice by some participants in certain contexts. For instance, Eva (Case Four) compared the North American patient-physician relationship with a Western European approach. Although she has lived in Canada for many years, Eva grew up in a large urban city in Western Europe.

“In (Name of Country) you don’t approach physicians. They tell you what to do, and what you can do, or what you have to take and that’s it. You have no choice. You don’t
talk to your doctors. My brother keeps saying that the way that you are interacting with your doctors is mind boggling”.

(Eva, Case Four, Interview Two)

According to Eva, there is less cultural permission in her country of origin to resist the authority of physicians. She later described how physicians often are viewed as “Gods” in that country. Within the North American context, Eva feels that she is able to exercise power relations with physicians in a more authoritative way, to the extent that it surprises her brother in Europe. Later Eva declared, “I mean I love doctors. God knows they’re keeping me alive, but they’re not infallible” (Case Four, Interview Two). Under this rationale, the ability of clinicians to keep Eva alive to this point does not make them immune from being challenged in clinical consultations when needed.

Distinctive from other participants, Isabel (Case One) and her natural healer (Case One) presented a harsh critique of the mainstream cancer system, as exemplified by their belief in the unethical partnerships between the pharmaceutical industry and the healthcare system. In addition to these almost radical perspectives, more mainstream sources endorsed being resistant to certain clinicians and the care they provided. For instance, Daniel (Case Two) joined a local peer support group that was administered by former or current patients with prostate cancer. As it regularly invites renowned oncologists and health psychologists to speak at its publically held information sessions, it is well integrated into the traditional cancer system. The support group website page outlines “Questions for Your Doctor”, a suggested list of questions individuals can ask their oncologists. In addition to questions about side effects and the length of recovery, this website offers bolder questions that probe the physician’s clinical skills and professional expertise. These questions include, “How many of these procedures have you done?” and “What is your success rate in terms of getting rid of the cancer and minimizing side effects?” (Case Two, Document Data). Shaped by the discourse of self-care, individuals with cancer are often supported to feel they should have the authority and right to hold oncologists accountable for their individual healing capabilities.

Although it is reasonable to want a well-skilled physician, oncologists who treat advanced cancer are often put into a difficult bind. Falling outside of the current possibilities of biomedical
therapies, the cure rate may be extremely poor for certain forms of cancers. Yet, this way of thinking about holding physicians accountable to the current shortcomings of biomedicine permeated how patients and family members questioned and challenged physicians. If participants did not feel comfortable with the skills of certain physicians, they utilized different strategies to circumvent this clinician when possible. For instance, each patient in this study described getting second or third opinions from different oncologists, with getting consultations from physicians from other provinces, and having friends and/or families who were physicians also review their case. In undertaking this practice, participants worked around the hierarchical position of their assigned oncologists and facilitated their own therapeutic choices in the healthcare system.

Formed by the discourse of self-care, participants employed multiple relational practices when challenging physicians in the medical encounter in order to locate information or obtain treatment that they considered to be significant. Gathering knowledge of the time left to live became a critical focal point of patient’s resistance to biomedical authority, forcing certain participants to use rather forceful interpersonal strategies. For instance, to obtain a clearer estimate of prognosis, Eva (Case Four) and her sister Magda described how they manipulated certain oncologists. Magda mentioned that one often has to “drag it out of them” (Case Four, Interview One) in order to obtain this knowledge. When I asked Magda if she researched the details of her sister’s breast cancer, she irritably said: “Like come on, what is the progress of the disease? What can we expect? Why do we have to go on the Internet to find it out, if you have a doctor sitting in front of you” (Case Four, Interview One)? Madga is surprised that she would need to conduct her own independent research when the physician could easily provide this information. Unlike other participants with cancer, Eva did not describe using self-directed research as a crucial knowledge source to inform her search for life-extension. Because of their heavy investment in the medical system and the knowledge of oncologists, Eva and Magda were thus forced to challenge physicians in an intense and direct way. Later in the interview Magda admitted, “We bullied one doctor and literally bullied her into…. I said, ‘Tell me I need to know’” (Case Four, Interview One).
36.2.3 Participants' Use of Scientific Knowledge

One of the most interesting ways in which the discourse of self-care shaped the knowledge practices of individuals was the active utilization of bio-scientific knowledge. In doing so, participants attempted to work around the existing hierarchical arrangement of knowledge set forth by the discourse of biomedicine. In the conventional arrangement, physicians monopolize and translate bio-scientific knowledge into medical therapies. In the new arrangement described in this section, participants actively utilized their own bio-scientific understandings to generate their own treatment possibilities. By bypassing conventional routes to obtain access to biomedical treatment, certain participants utilized bio-scientific knowledge in a savvy and often confident way.

As demonstrated by his ability to maneuver around standard cancer treatment to enrol in an experimental drug trial, Daniel provides the most potent example of how individuals employed bio-scientific research. Following his first unsuccessful round of standard hormonal and radiation therapy, Daniel capitalized on the informational resources of a peer-based cancer support group to assemble his own information about experimental scientific trials. The website of this group openly encourages patients to ask their physicians, “Are there clinical trials available? It is often beneficial to become part of a trial, if possible” (Case Two, Document Data). Although peer moderated, the website is linked to clinical trial registries and maintains an updated list of scientific studies that patients can join. The organization recommends participation in a trial, although the suitability or criteria for enrolling is often not discussed. Joining a clinical trial is strategic because it is assumed to provide a higher level of care than standard oncological treatments: “The researchers are interested in quality results and therefore you are well looked after, often getting more tests and better attention” (Case Two, Document Data). Scientific researchers may be more narrowly focused on obtaining positive curative results (in particular, extending survival) than healthcare providers, whose therapeutic intentions may be broader, such as preparing the individual to come to terms with their death.

During a publically open information session sponsored by a peer support group, Daniel began to develop connections with a well-renowned clinical scientist who was conducting a clinical drug trial for prostate cancer. Recognizing that his treatment options were dwindling, Daniel was
intrigued by this study because he fit the inclusion criteria. In order to obtain more information to bring to his oncologist, he later contacted this scientist. After some tactful petitioning, Daniel eventually persuaded his oncologist to refer his case to this research scientist. Daniel locates his ability to circumvent traditional routes of cancer treatment within his personal approach towards bio-scientific knowledge.

“Well as I said, my emphasis is, you still have an active approach. Some don’t as a patient. Ah, trying to be proactive. Try to learn your own illness and see. Well, knowledge is the king. And actually you can also make a judgment. You know continually not rely on others, including your doctor, right. So basically your object is to prolong your life”.

(Daniel, Case Two, Interview One)

According to Daniel, “knowledge is the king” is an important motto that articulates how patients with advanced cancer presently manipulate biomedical knowledge to their own ends. With knowledge one has the power to generate one’s own treatment possibilities. In order to accomplish the goal of prolonging life, one must transcend the conventional arrangement of bio-scientific knowledge, characterized by the passive adsorption of information by patients. From Daniel’s perspective, one’s capacity to locate and then translate bio-scientific knowledge into treatment extends beyond the jurisdiction of certain physicians. Unrestricted by the limits of one’s assigned oncologist, one must become a proactive subject (discussed in the following chapter on subjectivity) in order to effectively translate this knowledge into receiving a potentially life-prolonging intervention. Despite suffering from cancer related and treatment related pain, Daniel energetically conveyed his sense of excitement for his perception curative possibilities of the future during his interview.

Despite the reservations of certain physicians, patients and family members pieced together a bio-scientific understanding of cancer through a multiple and diffuse array of sources. For instance, participants located information on Internet websites, newsletters from support groups, medical textbooks, electronic scientific journals, emails from co-workers and friends, magazine articles, and television programs. Following a bio-scientific logic, participants often desired cutting-edge information about the latest biomedical therapies, which in turn changed their
perception of the treatments that were currently being presented to them in clinic consultations. For instance, Achmed (Case Five) discussed his reaction to his oncologist after he brought up new scientific research about the latest form of myeloma treatment.

“There is one thing that I heard about… I think tests were done on leukemia and myeloma patients in the States. I talked to the doctor and he didn’t know about it. I was surprised that he wouldn’t know about it right, so um… I heard that on the on news and then it was in the papers and then somebody sent me an email with the details of it, even pictures of how it effects the cells”.

(Achmed, Case Five, Interview One)

Achmed describes how the multiple ways of representing bio-scientific findings help confirm his belief that a new therapy is valid and could potentially be used in his current treatment. Drawing on his scientific background that he uses in his career, Achmed consumes and processes bio-scientific information from a variety of courses. In this quote, he reveals certain knowledge assumptions about physicians that are originate in the discourse of biomedicine. Achmed assumes that his oncologist possesses the most current bio-scientific data, and is surprised when his self-obtained knowledge of a new cancer treatment surpasses that of a healthcare professional.

Patients and family members often evaluated physicians on their knowledge of the most current cancer therapies, irrespective of whether the treatment was effective or even available in their local system. Krystal’s (Case Seven) husband Mark felt reassured that his wife’s current oncologist was aware of the latest pancreatic cancer treatments that he researched on the Internet.

“I think it was (Name of Oncologist) we saw last Friday. He was great. He was actually the first doctor who knew about everything that I had researched. So, it was great to talk to a guy that knew specifically about a particular treatment; who made it, the side effects of it and stuff like that. So he, he was great”.

(Mark, Case Seven, Interview One)
Although she is ready to relinquish the search for a cure, Krystal discussed how Mark stays up late almost every night to research experimental radiation treatments online. Although he does not have a scientific background, Mark is meticulous about the credibility of his data sources and evaluates them on the prestige of the institution. He focuses on websites from well-established American cancer research centres. For example, he utilizes the John Hopkins Medical Centre, which describes itself as a “cancer research powerhouse” on its website. Economically affluent, Mark admits that he focuses on American institutions because he would strong consider paying to send this wife there to receive treatment. Mark feels that his knowledge of the latest discoveries sometimes surpasses healthcare professionals; certain physicians did not even recognize any of the studies that he brought forward. Individuals sometimes assume that physicians possess the latest knowledge about cancer, yet this expectation is not always satisfied. So when Krystal’s oncologist finally matches his personal knowledge, Mark feels reassured.

Later in the interview, I asked Mark to suggest how the cancer care system can better support individuals to utilize bio-scientific research. To satisfy his curiosity, Mark wants an expert (he mentions a medical resident or another “young person”) to go through the online research process with him in front of a computer.

“Yeah, to be able to go someplace where someone is really knowledgeable and even have the long conversations about the research. What about this? We saw this and what about that? And that’s what was comforting about that guy on Friday. He knew all the stuff I had seen. He knew about the machines. He knew manufacturers. He’s goes, ‘There’s one machine that could be used, but there’s none. None in Canada because it’s so expensive.’”

(Mark, Case Seven, Interview One)

Researching cutting edge treatments that are scientifically valid, yet not are being offered to a loved one, is isolating and agonizing to Mark. He is forced to wonder why Krystal is not receiving treatments that the Internet depicts as valid and could legitimately prolong her life from his perspective. To reduce this sense of anxiety, Mark would like an in-person confirmation that either discredits these forms of treatments as therapeutic possibilities or explains why they are not being offered to his wife. Mark’s need to double-check the bio-scientific understanding of
clinicians is shaped by the discourse of self-care. Influenced by the global reach of the Internet, he expects oncologists not only to understand locally available treatments, but also to have working knowledge about what is available in an international context.

36.3 Discourse Three: The Discourse of Palliative Care

36.3.1 Introduction to The Discourse of Palliative Care

As participants were recruited from a palliative care clinic, the discourse of palliative care also established individuals’ rationales towards the search for life-extension. From the perspective of the three palliative care physicians interviewed in this study (from Case One and Two, Case Three, and Case Seven), palliative care involved a series of care practices associated with mediating the dying process. These included pain and symptom management, psychosocial support for patients and families, advanced care planning, and establishing the goals of care. Both patients who were imminently dying and the chronically dying that live at home (i.e. participants from this study) were receiving these services. Each of the palliative care physicians that were interviewed affirmed that their patients were often simultaneously receiving palliative therapies and treatments traditionally associated with the eradication of cancer. For instance, a physician remarked, “I would say probably about 50 percent, maybe more, 60 percent of patients that I see are going through chemo and radiation still. For the majority of them, the intent is cure” (Palliative Care Physician, Case Seven, Interview One).

Although intertwined with the discourse of biomedicine, the discourse of palliative care had certain characteristic features. During interviews, palliative care physicians articulated the sense that palliative medicine was different from other forms of oncology practice and was conducted in a more empathetic and relational style. For instance, one physician remarked, “Our view of patients and families and the care that’s provided is this intangible quality of… {Long pause} humanizing the experience” (Palliative Care Physician, Case One and Two, Interview One).

Interestingly, palliative care physicians did not overtly critique participants for their search for life-extension, possibly because they knew these individuals had referred them to me. Rather than categorically judge the invasive treatment of advanced cancer, these physicians often
employed criteria around the physiological consequences of treatment to determine whether receiving these approaches were morally problematic. For one physician, receiving potentially life-extending biomedical therapies was appropriate as long as it did not cause the patient to suffer: “If their function is fine, I leave that totally to oncologists, unless someone directly asks me to discuss this” (Palliative Care Physician, Case Seven, Interview One). Palliative care physicians did not critique the treatment approaches of oncologists. Only when patients experienced the side effects of harsher therapies would this particular physician be more prepared to openly discuss the direction of treatment. Another physician noted that although the style of practice may be different, the goals of treatment between palliative versus oncological medicine were not that different. This physician commented, “It’s about the integration of the philosophy of palliative care and the skill set amongst the team that’s providing care already” (Palliative Care Physician, Case One and Two, Interview One). In this view, the goals of palliative care, such as facilitating good communication with the individual and developing an appreciation for the goals of patients, should be intertwined with oncology practice across the entire spectrum of care from diagnosis to end of life care.

Although physicians did not necessarily discuss a sense of opposition between palliation and the search for life-extension, palliative care as an approach to cancer treatment generated a sense of discomfort for certain participants. Because of its associations with preparing for death, palliative care did not seem to fit smoothly with the circumstances of certain participants. Daniel described some of the limitations associated with palliative care in the context of seeking experimental biomedical therapies.

“Because it’s a dead end, right? It doesn’t give you hope that word, yeah. So no patient would like to hear that. Oh yeah, I have to prepare myself. At the same time, I try to be very optimistic and cheerful…. People cannot pay attention to you, right, and then you feel down. You feel you are about at the end, right? There’s no point to live. You want to erase that kind of negative feeling of having that for patients, for people with terminal illness”.

(Daniel, Case Two, Interview One)
Although palliative care is the process by which pain and suffering are reduced, Daniel equates this term with death. Rather than the active positioning for life-extension from cancer, palliative care is constructed by Daniel as a passive waiting to die. Diminishing a sense of hope and optimism from the situation, palliative care closes off the possibilities of a cure that is kept open by further biomedical treatment from his perspective. Moreover, he perceives palliative care as form of socially veiling the individual with advanced cancer: “people cannot pay attention to you”. In contrast to this the more passive approach of palliative care, the extensive efforts one puts into advocating for treatment keeps one highly visible in a social sense. Not only has palliative care become incompatible for Daniel’s treatment goals, but also this approach and the social associations that come with it needs to be “erased”.

Although Daniel felt threatened by the social effects of receiving palliative care, other participants recognized the usefulness of palliation, but still called attention to the complications that this approach caused in their lives. Despite the support of an integrated palliative approach from physicians, some patients and family members found it difficult to simultaneously navigate both palliative care and the search for life-extension. For instance, Todd’s (Case Three) description of palliative care illuminates the difficulties of integrating these apparently different approaches in his life.

“One of the first doctors recommended reading about what is palliative care. So once we realized there’s a lot more to it then, you know. You just hear your painkillers and we will hold your hand [Laughter]. Then you view it a little bit differently right? Now it’s just words. It’s just a bad name. Like say from Nancy’s perspective, she would just say it’s a bad choice. Bad name, you know. Bad connotation that you hear with it right?”

(Todd, Case Three, Interview Two)

In contrast to Daniel’s perspective, palliative care has some therapeutic value to Todd. In addition to pain management and other supportive benefits, palliation plays a significant role in medically stabilizing his advanced disease. Todd later mentions, “Palliative care is designed to also maintain the cancer where it’s at and to do different things right” (Case Three, Interview Two)? In this view, the stabilizing functions of palliative care in dealing with the ramifications of metastatic disease are not necessarily incompatible with his desire to search for biomedical
treatment. Yet, despite Todd’s claim that “its just words”, he and his wife Nancy still struggle with the connotations of this term. Because the discourse of palliative care is often associated with a preparation for dying for some participants, it may not speak to the complexities of simultaneously dying from cancer yet intensely strain ing to prolong-life. Surrounding Todd’s discussion in this quotation was his intense deliberation about whether to enrol in a clinical trial that may or may not extend his life. Despite the benefits of palliation and also the therapeutic prospects of the clinical trial, Todd later mentions, “there’s no getting away from that the fact that you’re dying” (Case Three, Interview Two).

Physicians in this study described the current trend in palliative medicine to utilize palliative consultations across the entire cancer trajectory from diagnosis, active treatment, to end of life management. Physicians discussed how this was increasingly becoming part of their everyday medical practice in the clinic. The physician from Case Three suggested that earlier palliative involvement helped to ease the transition from curative to palliative approaches to care. Despite this perceptions of an integrated approach, the sense of unease between extending one’s life with medical treatment and preparing for one’s death through palliative care often came to the surface in interviews with patients and family members.

One palliative care physician described some of the tensions between curative approaches in cancer and palliative care discourses.

“There’s several sort of studies. 100 percent of people want to be hopeful, optimistic and 92 percent want practical and realistic. So… it’s the seemingly mutually exclusive coexistence of a palliative care approach and a disease modifying approach right? And in some ways it’s this optimism and hopeful versus realistic and practical. The bottom line is that as clinicians it’s about having insight into the fact that these are not mutually exclusively constructs and that they must coexist. We have to figure out a way to make it meaningful for each individual patient”.

(Palliative Care Physician, Case One and Two, Interview One)

Located between two divergent notions, physicians are once again placed in a challenging position. On one hand palliative care clinicians need to maintain hope and optimism in the face
of advanced disease, yet on the other hand they need to be practical and realistic about the possibility of death. Despite these tensions, this particular physician suggests a balanced approach between being optimistic about the chances of life-extension, yet coming to terms with the closeness of death in order to establish “what is meaningful” to individuals. Although this recommendation is well intentioned, it does not take into account the conflicts and complexities that patients and family members were experiencing in their current lives. Despite the intensity of individuals’ circumstances, healthcare providers only offered vague suggestions as to how resolve the tensions between preparing for death and seeking life-extension.

36.4 Discourse Four: Self-Healing as an Emergent Discourse

36.4.1 The Discourse of Self-Healing

Although this study focused on the search for life-extension through biomedical treatment, my analysis found that participants were often actively treating advanced cancer through other therapeutic modalities. Several conditions of possibility in the current climate of cancer care allowed the discourse of self-healing to emerge in this study. In order to compensate for biomedicine’s inability to significantly extend life and to resist palliative care’s perceived passivity, self-healing emerged as an attractive alternative for particular participants. Constituting certain practices and rationales about treatment, the discourse of self-healing was characterized by taking active ownership over one’s illness outside the limitations of the discourse of biomedicine. Practices of self-healing in this study not only addressed the negative side effects of treatment and disease, but also moved outwards to include extending one’s life and even the quest for an elusive cure for some participants. The emergence of self-healing as an emerging discourse was further supported by the popular and widespread availability of self-help information from several different cultural locations. Participants obtained knowledge about self-help from eclectic sources: websites, chat rooms, books purchased at mainstream bookstores, talk shows on television, newspapers, other patients, and informal social networks. These self-healing materials came from divergent perspectives: talk shows, popular psychology, alternative therapies, integrated healthcare, and motivational speakers. As evidenced by a motivational self-
help book from Dr. Elizabeth Kubler-Ross (Case Three), a renowned palliative care psychiatrist, self-healing knowledge was sometimes embedded within the dominant discourse of biomedicine.

Generating an internal environment that is conducive to healing cancer became one of the most important hallmarks of the discourse of self-healing. Isabel (Case One) provided the most colourful example of cultivating an inner environment where advanced cancer is restricted from flourishing.

“Videos and books that I’ve read and in talking to people they’ve know or the person themselves saying, ‘I’ve been through this and, you know, I cured myself.’ Some of the sources, I don’t know first hand and some of them I do. But there are plenty of people out there. And some of them aren’t just for cancer, but other related health things. We’re talking about helping the body to heal itself… whatever the illness it. Cancer I guess, one of the most insidious and no one really knows what causes cancer. Except what I say is, it’s a disease. It’s an imbalance in the body”.

(Isabel, Case One, Interview Two)

For Isabel, promoting an inner environment for self-healing represents a shift away from the core principles of conventional oncological medicine. Whereas traditional cancer treatment is directed towards eradicating the tumour through radiation, surgical resection, or chemotherapy, self-healing focuses on restoring the natural balance to a body that has been disrupted by cancer. According to Isabel, cancer cannot grow and propagate within a so-called balanced body. In contrast to mainstream oncology, self-healing presents a more accessible therapeutic route that individuals can actively participate in. Whereas physicians had the authority to regulate the use of biomedical treatments in advanced cancer, the discourse of self-healing opened up a seemingly limitless therapeutic terrain to Isabel.

Self-healing was more satisfying to certain participants because it was perceived as more complete and holistic than mainstream medical treatment. As part of her self-healing practices, Isabel practices “Emotional Freedom Technique”; a system of healing that involves acupressure and relaxation to promote psychological health and well being. This meditative technique helps alleviate negative emotions like stress and anxiety that can cause “a more acidic environment in
our bodies” (Isabel, Interview Two) and the propagation of an inner state that is conducive to growing tumours. In addition to cultivating physical balance, an effective self-healing environment includes emotional and psychological aspects based on this perspective.

In contrast, other participants were highly critical of the therapeutic value of self-healing practices. Achmed (Case Five) drew upon his scientific background from his work to critique certain alternative therapies that were highly recommended by his informal social network. In doing so, he draws a discursive comparison between the discourses of self-healing and biomedicine. The treatment he discussed is soursop, a type of tropical fruit used as a lay herbal remedy.

“My view is that allopathic medicines come after a very specific targeted trial. When they say it will work on cancer, they mean that it will work on myeloma. It’s not generalized. It’s very specific right? Whereas what the Internet and what other people tell you is very general information because it’s not targeted on some particular sort of thing. It may have worked on this particular type, but it may not work another type. Because there’s no scientific method. I mean if somebody tells me that okay, ‘We have done a trial on thousand multiple myeloma patients and, 50 percent or 70 percent of them were cured or treated with soursop.’ Then I would say yeah, okay that makes sense right? But when somebody tells me that oh soursop is working on somebody’s lung cancer, I mean how does that apply to me?”

(Achmed, Case Five, Interview One)

Whereas Isabel employs testimonials from fellow cancer patients to determine the suitability of a therapy, Achmed applies conventional scientific principles to evaluating self-healing therapies. His social location in mainstream science, developed through his career, shapes how he approaches his treatment. Critiquing the universal application of certain therapies to all cancers, Achmed seeks treatments that specifically target his myeloma. He seeks a tailored and individualized approach, which he feels only allopathic medicine can provide. Achmed also demands statistical confirmation of the curative value self-healing, or really any type of therapies for that matter. Whereas certain participants gravitated towards self-healing, other participants
employed dominant the discourse of biomedicine as a comparative framework to discredit less conventional forms of healing.

36.4.2 Positive Thinking as a Self-Healing Practice

The discourse of self-healing shaped multiple practices in this study, but the most prevalent and intriguing practice of self-healing was positive thinking. When discussing their rationales for seeking life-extension, each participant with cancer described the significance of positive thinking to varying degrees. For example, Krishna (Case Seven) described how he completely avoids social interactions with other patients in the cancer clinic because of a concern that hearing about their negative experiences might disrupt his abilities to think positively. Other participants (Case One and Three) often read books and consulted websites about the power of positive thinking. Although it was viewed as a frame of thinking to deal with the hardship of disease, certain participants characterized positive thinking as a way to seek life-extension and potentially eliminate cancer from the body. Intertwined with positive thinking was the belief in mind of matter, which followed the rationale that one could actually manipulate physical matter (in particular, the body and the tumour cells) through the power of positive thinking.

Todd (Case Three) became the most vivid representation of positive thinking as a self-healing practice. When discussing his rationale for enrolling in a clinical drug trial, Todd explained his use of the book, *The Healing Journey: Overcoming the Crisis of Cancer* by Dr. Alastair J. Cunningham (2010). Cunningham’s ideas about positive thinking do not necessarily lie outside of the mainstream oncology system. Todd mentioned that a well-known cancer support group runs a patient focused educational program based on this book. Cunningham undertakes certain strategies to legitimize the controversial “truth” of mind over matter to a lay audience. In this preface, he writes:

“This book is intended to provide a reasoned account of what we can do to help ourselves against cancer, a middle way between the extreme conservatism of modern Western medicine and the un-founded radicalism of a lot of New Age thinking. I am a scientist, which may put some readers on the defensive, while reassuring others”.

Cunningham establishes his credibility with individuals with cancer by locating himself as a reasonable voice in between two competing discourses. Although his background is in biophysics and psychiatry, which conveys a sense of scientific authority, he locates himself as separate from the mainstream medical community. Later in his book, he claims that traditional biomedical discourse is often too restricted by its scientific conservatism to recognize the merits of positive thinking. Cunningham goes to claim that claims that Western medical practices, “keeps patients passive and prevents us from learning what we can from illness” (p. 38). In a similar fashion, he positions himself away from the seemingly irrational approaches of New Age healing that make unscientific claims about mind over matter. By doing so, he engenders trust from individuals who may in fact feel disillusioned by both discursive positions.

Cunningham’s (2010) main argument is that mind over matter, which is intertwined with positive thinking as a practice, not only influences the quality of individuals’ lives, but also determines the biological course of disease. To build his argument, he discusses scientific evidence about mind over matter. He introduces psychosomatic medicine, biofeedback research, and Psychoneuroimmunology, a research field that is concerned with the influence of the mind on the immune response and cancer. Overall, the science suggests that individuals can consciously learn to exert mental control over bodily functions that were previously thought to be involuntary. As evidence, Cunningham offers several case presentations of individuals who have remarkable abilities to perform extraordinary physiological feats, such as voluntarily controlling bleeding or pain. The most dramatic examples of the mind over cancer are the few cases of “spontaneous remission” (Cunningham, p. 67), in which tumours disappeared in the absence of any medical treatment. When considering if the mind can influence the course of cancer, Cunningham claims, “we are not proposing something outside the realm of existing knowledge” (p. 64).

Through positive thinking, an inner state of self-healing must be cultivated well beyond the conventional abilities of traditional biomedicine. According to Cunningham (2010), “we cannot rely on medicine at its current stage of evolution as the exclusive treatment for cancer” (p. 38). In Cunningham’s view of mainstream cancer therapies, the external application of chemotherapy or radiation to treat cancer positions the patient as a passive recipient of treatment. Cunningham
suggests this “failure of biomedicine” (p. 85) leads to a perspective that, “concentrates almost entirely on the material; the only way to treat a tumour is to cut it out, irradiate it, or poison it!” (p. 85). By contrast, positive thinking discourse supports individuals to actively participate in the process of internal healing or “healing from within”. (p. 58). Cunningham states that positive thinking has a powerful therapeutic effect because it produces, “an ‘internal chemotherapy,’ albeit of a benign and nontoxic kind” (p. 86). According to this view, individuals themselves can initiate internal healing independently and safely, unlike cytotoxic agents like chemotherapy.

Mind over matter assists individuals to “mobilize their own internal resources in the struggle against disease” (p. 76) and facilitates “using people’s minds as a weapon” (p. 76) against cancer.

The training of the mind to combat cancer characterises positive thinking as an emergent practice of self-healing. Cunningham (2010) outlines several steps in this process.

“The first is ‘taking control’, learning what can be done to have some control over the way in which we react, mentally and physically, to our environment. The second phase I call ‘getting connected’, to signify that the process of self-understanding has now become of value in and for itself. The third may be term the ‘search for meaning’; it seems to evolve naturally from a growing realisation that we are not entirely separate entities, but are part of a larger social, natural and spiritual world”.

(Cunningham, p. 92, Case Three)

From this perspective, mind over matter is inscribed with certain social obligations to actively take ownership over what happens and to “control” one’s biological destiny. This view establishes new expectations to understand the self in a very deep way in order to cure one’s own cancer. Cunningham mentions, “patients with a ‘helpless-hopeless’ attitude to their disease were more likely to die quickly” (p. 67), whereas a “fighting spirit” (p. 67) can have protective effects. In this perspective, there are certain demands on the person with advanced cancer to think positively in the face of suffering and warnings about the dire consequences of not complying with this approach.
Positive thinking as a practice, and by extension the discourse of self-healing, was also influenced by the notion that having a strong will has particular protective effects against cancer. According to this system of belief, one can “will” one’s cancer to be cured. In a subsection of Cunningham’s (2000) book entitled, “The role of the will in self help”, he argues:

“There needs to be a genuine strong desire to live, which also implies some sense of purpose. Nobody wants to suffer, and few are aware of any desire to die prematurely, but it is not uncommon to find that, under the surface, there is a lack of enthusiasm for life, or a wish to escape from a demoralising situation (such as an unhappy marriage), which undermines the struggle to survive”.

(Cunningham, p. 99, Case Three)

Fortifying one’s will to survive comprises a new type of social responsibility to retain a sense of purpose in one’s life. According this view, an individual with cancer needs to be self-critical about how they frame their life and disease; losing enthusiasm for life is not only difficult to manage emotionally, but can be an actual threat to survival. To survive, one must fully internalize positive thinking as a discourse in order to shape one’s outlook about disease. Underlying this quote is a kind of warning about vigilantly holding suffering at bay: with negative thinking one’s cancer can grow and progress. In this framework, there is little room for suffering, particularly if an individual wants to “will” him or herself to survive. Under this framing of mind over matter, imagining the possibility of one’s death can have negative physiological consequences.

37 Conclusion to Results Chapter on Discourses

In this chapter, I answered the first research question of this study: How do discourses constitute the search for life-extension through biomedical treatment for those with advanced cancer? In addition, I described the current biomedical and cancer treatment field in advanced cancer that provided some of the contextual backdrop for my discussion of the discourses in circulation. I then moved on to discuss the multiple discourses that are in operation in this phenomenon, the
main focus of this results chapter (see Figure 1 on Discourse). A key finding in this study, the major discourses in operation were found to compete and disrupt each other.

In this chapter, I identified four broad categories of discourses that constituted the search for life-extension. These main discourses were: (1) The Discourse of Biomedicine, (2) The Discourse of Patient Self-Care, (3) The Discourse of Palliative Care, and (4) The Discourse of Self-Healing.

In the following results chapter, I build on my discussion of the multiple discourses in operation to examine the different subjectivities generated by the search for life-extension through biomedical treatment. Considering the particular discourses in this phenomenon, I examine how one becomes a subject or the process of subjectification in the next chapter.
38 Introduction to Chapter

In this chapter, I present the findings of analysis in order to answer the second research question of this study: *What kinds of subjectivities are produced by the discourses in operation when individuals with advanced cancer seek life-extension through biomedical treatments?* My main focus of this chapter is to characterize the different subjectivities of individuals who seek life-extension, although I also consider to a lesser extent the subjectivities of family members and healthcare providers. To accomplish this goal, I draw upon my discussion of the multiple discourses in operation from the previous results chapter. In particular, I consider how one becomes a subject (the process of subjectification) or how the numerous discourses in circulation shape the behaviours, perceptions, and identities of the different social actors involved in this phenomenon (Foucault, 1976).

I present the research findings in this chapter by characterizing eight types of subjectivities (see Figure Four). These subjectivities are:

1. The Cancer Expert Subject
2. The Proactive Subject
3. The Productive Subject
4. The Mistrusting Subject
5. The Model Patient Subject
6. The Positive Thinking Subject
7. The Suffering Subject
8. The Challenged Clinician Subject
The Use of Subjectivity in this Chapter

Before I begin my discussion of the results, I briefly outline how subjectivities are employed in this chapter as a theoretical concept in poststructuralism. The eight types of subjectivities identified in this chapter are the result of my analytical focus and are not intended to be an exhaustive list. Furthermore, I do not assume that these eight types of subjectivities are rigid or apply evenly to each patient, family member, or healthcare provider. As multiple subjectivities exist simultaneously within one individual (Foucault, 1976), participants in this study are not limited to one type of subject. The different social actors in this phenomenon may have a different set of subjectivities that were not examined in this study because they were not an analytical concern. As previously described in the theoretical chapter, different subjectivities are intertwined with each other, are transitory, and shift with changing social locations (Foucault) and I convey this sense of movement in this chapter.

39 The Types of Subjectivities

39.1 The Cancer Expert Subject

The medical uncertainty of advanced cancer necessitated that participants assume more control over disease knowledge from healthcare providers. The rise of the emergent discourse of self-care, which was characterized by the practice of challenging the authority of physicians, also provided the conditions for individuals to take on more assertive knowledge roles. The institutional practice of ensuring that patients become informed of their disease status in a sophisticated way (for example, the electronic chart) in part constituted the cancer expert subject. This approach, however, focused on how the cancer care system could smoothly conduct the work of biomedicine (for instance, understanding a terminal diagnosis) by keeping patients informed of their medical status. In contrast, the cancer expert subject moved beyond a merely informed individual to assume a more expert role that has certain knowledge and therapeutic abilities that are not only on par with physicians, but from the perspectives of some participants, often surpassed their expert abilities. Unlike the institutional practice of keeping patients
informed of their disease, the cancer expert subject often utilize knowledge claims about treatments as a way to resist the authority of certain physicians.

Through different practices and beliefs about their own skills, certain individuals and family members (in particular Cases One, Two, Four, Five, and Six) constituted themselves as cancer experts. As discussed in the previous chapter, the discourse of biomedicine legitimized the traditional view that physicians are the principle experts in oncology. In contrast, the categorization of expertise was found to be more flexible by participants and was often renegotiated through the pursuit of treatment. For instance, to detect the bodily changes of disease, some participants described their expertise in a first hand knowing of their own bodies (and its internal physiological processes). These individuals could describe, for example, the physical perceptions of the growing tumour, infiltrated lymph nodes, and the body’s rejection of chemotherapy. In describing her intolerance to Tamoxifen, a common hormonal treatment for breast cancer, Isabel (Case One) summarizes her sense of expertise: “So I trust my instincts. And I trust my knowledge and I trust my body in that I listen to it and I know. And I’ve never been wrong” (Interview One). As opposed to trusting the diagnostic power of biomedicine, she trusts in her embodied expertise, which is perceived by Isabel as inaccessible to healthcare providers.

In addition to embodied expertise, individuals developed their own sophisticated practices of health research in the search for life-extension. All participants (except Eva from Case Four) described their research knowhow when searching for knowledge about disease and treatment. For example, Isabel articulates the extent of her research expertise and also how physicians in medical consultations sometimes receive this sense of expertise.

“And no I’m not a doctor. I don’t have the same kind of degrees that they do, but a lot of things I know, they don’t know. There are a lot of things they haven’t studied. And I think at the very least I deserve some respect for, you know, for the amount of work that I’ve done. I don’t just Google everything. As you’ll see, I’ve done research on a lot of different areas. But I’m not your typical patient and there are a lot of people that will go to doctors and just say fix me”.

(Isabel, Case One, Interview Two)
Isabel admits that she does not have a medical degree, and by extension the institutional authority as a health expert that this title would confer to her. Yet, her long term experience dealing with disease and perceived identity as a health researcher gives her a level of expertise that equals, or sometimes surpasses, that of some physicians. Because she positions her research expertise beyond that of a typical patient, she feels frustrated when she is not given the proper level of respect. As opposed to the traditional patient role as the recipient of professional advice, Isabel wants to be treated more like a colleague. A reflection of her subjectivity, Isabel refused radiation to the metastasis in her brain because she felt that the procedure would severely impair her intellectual capacities. She goes on to describe her elaborate use of bio-scientific knowledge in her defence of expertise. Isabel often surveys the scientific literature and mass media to locate treatments that fulfill her highly individualized criteria of what are acceptable therapies. She insists that the treatment stop or slow down her metastases, but not cut off her intellectual abilities to digest knowledge. For Isabel, the ability to process knowledge as a cancer expertise is a top priority in the search for life extension.

Shaped by Isabel’s displeasure with medical uncertainty and her mistrust of certain oncologists, the expert subject is also inscribed with her critique of how patients’ abilities are downplayed in cancer care system. Isabel describes her attempts to share her different practices of self-healing, such as herbal therapies, with physicians: “Its encouraged that whatever I am doing, I should present to my oncologist, whether they agree with it or not. Just so they know” (Case One, Interview One). Despite her attempts to bring forward her abilities, physicians have not always been receptive. Her husband James summarizes his interaction with physicians: “His attitude was that he knew everything and we were just morons” (Case One, Interview One). For certain healthcare professionals, the expert subject exists beyond the safe constructions of non-threatening patients who are mere partners in care. In the case of individuals like Isabel, who aggressively use their expertise to challenge biomedical authority, the expert subject was either ignored or critiqued by clinicians. As previously discussed, healthcare providers tried to assert the dominance of the discourse of biomedicine by legitimizing or discrediting disease knowledge. The struggle between professionals and patients around the credibility of knowledge became an important point of contention around who can legitimately be labeled a cancer expert.
The cancer expert subject was constituted differently for Eva (Case Four) than in other cases in this study. Unlike participants such as Isabel, Eva was not actively researching information about her disease. Her social location and previous history with cancer shaped her subjectivity in a different way than the other younger participants. Although she was receiving chemotherapy, Eva was in her seventies, had a long-term history with breast cancer (for instance, her current diagnosis was a reoccurrence), and was actively planning for hospice care. For instance, when I asked for her perspectives on who is an expert, Eva’s response was: “I am not an expert because I don’t know the disease. I mean I know of the disease. I know a lot about it, but I don’t consider myself an expert. I never. My expert is my oncologist” (Eva, Case Four, Interview Two).

Although she later articulated her own sense of expertise around assertive forms of communication, Eva accepts the traditional role of the physician as the purveyor of legitimized disease knowledge.

At the same time, Eva described other types of expertise, such as her ability to critically appraise treatment options presented to her and make decisive decisions about her breast cancer. When articulating this form of expertise, Eva described how she often needs to be her “own physician” regarding her cancer treatment:

“You have to make decisions and you have to be your own doctor sometimes. It’s very important that you have to. You cannot blindly accept everything that they tell you whether they’re an expert. And she’s fabulous and don’t get me wrong and she knows what she’s doing. She’s very good, but I am not stupid either you know? And I have a voice too…. I have no complaints and I wouldn’t want to change to another doctor if you paid me. But I still have to be my own doctor too; somebody cannot make the decisions for my life…”

(Eva, Case Four, Interview One)

Unlike in Isabel’s case, being one’s own physician was not necessarily undertaken to resist the dominance of physicians. Eva claims to be happy with her medical care, but still considers it important to take on the cancer expert subject by becoming her own physician. According to her perspective, the expert subject should be cautious of disease information and not “blindly accept” what is recommended in the clinical encounter. For Eva, becoming one’s own physician was
coupled with certain prized personality traits, such as assertiveness and taking ownership over an important situation. It was also associated with being more visible in the medical encounter, an attempt by Eva to grab power and control from physicians as traditional cancer experts. Although they did not use Eva’s exact terminology, other participant described similar rationales of appropriating their own sense of cancer expertise in order to negotiate for further treatment.

Produced by the discourse of self-care, the record keeping practices of personal health data was another distinctive practice of the cancer expert subject. Although other participants reported various forms of record keeping techniques, Achmed (Case Five) distinguished himself by drawing on his scientific background to keep highly sophisticated biomedical records. Using the electronic charting system and detailed personal notes taken after every consultation, Achmed assembled professional looking colour graphs and pie charts that traced his most current laboratory values back to when he was first diagnosed. A personal artefact that he brought to his first interview, Achmed filed his detailed records in a thick three-ring binder. A form of cancer that is closely checked by blood work values, multiple myeloma could be accurately mapped by these records according to Achmed: “I have charted it myself right. Neutrophils, then the white blood cells, then the platelets, the haemoglobin… those are the four things mainly they monitor right?” (Achmed, Case Five, Interview One). When I questioned Achmed about his rationale for keeping detailed records, he explained, “Whatever I do home, at work. I do in a more methodical way right? So this is part of it too right. So this is my own health that I have to make decisions about” (Case Five, Interview Two). Achmed’s record keeping practices are intertwined with the discourse of self-care, where individuals take control and ownership over their disease and their own therapeutic possibilities from the healthcare system.

An important knowledge practice of the cancer expert subject, Achmed’s record keeping activities also help promote his own sense of personal responsibility. In order to keep accurate records and following a scientific rationale, Achmed made certain demands for the most current biomedical information with his oncologist.

“So, I told (Name of Oncologist) that I would like to have my blood work done a week before my appointment, so that when we meet we are discussing the results which are current right? Not a month back or two months back. He agreed and said we should do
that… but I have to call the nurse almost every time before my appointment that I want to come in for my blood work, so please put in my requisition in… so when I meet him I am discussing the current results…”

(Achmed, Case Five, Interview One)

As one or two month old medical information is viewed as not as useful, Achmed is preoccupied with having only the latest laboratory results to discuss with his physician. Achmed’s extensive record keeping activities encourage him to continually revisit the status of his cancer and demand a sense of efficiency when it comes to assembling biomedical information. As a result, he only requires the most up to date blood work figures to support his own expertise in his illness; data that is a month old is not as relevant in discussions with his oncologist. Rather than passively waiting for his personal health data according to the predefined test schedule of the oncology clinic, he actively advocates for this information with healthcare providers and expects it presented to him in a timely manner.

39.2 The Proactive Subject

The uncertainty of biomedicine in outlining a clear treatment pathway in life-threatening cancer necessitated that individuals generate their own treatment possibilities proactively by circumventing traditional medical routes. The desperation to locate treatment meant that patients and family members drew upon whatever therapeutic resources were immediately available to them and often sought out new and unexpected resources proactively. Similar to the cancer expert subject, the discourse of patient self-care and patients’ increased utilization of scientific knowledge generated the proactive subject.

As with Isabel and Krishna, Daniel (Case Two) used the term “proactive” to describe the kind of subject one must become in order to obtain biomedical treatment. By circumventing the conventional ways patients access further treatment in the traditional cancer system, Daniel maneuvered around his assigned oncologist to locate an esteemed clinical scientist and to eventually become enrolled in an experimental oncology trial. Daniel often drew on a local peer run support group for men with prostate cancer to shape his proactive approach. For example, the
website that he regularly accessed recommends that individuals, “Use any contacts you have to find out which doctors are experts on each treatment” (Case Two, Document Data). Under this approach, individuals with cancer must proactively call upon their resources (for instance, their personal or professional contacts) in order to gain access to experimental treatment. Through its institutional website, the organization openly recommends participation in an experimental trial. Enrolling in a clinical trial is itself proactive because it is sometimes associated with a higher level of care than standard treatment: “The researchers are interested in quality results and therefore you are well looked after, often getting more tests and better attention” (Case Two, Document Data). Under this perspective, researchers, as opposed to healthcare providers, are interesting in obtaining results, as opposed to providing care.

Prior to his diagnosis and his impaired functionality because of his metastases, Daniel worked as a successful life insurance agent. Making a link between his work life and disease, he applies certain rationales needed to be successful in the business world towards his approach to clinical trials.

“When I was being diagnosed with the cancer, one thing I noted was I needed to help the medical team help me. Because in that way, I’m the only one who benefits in the end right? {Laughs} And if you’re not proactively looking at different situations, you just make the treatment less effective. Like if I totally rely on what the hospital offers you, passively, then maybe you only get say 70 percent of the effect. Obviously I want to get 99 percent, if I can do anything to help that. I’m the one who benefits right? That’s my philosophy. I just see it as a business venture. You maximize your profit right? {Laughs} Treat it like that and it becomes fun. Otherwise you always feel miserable thinking about this”.

(Daniel, Case Two, Interview One)

Downplaying the passive subject who only obtains a partial therapeutic effect, Daniel takes up a form of subjectivity that is able to capitalize on the full benefits of treatment. In order to be successful at cancer treatment, one must adopt a spirit of entrepreneurialism according to Daniel. As evidenced by his comparison of percentages, Daniel applies a business rationale to his cancer treatment in order to maximize his profit. Profit, in this context, is the lengthening of one’s life
through clinical therapies. Entrepreneurialism is associated with actively moving beyond the standard treatment that is offered to every other patient to try different therapeutic ventures, such as experimental drug trials. By becoming a proactive subject, Daniel is assuming individual responsibility over his prostate cancer and manipulates the healthcare system and beyond in order to receive non-standardized treatments.

Drawing on his sense of privilege, Daniel linked his abilities to be proactive with his socioeconomic position. During his interview, he contrasted his own proactive approach towards his treatment with his brother in law’s seemingly passive approach. The less affluent neighbourhood that he refers to is in a larger urban center city in Asia.

“As I told you, my brother in law went to this neighbourhood hospital in a poor neighbourhood. They don’t care about you, right? They don’t make the extra effort. That’s very important with nurses. I feel very positive. They are nice to me; my primary nurse, my clinical trials nurse. So you become a partner, you react more proactively”.

(Daniel, Case Two, Interview One)

In this perspective, a lower quality hospital in a poorer neighbourhood does not provide the same rational or attitudinal conditions for becoming a proactive subject, in contrast to Daniel’s large tertiary hospital. They do not have the resources to make the “extra effort” beyond standard care, which is tied into being treated as a partner in one’s care. In this quotation, Daniel suggests that enrolling in a clinical trial is a choice that reflects one’s social position. More affluent individuals go to better institutions that in turn provide the conditions for individuals to become proactive. Later in the interview, Daniel expresses his surprise with his brother-in-law’s decisions. Without consideration for the social conditions that lead to certain health choices, Daniel blames his family member for not being proactive enough to make the proper decisions about his care. A social performance of his sense of privilege, Daniel demonstrated his affluence during several instances in his interview. When I asked him about the Korean newspapers he brought to the interview as an artefact of his subjectivities, Daniel claimed that he only reads papers on finance to guide his business investments: “You are intellectual, you tend to be on the left side. Until you grow up and you are in business, then you are on the right {Laughs}” (Case Two, Interview
One). To Daniel, the ability to become a proactive subject is intertwined with higher level of socioeconomic class.

In contrast to his own proactive health decisions, Daniel did not hesitate to assign blame to individuals for certain health decisions during other points in his interview. Daniel described his decision to pay for his own massage therapy. Given the importance of this therapy for improving his own physical function, he was surprised that some of his peers from his support group could not afford the same kinds of therapy. Daniel stated, “Some Canadians they live pay cheque by pay cheque, even though they dress very nicely and eat very generously in the restaurant. To me, I cannot understand” (Case Two, Interview One). The proactive subject is thus characterized by an ability to take individual responsibility for certain treatment choices by making therapeutic concerns a priority. According to Daniel, one must be attentive to one’s financial behaviours (for instance, spending habits) in order to take up the proactive project of obtaining cancer therapies in a committed way.

In contrast to other more passive approaches to cancer care, the drive to receive biomedical cancer treatment despite advanced disease was itself viewed as a proactive move. When describing his personal objectives for being on a clinical trial, Daniel equated the proactive subject with his goals of obtaining life-extension. In doing so, he compared a proactive approach with certain assumptions about palliative care as a discourse that was discussed in the previous results chapter.

“Because I don’t really like the term… palliative, right…. So how long you can stay on. That’s all you hope for and that’s your objective and be proactive always. Don’t do it passively. Because you help your doctor to help you live longer. Ah, that’s the motto”.

(Daniel, Case Two, Interview One)

Because he views it as a passive waiting for death, Daniel views palliative care as a docile approach that he feels uncomfortable with. Although this may not be the formal definition of palliative care as defined by the cancer care system, he appropriates the healthcare term to illustrate his perspective. He warns that one that must always be vigilant about being proactive. Although Daniel understands the seriousness of his metastatic disease, appropriating this type of
subjectivity seems to offer him some protection against death. As opposed to the passive palliative patient, he positions himself as a proactive subject in order to prolong his life.

Demonstrating his ability to take advantage of the therapeutic resources at hand, Daniel recognized the privileged position of physicians and wanted to capitalize on their expertise. Daniel’s palliative care physician disclosed that he did not necessarily need to be followed by the clinic for symptom management. This physician also disclosed the relationship with Daniel is not necessarily close: “He doesn’t use our relationship as a mechanism for decision making or as an input for decision making” (Palliative Care Physician, Case Two). From this physician’s perspective, Daniel maintains regular contact with the clinic in the event that his symptoms from metastases were to worsen. The proactive subject consumes healthcare resources in a savvy way in this example. Daniel is thinking ahead by stocking pile treatment resources, including the skills and authority of carefully selected physicians. He capitalizes on his understanding of which physicians can provide him access to life-extending treatment (clinical scientists), and which physicians can provide him help with controlling symptoms (palliative care physicians). The physician recognizes Daniel’s business-like approach towards the medical team, “it’s quite compartmentalized, I think in terms of what the various roles are” (Palliative Care Physician, Case Two).

The proactive subject was also supported by family relationships. Certain family members viewed being proactive as so integral to life-extension that when a patient was too fragile to be proactive they appropriated this role. Diagnosed with a metastatic and rapidly growing form of pancreatic cancer, Krystal (Case Seven) appeared too ill to be proactive. In her interview, she described how she was ready to end her search for treatment because of her sheer physical exhaustion. Although difficult for her to admit in the interview, Krystal hinted at feeling prepared to accept the closeness of her death. Yet, when I interviewed her husband Mark, he appeared to have a different agenda and was determined to proactively draw on different curative resources. He was still determined to actively investigate different treatment options, such as an experimental radiation treatment that was only available in the United States.
“I have called and spoken to them at Hopkins and I spoke to them at Anderson. And I have talked to other people who have got, or are connected with the cancer world. Um, I got some very influential friends that have all helped us, so a variety of sources”.

(Mark, Case Seven, Interview One)

Mark takes up the proactive subject in way that is similar to Daniel’s. In an effort to manoeuvre around standard treatment protocols to obtain experimental treatment, Mark draws upon personal connections available to him through his social influence. He mentions two prominent and well-known American cancer hospitals, John Hopkins and MD Anderson Cancer Centre, and suggests they might have an experimental treatment not available in Canada. By adopting the proactive self, one can attempt to access these treatments for advanced cancer that may lie beyond local networks of physicians.

39.3 The Productive Subject

The productive subject was characterized by the drive for participants to be productive, despite their suffering and the possibility of death. Individuals were concerned about being productive in multiple ways, such as contributing to their home and family life, but also were concerned with making a wider social contribution through the search for life-extension. As discussed in the previous chapter, the prolonged period of having advanced cancer permitted individuals to be industrious in their everyday lives. The lay uptake of bio-scientific knowledge, which was shaped by the discourse of patient self-care, also encouraged individuals to be productive by participating in experimental research.

Certain participants rationalized their search for life-extension in order to live long enough to fulfill certain family duties. Participants also felt that they needed to make use of the limited time they had left. For instance, when I interviewed Todd (Case Three) in his home, there were several stacks of ceramic tile boxes in his kitchen. When I asked him about this, he seemed teary. Concerned about the financial status of his wife and children after his death, he was preoccupied with refinishing his family home in order obtain the most profitable sales price. In a similar way, Eva (Case Four) was concerned with positioning her sister Magda in a financially and socially
stable position before she died. In addition to leaving Madga with some money, Eva was preoccupied with ensuring that mutual friends would include Madga in social events.

The productive subject was also formed by certain expectations that individuals needed to meet in order to receive treatment. Todd (Case Three) was enrolled in a clinical trial involving a combination of chemotherapy and radiation. I interviewed one of his oncologists, a prominent clinician scientist, about the clinical criteria that are used to determine which patients are good candidates for experimental trials. In addition to prognostic criteria, the capabilities of individuals to be productive in meeting the interventional requirement were equally a vital criterion.

“How reliable they are, how they appear to be. Do they have a history of being last to follow up or neglecting they had a biopsy. But yet they didn’t follow up with it. So that would concern me a little bit because if you put them on the study and they just kind of not follow up, then you’ve learned nothing. You’ve contributed nothing to the trial”.

(Oncologist Two, Case Three, Interview One)

Participation in a trial demands that individuals uphold a sense of productivity as defined by the knowledge needs to biomedical science. In spite of one’s vulnerabilities, one is a responsible patient if one contributes to scientific discovered, and society in general, through participation in a trial. Still, there were somewhat divergent agendas between patients and this oncologist regarding clinical trials. Whereas the trial represented a significant opportunity for Todd to slow down a very aggressive form of cancer, the oncologist described the trial as a way to contribute to the body of bio-scientific knowledge, as evidenced by his desire to contribute “something” to the research. Contributing knowledge to the trial, as opposed to the patient’s well being, seems to be the focus of this physicians’ need to select productive candidates for experimental therapies. Based on this perspective, clinical trials can make cancerous bodies scientifically useful to society and can harness the productivity of bodies marked by disease to the scientific community.

Despite biomedicine’s attempt to harness the productivity of individuals, participants established their own limits for the productive subject. Intertwined with the demand to be productive was the
concern with becoming incapacitated by invasive forms of biomedical therapy, where individuals may no longer have the opportunity to contribute to society in a meaningful way. For example, Todd (Case Three) stated that he would be satisfied with participating in clinical trials and continuing to “fight” the cancer, as long as he does not become incapacitated by treatment.

“Say okay, well I am going to fight. Well what I am fighting you know? And that’s why I narrow it down. I break it down into two things, time, extending my time, but don’t give me time where I am sucking on a fucking tube. I don’t want that time right. I would much rather be dead you know. And the other thing is quality. So length of time and quality of time, and this study, which was appealing. Like I said, I think it increased the quality of time”.

(Todd, Case Three, Interview Two)

Intertwined with extending his life is a concern with becoming debilitated by chemotherapy or radiation and thus not being able to fulfill Todd’s important familial role as father and husband. In this quotation, Todd redefines the health science term “quality of life” according to his own personal values. Quality of life is not “sucking on tube”, which evokes images of being intubated or incapacitated in a hospital bed. The parameters of what Todd was willing to receive in terms of treatment were moulded by his concern with being productive as a caregiver. While conducting interviews in Todd’s home, I observed his daily routines of caring for his wife and family, despite his immense pain and physical immobility. For example, Todd started composing a grocery list immediately after ending our second interview.

39.4 The Mistrusting Subject

As discussed in the previous chapter, the long and extensive history of dealing with the cancer care system generated the social conditions for some individuals to mistrust healthcare providers. Because of the inability of physicians to provide sufficient disease knowledge or take a more aggressive treatment approach, the discourse of medical uncertainty also contributed to the sense of mistrust. The discourse of self-care also meant that participants tended to invest in their own
capacities to generate the possibilities of life-extension, thereby downplaying the need to trust healthcare providers in clinic encounters.

The mistrusting subject focused on discussions and materials that questioned the dominance of biomedicine. In particular, Isabel (Case One) had strong critiques of the pharmaceutical industry and was suspicious of its business intentions to develop cancer therapies to reap profit. Isabel and her natural healer were distinctive in this study because they both colourfully presented more radical critiques of the health sciences as an industry.

“The choices aren’t different today than they were years ago. Except that if there’s a new drug… I’m really kind of against drugs, unless… I mean okay, let’s clarify something. There’s a place for everything and drugs have done a lot of good, okay. So I’m not totally against all this, but I find that doctors and institutions and TVs, pharmaceutical companies, are all pushing drugs a lot more than they need to be. Of course, doctors are because the pharmaceutical companies are leading the doctors. Oh, we got a new drug, new studies, and then you find out later about the effects of some of these drugs”.

(Isabel, Case One, Interview Two)

After being previously unsuccessful with conventional treatments, Isabel feels angry about the limited treatment options left available to her and attributes some of the blame to the pharmaceutical industry. Later in the interview, she questions the efficacy of conventional cancer treatments like chemotherapy and radiation, comparing them to leeches within the history of Western medicine. Although her critique is directed at multiple players, she focuses on the pharmaceutical industry in this quotation because it negatively influences the rest of the system in a top-down approach. In addition to her mistrust of the actual treatment, Isabel mistrusts both the wider health science industry and individual clinicians for what she perceives as the unethical distributions of drugs. By describing her suspicions about certain therapeutic decisions, Isabel questions the ethical intentions of some of the clinicians that previously cared for. From her perspective, physicians often prescribe anti-cancer treatments as a result of the economic interests of the pharmaceutical industry, rather than keeping the best therapeutic interests of patients in mind.
Although largely incurred through paying for expensive alternative therapies, Isabel was the only patient in this study to describe the harsh financial consequences of seeking cancer therapies. Embedding her wider economic critique of the health science research industry within the economic crises of her own life, Isabel’s case highlights how one’s social positioning shapes mistrusting forms of subjectivity.

“I’m on (financial disability) right now. So I have that to help out, but anytime you make money, they want to deduct whatever you are making. So it’s almost as if it doesn’t help. Ah [sighs], finances are a huge, huge, difficulty. When we found out about the cancer in December, and not having money to be able to, you know… Cancer patients probably make the industry. When I say the industry, I’m taking about the medical industry, whether it’s pharmaceutical companies or the companies that supply these machines that do these tests. All that is well and good, but we must consume anywhere from 250 to a million dollars’ worth of expenses on cancer patients”.

(Isabel, Case One, Interview Two)

Isabel places her own financial challenges around cancer treatment within a larger political economic framework. In this quote, she compares the financial difficulties of her life to the larger economic injustices of the pharmaceutical industry. While cancer patients sustain the multi-million-dollar industry, Isabel is financial sustained through social assistance. This fuels Isabel’s sense of mistrust towards the system. Isabel was distinctive as a participant in several ways: her financial vulnerability, her extensive use of alternative care providers like naturopathic healers, and her desire to replace the existing system with an integrated framework. Integrated healthcare involves combining complimentary medicine within an allopathic framework. Isabel’s mistrusting nature relative to other participants was reflected in how the healthcare team approached her case. Although other participants were viewed as challenging, the palliative care team often positioned Isabel as particularly problematic because she sometimes was abrasive from their perspective.

In our second interview, Isabel identified the website www.drkelley.com as an important information source in shaping her mistrust of biomedicine. Dr. Kelley is an American trained dentist that was diagnosed with terminal pancreatic cancer thirty-five years ago. Through a series
of detoxification diets, coffee enemas, and other metabolic correcting regimes, he supposedly cured his cancer. Written in a pseudo-scientific style that is still understandable to the lay audience, the website outlines his unique views on the metabolic origins of cancer, such as the link between cancer and diabetes. To generate a sense of authority, the website is written in a “scriptural” style and uses undercurrents of religious preaching (such as using the term “the creator”). The website also presents harsh critiques of the traditional biomedical system. Although Isabel describes her reservations about particular oncologists, she admits most are well intentioned and trusts physicians who she views as sympathetic listeners. In contrast, Dr. Kelley portrays all oncologists in an unflattering way. Medicine is termed a “science industry” and is described as a “plundering, murdering, deceiving creature living off cancer” (Case One, Document Data). The website presents several case descriptions of individuals with cancer who were misdiagnosed, poisoned with excessive chemotherapy, had their treatment prematurely terminated, and treated only for profit. Patients viewing this website are given a troubling but cautionary message: be responsible for your own treatment because biomedicine is both ineffective and should not be trusted.

For individuals who feel disenfranchised by biomedicine or who have been told by physicians that there is “nothing more we can do”, this website provides a confirming space that aligns with patients’ mistrust, suspicions about malpractice, and reservations about the kind of care they have received. The discussions to of mistrust embedded in this website appeal for equal power relationships between patients and physicians. Shaping the mistrusting subject, the general motto employed by this document is that since biomedical science cannot effectively cure you, it really does not have any more power over cancer than ordinary people do.

Although more radical perspectives, which called for an extensive overhaul of the cancer care system, partly constituted the mistrusting subject, more mainstream perspectives also produced the mistrusting subject. Based on his own professional background, Achmed (Case Five) comes from a traditional scientific background. In his second interview, he recounts attending a seminar on human performance errors for his work that used the biomedical and pharmaceutical system as a powerful example.
“I think it was in 2010 they reported pharmaceutical errors were about 77 million, which caused 7,000 deaths? Which means that those deaths were caused by giving the wrong medication to the patient? What the doctor’s wrote, what doctor’s intended, which is what the pharmacy prepared for that patient? What was given to that patient who took it himself? So what that tells me is that, when I am with the doctor I must know what doctor is prescribing and why is he prescribing it to me. Is he or she right? And why should I take it?”

(Achmed, Case Five, Interview Two)

As he recalls the specific number of errors and deaths, Achmed is deeply troubled by the implications of this presentation. Although the healthcare team often idealized Achmed as a cooperative patient, his knowledge of hospital errors has lasting effects on feeding into his sense of mistrust in the biomedical encounter. According to Achmed, the risk of harm comes from two possible sources: cancer treatments have the potential to be toxic and physicians are not infallible, but rather susceptible to human error. The particular strategies that he employs in the clinical encounter (for instance, to come prepared to biomedical consultations and to keep detailed biomedical records) may be a way to curb the risks of medical and pharmaceutical errors. Following the logics of this practice, one cannot completely trust the biomedical system to always do what is in one’s best therapeutic interests. As a result, advanced cancer patients like Achmed are compelled to take ownership over their treatments and overall health.

39.5 The Model Patient Subject

Whereas the mistrusting subject is often caught up in the harsh critique of the cancer care system, the model patient subject operates cooperatively within the system. Although both types of subjectivities have their own rationales for the different approaches to life-extension, each is strategic in their own way and the end result of obtaining potentially life-extending biomedical treatment may be the same for both. The model patient subject closely aligned itself with the privileged social location of traditional biomedicine and worked within the existing power relations between patients and care providers in the search for life-extension.
Although he had certain reservations about the knowledge and skills of healthcare professionals, Achmed (Case Five) most vividly fit the model patient subject. In Achmed’s first interview I asked him to recount how he was diagnosed with cancer. Although his initial cancer diagnosis was delayed when his family physician did not follow up with the first physical symptoms of his cancer, Achmed and his wife Fatima recounted the story calmly and without complaint. Whereas the mistrusting subject might have viewed a similar situation as example of medical neglect, the model patient subject was able to sit with certain medical inadequacies in the interest of preserving their favourable status with healthcare professionals.

Achmed was preoccupied with making the healthcare encounter easier for healthcare professionals by being polite, not aggressively questioning their orders, coming prepared with good questions, and even respectfully reminding practitioners about the direction of his treatment. For example, in an interview with his oncology nurse from the medical oncology clinic, this nurse outlines some of the parameters of a model patient subject that Achmed was able to meet.

“I guess they have that ability to want to participate in their care. Some patients, you know, you have to kind of be their parent. Those patients they are a little bit harder to look after. Having patients that are, you know, don’t need so much parenting. When you’re looking after so many patients it actually helps you… {Long pause} it’s tough. It’s nice to have patients having that responsibility because I think they realize that taking that responsibility will only benefit them…”

(Clinic Nurse, Case Five, Interview One)

Based on this perspective, a model patient subject is one who actively takes responsibility over care, thereby making it easier for nurses to perform their work. In contrast, this oncology nurse indirectly characterizes a bad patient as one who requires some form of parenting. Assigning the verb “parenting” to individuals who are not able to behave responsibly conveys this nurse’s sense of annoyance; certain patients act like children and require supervision. In doing so, this nurse outlines parameters for ideal conduct in the oncology clinic in order to become a model patient subject. Achmed shaped his behaviour to fit within these parameters, thereby maintaining altruistic relationships with clinicians. Little consideration is given to the vulnerability or social
location of individuals and how this might constrain the abilities of patients with late-stage cancer to assume personal responsibility. Rather, this particular nurse emphasises the positive benefits of the model patient subject on preserving the daily workflow of nursing.

Unlike the mistrusting subject, the model patient subject was often idealized and rewarded by healthcare providers in the clinic setting. The healthcare team seemed to respond to Achmed in a positive way. The referring palliative care physician mentioned that Achmed was a favourite patient. Achmed was recommended for participation to this study because he was perceived as friendly, open, compliant, respectful, and willing to share his experiences. As these types of patients were often more sympathetic to the perspectives of physicians, this idealized view may be understandable. In contrast, the mistrusting subject was often depicted as demanding and more likely to openly complain about their treatment. For instance, a physician told me “good luck” when Isabel was referred to me, with a slight tone of sarcasm. The differences between these two types of subjectivities were also illustrated in the building of trust throughout the research process. Achmed invited me to his home and prepared afternoon tea before I arrived to start the interview, whereas Isabel required about half an hour to meticulously go through the consent form before she gained my trust.

Adopting the model patient subjectivity also shaped how individuals viewed bio-scientific research in the search for life-extension. As a counter to Isabel’s more radical critique on the health science industry, Achmed defended the economic approach of the pharmaceutical industry in his explanation of why one of his cancer therapies was so expensive.

“I think it’s just a new medication and it seems to work on patients. So the pharmaceutical people, who have spent so much money on it making discoveries. It takes years, ten, 12 years to get a medication to a point where patients can take it right? So, like billions of dollars goes into it right? And so, I think they have to recover their costs too”.

(Achmed, Case Five, Interview Two)

Rather than call attention to economic injustices, Achmed appears to forgive the pharmaceutical industry for their financial approach in the interest of developing new cancer drugs. Economically affluent and successful at work, his own social position shapes his approach to the
business of the pharmaceutical industry. Later in the interview, Achmed expressed his personal investment and sense of faith in medical science. Despite having advanced myeloma, he believes that scientific research will eventually develop a cure for haematological disease. Over his several year experience of being treated for advanced cancer, Achmed observed that many pharmaceutical interventions have slowly progressed in efficacy. Because of his perception of a gradual improvement, he is willing to forgive the drug companies for the extensive amount of time and money it takes to translate scientific research into oncological drugs.

The contrast between the mistrusting and model patient subjectivities highlights how participants sought life-extension using different types of practices. Whereas certain subjectivities strove to transcend the boundaries of biomedicine at different intensities, other subjectivities worked within the mainstream system in order to accomplish its goals. Because Isabel was positioned both by herself and the healthcare team as on the periphery, she was perhaps compelled to advocate for herself in a more desperate way than other participants. Achmed utilized a different and more nuanced social strategy in advocating for treatment by aligning himself with the discourse of biomedicine and sympathizing with healthcare providers. Yet, for Achmed, there are traces of the mistrusting subject that bled into his rationale to be a model patient. His routine practice of coming prepared to clinic appointment with extensive biomedical records are in response to his sense that healthcare provides might be inadequately prepared to meet his therapeutic goals. Despite these tensions between mistrusting and model patient subjects, the end result of gaining access to potentially life-extending treatment was the same for both cases. The reverberating social effects of the two types of the subjectivities were, however, very different.

Besides Achmed, Krishna (Case Six) also positioned himself as a model patient subject. The only patient participant to describe a religious perspective in depth, Krishna outlined how his faith in Hinduism framed his search for life-extension from advanced leukemia. In particular, Krishna discussed the notion of dharma (one’s duty to be obedient) that is outlined in the Bhagavad Gita, the main religious text of Hinduism: “It’s a book which tells you all about your duties, about all facets of your life towards your children, towards your parents, towards your neighbours, towards society” (Case Six, Interview One). Krishna’s sense of religious duty translated into how he meticulously approached his responsibilities as a patient enrolled in a clinical trial: “I met all of the obligations they required… I answered every question and filled in
all the forms they needed me to... I would come and see my physician the day he wanted to see me. I contributed 100 percent” (Case Six, Interview One). Because he is so keen on articulating his diligence in meeting the requirements of the trial and is proud of meeting this duty, Krishna’s response reflects a social performance of his ability to be the model patient subject.

In addition to discussing how well he was meeting his perceived responsibility as a patient, Krishna reassured me how good the clinic team was during the remainder of his interview, as if almost to convince me that the care he received was of the highest quality. In particular, Krishna discussed how much faith he had in his oncologist because he appreciated the assertive approach of this particular physician: “I found him very dedicated… every time I went to him he knew my case history…. I found him to be a very aggressive physician. I found that he took a very good interest in the treatment” (Case Six, Interview One). By conducting regular biomedical assessments of his progress through diagnostic tests like CT scans, an “aggressive physician” to Krishna was one who took a thorough biomedicine approach that eventually lead to receiving experimental treatment. Reflecting other dimensions of his identity, Krishna’s view of a good physician is one that is invested in the treatment, as opposed to being invested in a therapeutic relationship with him.

Krishna was the only patient participant in this study who vehemently refused to refer me to any healthcare provider in order to build a richer case. At first he seemed scared when I asked him, but then he suddenly became angry and this sense of hostility remained for the rest of the interview, as evidenced by his lack of eye contact and gruff demeanour. When I probed Krishna for this rationale around refusing to refer me to physicians, he was unwilling to answer the question. Based on my observations, it seemed that Krishna was worried that any uncovering of his sense of discontentment would disrupt his current advantageous arrangements with physicians. In contrast to the mistrusting subject, the model patient subject was concerned with preserving their favourable status with healthcare professionals. Moreover, it seemed that this avoidance of a discussion about healthcare professionals was a result of a particular form of emotional suffering, which I unpack later in this chapter.
39.6 The Positive Thinking Subject

The positive thinking subject was constituted by the discourse of self-healing and positive thinking in cancer. From the perspective of certain participants, positive thinking not only addressed the physical and emotional symptoms of progressive cancer, but also extended outwards to include broader curative realms. Todd (Case Three) became the most vivid representation of the positive thinking subject. When discussing his rationale for enrolling in a clinical drug trial, Todd both outlined his approach to positive thinking and described what influenced his investment in this rationale towards treatment:

“So they run a course on this book and it’s an amazing book. I will say it really changed my way of thinking and put it in a more positive role… its controversial to the extent that his position is your mind can control your body essentially. There’s perfect examples where it can you know. You think of something sour and your mouth waters, right? So we know that these things do happen right? The book itself really put me in a more positive frame of mind. I should really get back to reading it…”

(Todd, Case Three, Interview One)

The book Todd mentions is written by Cunningham (2010), which was discussed in the previous chapter. His comment reflects a certain social expectation to think positively irrespective of the physical consequences of advanced disease. Todd’s account of his positive frame of mind coexists with his vivid description of bone metastases and severe cancer pain. According to this perspective, even though prostate cancer does not respond to conventional biomedical treatments, it may respond to interventions of the mind. To illustrate this particular rationale, Todd provides the example of thinking of something sour that can lead to the physiological response of salivation. Given the circumstances of his disease, it may be reassuring and provide him with a sense of personal agency to think that he can perhaps control the biological inevitability of his dying though his everyday thoughts.

The positive thinking subject elicited certain social effects in the study setting. His palliative care physician discusses both Todd’s and Nancy’s positive approach towards his disease.
“I really enjoyed caring for them because they were such decent people. In a sense they were always very grateful and had a very positive outlook. A very realistic one on the one hand. Todd was the first person to tell you that he was dying. The first person to tell you that he knew that his disease was incurable... he knew that he had a very limited life expectancy. It was very realistic, and yet at the same time he didn’t ever come across as somebody who was depressed or had given up on life”.

(Palliative Care Physician, Case Three, Interview One)

Because this approach elicited a certain sense of sympathy from some healthcare providers, the positive thinking subject derived multiple social benefits from adopting this type of subjectivity. Allowing him a privileged level of access to healthcare providers, Todd’s positive approach allows him to be almost valorized by this physician. For instance, during my first interview with Todd and his wife Nancy at their home, this particular physician made a special follow up telephone call. The physician later described that despite having to use a cane because of Todd’s extensive metastases, he still retains a positive approach. Inspired by Todd’s almost heroic approach, the physician further stated, “He seemed to give me strength, you know, because of his positive outlook. So who doesn’t want to see a patient like that” (Palliative Care Physician, Case Three, Interview One)? In addition to his positive demeanour, this physician appreciates Todd’s realism about the severity of his cancer and his recognition that he likely will not be cured. Todd’s positive thinking does not seem to threaten this physician’s medical authority and bio-scientific assessment of his prognosis. In Todd’s case, the positive thinking subject coexists with the dying subject, but not necessarily in an antagonistic way. Although this tactic keeps certain clinicians (including those in palliative care) engaged in one’s case, this quotation reveals the incredible demands on the positive thinking subject to mediate suffering at the end of life in order to maintain this way of thinking.

Although some participants took advantage of the social benefits of the positive thinking subject, other participants endured negative consequences. Isabel (Case One) discussed some of the tensions generated by her aspirations to become the positive thinking subject.

“Instead of fighting illness and disease I choose to embrace health and wellness. And it’s like Mother Theresa saying, ‘Stop fighting against these wars.’ And, you know, embrace
positive relationships and whatever because the more you push against something, guess what, the more it {Pauses; Slaps hands together hard} resists”.

(Isabel, Case One, Interview Two)

Forming a context to this quotation, Isabel was employing an alternative therapy called, Emotion Freedom Techniques (EFT), which focused on eliminating negative emotions from one’s consciousness as a protective technique of the self. Under this approach, the positive thinking subject must continually self-regulate his or her thoughts to ensure that one remains positive. According to Isabel, positive thinking can cultivate an internal environment that heals cancer. Here, Isabel uses irony to illustrate the difficult position that restricts the positive thinking subject. Although Mother Theresa suggests a peaceful end to war, the violence of Isabel’s hand slap suggests a darker internal struggle that is often concealed by positive thinking as a restrictive practice. Leading to further turmoil and conflict, the positive thinking subject does not give itself permission to suffer, but rather must discipline itself to resist negative thinking. At multiple points in her interview, Isabel describes how negative thinking can often breed a toxic inner environment that may allow tumours to propagate. At the same time, positive thinking, as a rigid way of thinking and feeling, provides little space for individuals to experience suffering in a painful disease that will end one’s life.

39.7 The Suffering Subject

The suffering subject is characterized by the sense of incongruence between the other types of subjectivities previously described in this chapter. Participants endured much anguish as a result of not being able to sit with the multiple tensions in circulation. In particular, the struggle between accepting the likelihood of death and the desperate search to extend one’s life became almost unbearable for certain patients and family members. Characterized by a fragmented and contradictory sense of self, this new type of suffering subject exists as the result of the conflicts between the different types of subjectivities constituted around the search for life-extension.

During Isabel’s (Case One) interviews, I could intuit a sense of suffering that was located just beneath her assurances that she was a cancer expert and that she was effectively self-managing
her cancer, which she enacted as a social performance of strength and confidence. Towards the end of her second interview, the intensity of her suffering could no longer be contained and bubbled to the surface.

“I had already tried so many different alternative medicine and things weren’t working. And I thought, well what am I doing wrong? Well I thought am I doing too many things and having too much control. When you’re faced with death, you realize you have absolutely no control in your life {Lowers Voice}. There is no control and I’ve never really been religious. I’m more spiritual, but I think that I became a little bit more religious and said, ‘You know what, it’s time just to give it up to God’ {whispers}. Because I have absolutely no control. As much as I like to think I do. I have no control whatsoever”.

(Isabel, Case One, Interview Two)

Isabel’s conflicting subjectivities give rise to a particular type of suffering. In spite of juggling both alternative and allopathic anti-cancer treatments at an almost frantic pace, the quest to eliminate advanced cancer ultimately escapes Isabel. Regardless of her aggressive search for life-extension and her attempt to reassure herself that she can control her destiny, Isabel cannot escape the inevitability of death from her advanced breast cancer. The illusion of being in control, the desperate search for life-extension, and the closeness of death collide in Isabel’s situation. This sense of conflict led to an immense sense of suffering and the uneasy feeling that many crucial elements in Isabel’s life are gradually spinning out of control.

The suffering subject was troubled by a deep sense of frustration with participating in the challenging quest to extend one’s life. For participants that had suspicions that their current treatments may not generate the prognostic effects that they desired, the search for life-extension generated certain tensions. Todd (Case Three) described some of his frustrations with seeking an experimental clinical trial for his advanced prostate cancer.

“I think that if you look at it from an outside perspective… I would think that automatically people would say, ‘Well why the hell wouldn’t you?’ There would almost be no reason not to, but as I progress I see why. I see why people say no, you know?
There’s days, I’ll be honest, there’s been days where yeah, I’ve been like okay, fuck this, you know? I’ve had it. I have had enough right? When the pain gets ahead of me and you know. I am watching Nancy upset and everything is just not going that good then yeah. There are days you think, let’s just end this right?”

(Todd, Case Three, Interview Two)

Todd describes some of the social effects of continuing on with cancer treatment. Based on his blunt comment, “why the hell wouldn’t you”, receiving potentially life-extending medical treatment seems to be the most socially appropriate course of action in his present situation. To a certain extent, seeking treatment keeps one socially engaged. Earlier in the interview, Todd reported that much of his social network provided him with the most current treatment information as an ongoing group project. By enrolling in a clinical trial, he retains a sense of potentiality to be cured that keeps others around him socially engaged. Yet, this pain he articulates in this quotation hints that Todd may be pushed to his absolute limits. As a result of his immense physical pain and witnessing the grief of his wife Nancy, Todd can barely tolerate his extensive suffering and ponders an end to his quest. Despite the social benefits of the search for treatment, he is able to empathize with others who seem to be able to end this search. At the same time, this is a dangerous proposition; he only occasionally allows himself to imagine letting go. In doing so, he seeks a kind of cultural permission to be allowed to die. Yet this cultural permission eludes him, leading to immense conflict, fragmentation, and ultimately frustration. Unlike a hospitalized and unconscious patient who is imminently dying, the ambiguity of living yet dying made it challenging for Todd to relinquish the search for treatment. The frustration with being caught between multiple ambiguities has shaped Todd’s extensive suffering.

Patients and family member’s search for biomedical knowledge about disease also positioned them in a vulnerable position and contributed to the production of the suffering subject. Krystal’s husband Mark (Case Seven) described some of the tensions uncovered by realising the harsh prognostic statistics for advanced pancreatic cancer that he located on the Internet.

“What he told us is what you see on the Internet, like you can read, all the websites. Look at pancreatic cancer; virtually 95 percent are, like 44,000 in the States, 38,000 deaths. The average prognosis is six months. On folfirinox, it’s like six you know. The stats are all
there right? So the trick is, can you beat them? What can you do to beat them or can you do anything right? I think from my perspective, no matter who it is, I think they are always going to try. Some people are diagnosed with this and then die in two weeks right, so I mean it’s a brutal disease…”

(Mark, Case Seven, Interview One)

The suffering subject was not restricted to individuals with life-threatening cancer, but was also extended to family members. Although Mark constructs bio-scientific knowledge as an essential key to potentially extending life, knowledge is equally harmful because it confirms the inevitability of Krystal’s death from advanced pancreatic cancer. For Mark, searching for knowledge about disease is a risky endeavour and has the potential to generate much suffering. It forces him to ponder the uneasy question, “Can you do anything right?” Yet, by drawing on different treatment resources, Mark is still willing to stave off death. When it comes to prolonging Krystal’s survival, he is willing to “always try”. At the same time, Mark articulates his ambivalence and sense of uncertainty about the search for life-extension in a disease that may lie outside of his control.

Later in this interview, Mark described the dwindling treatment options available for Krystal’s cancer. In doing so, he characterized the fragmented nature of the suffering subject and also highlighted some of taken for granted costs of seeking biomedical treatment.

“Well, there’s clinical studies at John Hopkins on liver and pancreatic cancer and they’re doing some at (Name of Cancer Hospital) as well. But stage one clinical trials are, as (Name of Child) put it you know, ‘The last thing that had that trial was a rat.’ So clinical trials are kind of, that’s when you’re being a good Samaritan. I mean they’re valuable, like I don’t dismiss that, but a stage one means you’re the first guinea pigs right? I know that the current treatments all sort of started that way, but at the same time, I am not keen on having my wife be the guinea pig. You see she’s tiny and she’s relatively frail. Last night she was just awful and this morning she was awful. So she can’t. She couldn’t do it even if she wanted to”.

(Mark, Case Seven, Interview One)
Given the aggressiveness of Krystal’s pancreatic cancer and that previous treatments were unsuccessful, Marks feels that a stage one clinical trial would be one of few viable options for experimental treatments. The first round of experimental science designed to evaluate the safety of a drug, stage one clinical trials are often thought of as the riskiest and most toxic forms of therapy. Exposed to her physical frailty in the everyday, Mark recognizes that these types of harsh medical interventions could potentially end her life. Despite his best efforts to locate experimental treatment, the options for Krystal are quickly running out. In spite of his desperation, the lay utilization of medical scientific knowledge, and his proactive attempts to draw upon certain resources, he recognizes that his wife will die from her disease. Leading to an almost unbearable sense of suffering, tensions exist between the illusion of being in control, actively seeking treatment, and the possibility of dying.

There is an uneasy sense for Mark that participating in a clinical trial does not provide an effective script to prepare for the discomforts of dying. Despite Mark’s heavy investments in researching scientific treatment, a clinical trial is focused on medical criteria and may not address the emotional or relational complexity of accepting death. Here, Mark uses the term “guinea pig” in an altogether different way than Daniel (Case Two). Whereas Daniel viewed being a “guinea pig forever” (Case Two, Interview One) as a proud symbol of his personal commitment to extending his life, Mark uses the term to convey his sense of ambivalence about his wife’s treatment. The suffering subject is also plagued by the uneasy sense that the current circumstances may not be easily resolvable. Mark’s immense suffering was palpable to me during research process. I first completed my interview with Krystal before I interviewed Mark, and she warned me to “be gentle” because of his fragility.

Unlike other participants in this study who conveyed their sense of suffering through the interview process, Krishna’s (Case Six) suffering most vividly came out in the observational data and other non-recorded discussions in the waiting room and social spaces in the study setting. When I first tried to probe Krishna in the interview about what his search for life-extension meant for him in the context of his life, he refused to answer, seemed almost angry with me, and even wanted to end the interview early. Despite this hostility in the interview space, he still invited me to have a coffee together and sit with him in the waiting room before his afternoon appointment. Perhaps he felt less threatened in a more relaxed social setting. While in a common
area, Krishna ran into a friend who also had advanced leukemia. Krishna introduced me to this man, but then unexpectedly tried to refer this person as a potential participant and even suggested that I interview this man on the same day. Angry at my attempts to discuss his sense of suffering, Krishna perhaps wanted to avoid any further discussion of this uncomfortable topic by passing me onto another patient with advanced cancer. Krishna’s actions highlight how suffering became almost unbearable for certain participants in this study. It was not until we shared a coffee together and spent approximately three hours together before he began to more openly discuss his suffering. Despite his claims in his interview that he is coping well, Krishna has many painful regrets about having advanced cancer and feels that many elements of his life are unresolved. In particular, he tearfully described his desire to return to his country of origin before he passed away.

39.8 The Challenged Clinician Subject

The challenged clinician subject focuses on the perspectives of healthcare providers in this study. This particular subjectivity is shaped by the multiple challenges of working with the emerging subjectivities of advanced cancer patients previously described in this chapter. Moreover, the discourse of biomedicine and the professional practice roles set by this discourse also form this subjectivity. Although clinicians and their various care practices are implicated in the production of the subjectivities of patients and family members, they often cannot handle the intensity that these individuals bring to the system. The challenged clinician subject is characterized by its location between many difficult positions as care providers and not being sure with how to proceed in caring for individuals who seek life-extension.

Healthcare providers in the study setting sometimes felt overwhelmed by the forceful demands of certain cancer patients and their thirst for biomedical information about disease. An oncology nurse (Case Four) from the breast cancer outpatient clinical described some of the challenges of contending with the cancer expert subject in the daily work of nursing.

“They want lots of information. They want all the resources going lots of them. They’re demanding you know. Many of them don’t understand why they aren’t scanned regularly.
Like I had a call from a lady this morning, ‘Well I’m having my mammogram and I am coming in such and such a time. How come I am not having a CT Scan or PET scan or blah, blah, blah kind of deal?’ It’s a valid question, you know. We just don’t do that unless there’s symptoms, etcetera is the policy”.

(Nurse, Case Four, Interview One)

Patient’s demanding behaviours in the clinic reflect the concomitant overlapping of subjectivities: the mistrusting subject, the cancer expert subject, and the proactive subject. Unable to tolerate the ambiguity of the unknown, certain patients aggressively push for more and more tests and information about their medical status. Underlying their demands is the assumption that the healthcare team will immediately dive into therapeutic action based on any abnormal test results. By reorienting the discussion to clinic policy and the suitability of tests based on symptoms, this nurse attempts to moderate this hostility. At the same time, this nurse conveys a sense of frustration and annoyance when dealing with these kinds of so-called demanding individuals, as evidence by the statement, “blah, blah, blah”. Moreover, this statement highlights how this particular clinician conceives of nursing work in the clinic. As opposed to being primarily centred on relationships or the personhood of individuals with cancer, the work seems to be focused on biomedical tests and numerical data. Based on this quotation, patients sometimes participate in this emphasis by using the clinical encounter as a vehicle to gather data about their disease status, as opposed to a source of relational support.

According to this oncology nurse (Case Four), the demanding nature of certain individuals is amplified by the widespread social acceptance of discussing cancer.

“ I think it helps to make them open up and ask more questions and tell you what they want or how they feel, etcetera. Just because it’s not hidden under a blanket anymore. There it’s right in your face all the time. I mean look at the bus that goes from uh, (Name of Main Cancer Hospital) to the different hospitals here for the employees or whatnot. It’s all pink because they’re trying to raise money for the breast cancer centre”.

(Nurse, Case Four, Interview One)
This nurse places the cancer expert and proactive patient subject within broader social discourses about the widespread acceptability of fund raising and developing awareness for breast cancer. Broadly located in the mass media and more locally at this nurse’s workplace, the various “all pink” media campaigns ground the critique. Although the intent of these campaigns may be to reframe the stigma of cancer, the social effects in terms of recasting clinical interactions with patients can be challenging according to this nurse. The broader message of being assertive and more open about cancer in these campaigns is increasingly translated into a sense of assertiveness and entitlement when pushing clinicians for more information and more access to services. From this nurse’s perspective, the more prevalent public discourse about cancer, in particular breast cancer, gives cultural permission to certain individuals to be increasingly demanding in the clinical encounter.

In addition to the assertiveness of the proactive patient, healthcare professionals found it difficult to contend with the desperation of individuals who wanted to aggressively attempt further cancer therapies. The term “aggressive” was occasionally employed by clinicians as a term to describe the intention and tone of certain cancer therapies. Todd’s (Case Three) medical oncologist described some of the challenges of working with individuals who want to eliminate cancer in an aggressive fashion.

“If I had a tumour, I would really think hard about if I would actually want to have treatment or not. I have certain ideas about how far I would go. I probably would not be as aggressive as many people would sometimes assume for an oncologist. So having said that, it’s probably easier for me to deal with patients that do not want to go to the full extent of what is possible and more restrict themselves to what seems reasonable, though reasonable is very individual and it comes from a very individual perspective. It’s actually more challenging for me when there’s a patient that never wants to give up. I mean I see cancer as a disease that at some point, unfortunately, you have to give in and you have to give up…”

(Oncologist One, Case Three, Interview One)

In describing the challenges of clinical work, this physician uses a personal view of treatment as a point of comparison. Earlier in the interview, this individual described how a non-North
American upbringing made this particular individual more comfortable with acknowledging death. For instance, this physician witnessed both grandparents die at his or her family home as a child. In contrast to this oncologists’ own rational and responsible personal view of chemotherapy and radiation, certain patients in clinical practice have what is considered to be unreasonable curative expectations. Preferring to work with patients that do not want to go “the full extent” (that is, treat cancer with aggressive treatment), he or she openly acknowledges the complexity of clinical work needed to deal with patients that assertively push for treatment. Immersed in this clinical issue in the everyday, this physician is unable to recognize how multiple subjectivities might shape patients’ so-called aggressive approach to treatment. Although he or she affirms that one has to eventually relinquish the search for treatment, how to help patients moderate this difficult transition remains a highly uncertain task.

Rather than assist participants with life-threatening cancer mediate the ambiguity of their circumstances, it became easier for some healthcare professionals to evade these tensions. The same oncologist (Case Three) describes the tendency to flee from the clinical challenges of working with individuals who seek potentially life-extending treatment.

“In my space it’s very easy to prescribe treatment. There’s actually very few patients who refuse to have treatment and the ones that refuse to have certain treatments tell you that early on. I think it’s more challenging not to prescribe further treatment and to at some point change the goal of care, more and less, to actively change the course of disease… I think it is just that amount of work we have to deal with and again, it’s easy to just order the chemo. Well you do actually at your computer. You don’t even have to have the patient close by”.

(Oncologist One, Case Three, Interview One)

In an honest and direct way, this oncologist describes some of the complexity of clinical practice needed to work with individuals that aggressively try to locate cancer therapy. According to this oncologist, ordering further chemotherapy at a technological distance is significantly easier than helping individuals navigate the complicated emotional tensions between actively treating cancer and dealing with the possibility of death. Given the busyness of clinical work structures, it becomes easier for healthcare professionals to disengage from the ambiguity of the situation.
Fleeing from face-to-face encounters seems less risky than contending with the intensity of these types of advanced cancer patient.

Yet, when healthcare providers even hinted at the possibility of ending potentially life-extending treatment, they are forced to tread very carefully. The oncology nurse from Case Four discussed a challenging case where a breast cancer patient misinterpreted a palliative referral that she read in her medical chart.

“She got a reoccurrence, so she was given chemo. She was a patient that I worked with, with the doctor and she saw there’s chemo, you know, under palliative. I guess she was reading her charts or whatever and she saw palliative and she wasn’t palliative. It was a chemo that was given I guess in a palliative situation, but could be used for other things. So she freaked out because she didn’t think she was palliative, etcetera. They don’t need anything extra or inappropriately freaking them out right?”

(Nurse, Case Four, Interview One)

As discussed in the previous chapter, participants often associate palliative care with the closeness of their own death, despite the formal view of palliative care as the multifaceted support of the seriously ill. Amplifying the intensity with how individuals approach their cancer treatment, multiple subjectivities circulate within this clinical scenario, such as the cancer expert, mistrusting, and suffering subjects. Even the fleeting mention of palliative care, let alone acknowledging the possibility of dying from cancer, causes this particular patient to “freak out” and react in a dramatic way. The prospects of palliative care opens up an uncertain horizon about the future that may lead to death. From this nurse’s perspective, there is an uneasy feeling of being overwhelmed in the clinical setting and not knowing how to handle individuals who strongly advocate for curative forms of cancer treatment. Based on the challenges of these situations, healthcare providers are forced to proceed with caution and employ much tact. Considering the volatile nature of these individuals, the tendency for certain clinicians is to avoid and disengage from supporting them through this conflict in the short clinical encounter that is already geared towards the exchange of biomedical data. Rather than engage in the complex and time-consuming relational work needed to help individuals come to terms with relinquishing their curative treatment, the healthcare team often categorize patients and family members as
troublesome in the clinical environment. Once again, how healthcare providers assist to individuals reconcile these multiple and contradictory subjectivities remains an uncertain endeavour in clinical practice.

40 Conclusion to Results Chapter on Subjectivities

In this results chapter, I answered the second research question: *What kinds of subjectivities are produced by the discourses in operation when individuals with advanced cancer seek life-extension through biomedical treatments?* To accomplish this goal, I characterized eight types of subjectivities: (1) The Cancer Expert Subject, (2) The Proactive Subject, (3) The Productive Subject, (4) The Mistrusting Subject, (5) The Model Patient Subject, (6) The Positive Thinking Subject, (7) The Suffering Subject, and (8) The Challenged Clinician Subject. To accomplish this goal, I considered how the numerous discourses in circulation shaped the behaviours, perceptions, and identities of the different social actors involved in this phenomenon or the process of subjectification (Foucault, 1976).

In the next chapter, I build upon the previous two results chapters in order to discuss the findings of this study on the search for life-extension. In this discussion, I reintroduce key Foucauldian theoretical ideas, as well as place the study findings within a wider scholarly perspective.
Chapter 7
Discussion Chapter

41 Introduction to Chapter

In this discussion chapter, I situate the research findings within the main theoretical notions of discourse and subjectivity, as well as additional Foucauldian ideas of power/knowledge, biopower, neoliberalism, and care of the self. Through introducing relevant scientific studies and the wider theoretical literature on dying, illness, and biomedicine, I also place the study findings within a broader scholarly perspective. This chapter is organized in three main sections: (1) An Emergent Form of Life, (2) Power/Knowledge Relations, and (3) Care of the Self.

In the first section, I discuss how the search for biomedical treatment and other unexpected therapeutic ventures positions those who are dying of advanced cancer as an emergent “form of life” that results from the current competing discourses in operation and the conflicting subjectivities that arise from these multiple discourses. I examine how the prolonged but uncertain encounter with dying (or not dying) from metastatic cancer, which is a recent development in oncological and palliative care medicine, generates multiple incongruences, instabilities, and ambiguities for those involved. In this section, I also describe participants’ uncomfortable, but open acknowledgement of death and how this complicates the search for treatment. I interrogate the notion of time and how this facet shapes the quest for life-extension. To end this section, I explore the eternal self that strives for longevity in the face of terminal disease, despite the uneasy limits of biomedical possibilities.

In the second section, I consider the shifting power/knowledge relationships between patients and healthcare providers in the current cancer care system. I discuss how the search for potentially life extending cancer therapies leads to new forms of resistance that counter the traditional hierarchical arrangement of biomedical knowledge. This current shift in power/knowledge relations then leads to the rise of new types of subjectivities, including the emergent and increasingly important renegotiation of who is considered to be an expert in the treatment of advanced cancer. In this section, I argue that this shift towards the proactive, expert, and mistrusting forms of patient subjectivities leads to particular social tensions for healthcare
professionals who are located between many uneasy positions when dealing with this emerging type of contemporary figure in the clinical setting.

In the third and final section, I return to Foucault’s (1984d) conceptual notion of care of the self to discuss how the search for life-extension involves more than procuring an experimental chemotherapy or other regimes of cancer therapy, but also constitutes an aesthetical process of shaping the self in order to become a certain kind of subject that is robust enough to reverse the biological destiny of advanced cancer. Given the discourses of self-care and self-healing, I argue that there are more tools, techniques, and overall possibilities than ever before to actively participate in care of the self. I suggest that through these different technologies of the self, individuals can now become particular types of individuals who strong enough to assertively push for life-extension, despite the debilitating and potentially lethal nature of their disease. Next, I explore how the care of the self in advanced cancer becomes an ambitious but indeterminate neoliberal project of the self, where individuals consume healthcare resources in order to fully maximize the curative potential of their still cancerous bodies. I also discuss positive thinking as a prevalent technology of the self that is intended to combat advanced cancer. To conclude this chapter, I problematize some of the ethical relationships one has with oneself in the active but seemingly impossible struggle to achieve longevity in late-stage cancer.

42 Section One: An Emergent Form of Life

42.1 Characterizing a Form of Life

The results of this study highlight the complexities of what it means to simultaneously have life threatening cancer and to actively search for life-extension at this point in history. To characterize this current complexity, I describe individuals who seek potentially life-extending medical treatment as an “emergent form of life” that results from the crystallization of competing discourses in operation and the multiple subjectivities that arise from these discourses. Unlike twenty-five years ago, advanced cancer patients are living longer with the persistent threat of death, which is a reflection of the current state of oncological and palliative medicine (Canadian Cancer Society, 2013; American Cancer Society, 2013; Lage & Crombert, 2011; Ferris et al.,
The participants in this study exemplify this new category of the chronically dying; individuals who require long-term and complex medical management because of severe disease (Lage & Crombert), but live at home and participate in everyday social life. More significantly to the aims of this study, the prolonged encounter with both the disease and the cancer care system permitted, and at times, intensified participants’ participation in the politics of fighting cancer, the negotiation of treatments with physicians, and the utilization of disease knowledge.

The form of life that results from the long-term but uncertain confrontation with dying or not dying approximates what Kaufman (2005) calls a “zone of indistinction” (p. 273). Whereas Kaufman focuses her ethnographic work on unresponsive patients who require long-term medical technologies like ventilation to live and are sequestered in institutions, the findings of this study suggest this sense of indistinction has now been extended to those who are well enough to live at home, actively engage in society, and are able to speak and advocate for themselves. The increased duration of living with life threatening cancer has been coupled with new forms of subjectification. Unlike previous studies that considered how the dying are sequestered from the living in hospices and palliative care units as a result of the widespread cultural taboos about death (Lawton, 1998; 2000), participants in this study actively made themselves visible in both the cancer care system and their local social networks through their particular political strategizing. These types of individuals comprised an emergent category of dying that is integrated within the rest of society and becomes a forceful participant in the local politics of negotiating potentially life-extending therapies.

At the same time, the discourses and subjectivities examined in this study gave rise to an uneasy sense of discord. In place of the spiritually, physically, and emotionally unified dying self that some palliative care researchers suggest is the ideal catalyst to realizing a “good death” (Walters, 2004), this emergent form of life is characterized by conflict, incongruence, and uncertainty. A previous study of patients’ long-term experience with advanced cancer by Nissim (2012) located a similar “borderland between life and death” (p. 361) that was characterised by controlling the processes of dying yet valuing life in the present. My study findings further illuminates some of these ambiguities: living with the hope of life-extension yet being acknowledging the possibility of dying, intense suffering yet continuing on in the everyday, being dependent on others for care yet actively seeking further treatment, and putting one’s faith in conventional medical treatment.
yet considering the possibilities of self-healing. Existing from clinical trial to clinical trial and medical treatment to medical treatment, individuals in this study clung to life “by a thread”. The desperation to survive often pushed patients and family members to advocate for more and more medical treatment in increasingly urgent ways. Yet, the decision to terminate the search for life-extension and the prospects of being freed from an existence plagued by having severe cancer weighed heavily on certain participants.

The results of this study shed light on the impossibility of holding the multiple selves generated by the struggle for life-extension. Some scholars have described the 21st century self as indeterminate and continually created and recreated through discourse (Gergen, 1992; Sampson, 1989). Under these conditions, “persons exist in a state of continuous construction and reconstruction” (Gergen, p. 71) and ultimately the center of one’s identity fails to hold. As demonstrated by the study findings, the search for potentially life extending cancer treatment generated a sense of incompatibly of the contemporary self. Individuals endured a particular brand of suffering as a result of not being able to “sit with” the multiple selves. In particular, the irreconcilabilities between the self who is permitted to die and the self that holds onto the possibilities of extending life became almost unbearable for certain participants to endure.

Because the tensions in individuals’ lives often came to the surface in my analysis, the uneasy circumstances of patients and family members did not seem easily resolvable. As my study highlighted the different discourses and subjectivities in competition with each other, no single overarching approach seemed to fit or offer a “quick fix” solution. I also did not attribute a form of blame to any one exclusive group like physicians who only need to alter their conduct, but argue that each actor in this phenomenon is constrained by their unique locations within the discourses and subjectivities in circulation. For instance, the intense search for biomedical treatments yielded its own forms of suffering, whereas openly preparing for death or embracing palliation also somehow did not seem compatible with the personal ethos of participants. Similarly, in his research on genetic engineering and the postmodern self, Rabinow (1999) suggests that biomedical science has problematized life to the extent that its current form escapes the “philosophical self-understanding provided by both the classical world and the Christian tradition” (p. 16). Rabinow also suggests that “no new political or ethical vocabularies” (p. 16) have adequately described or come to terms with the incongruences experienced in this new
arrangement of life. Similarly, the perspectives of participants in this study were inscribed with uncertainty, a sense of ambiguity, and a feeling of not knowing how to proceed.

42.2 The Form of Life and the Acknowledgement of Death

As previously mentioned, there is a significant body of scientific research on the factors that contribute to cancer patients’ willingness to receive potentially life extending medical treatment. For purposes of this discussion, I place this wider body of literature within three larger groups. The first group of studies suggests that cancer patients are often willing to receive more invasive forms of cancer therapy in exchange for relatively small gains in the length of survival (Slevin et al., 1990; Donovan et al., 2002; Sahm et al., 2005; Hirose et al., 2005; Voogt et al., 2005). The second group of literature suggests that individuals with advanced cancer often overestimate the curative potential of medical treatment that they are receiving (Chen at al., 2013; Chow et al., 2001; Penson et al., 2004; Weeks et al., 1998; Kass et al., 2010; Meropol et al., 2003; Sulmasy et al., 2010; Godskesen et al., 2013).

Proposing a more knowledgeable, medically informed, and savvy type of patient, the findings of this study suggest a more nuanced approach to treatment and show that participants adopted very strategic but different approaches in their search. Although individuals sometimes adopted aggressive tactics to advocate for anti-cancer therapy, participants were highly selective about which biomedical treatments to push for and which to overlook. Unlike what is sometimes suggested in the literature on treatment aggressiveness discussed in the literature review (Earle et al., 2004; Braga et al., 2007; Temel et al., 2010), participants were not willing to try everything to eliminate their cancer and their bodies were not “carte blanche” to receive any sort of intervention. Rather, by refusing certain treatments that they felt would lead to more harm than good or by positioning themselves to obtain the latest (and presumed most effective) experimental therapy not necessarily offered by their oncologists, participants attempted to maximize their own the therapeutic benefits. Having previously received multiple ineffective rounds of similar biomedical interventions, participants were not willing to trade what was described as by some as “quality of life” in return for harsh or toxic therapies. A commonly used term in clinical practice, quality of life was often reconstituted by participants to describe a
rationale where individuals become fully engaged in the search for life-extension, but do not becoming physically incapacitated.

The third group of scientific literature suggests that patients who seek life-extension may not fully comprehend the possibilities of dying from their disease (Zimmermann, 2004; Tattersall et al., 2002; Chochinov et al., 2000; Hancock et al., 2007; Quirt et al., 1999). As few studies on the search for treatment have previously examined the perspectives of those with life threatening cancer, my study offers new possibilities of understanding. Unlike this previous group of research, participants in this study understood their poor prognosis and in one way or another acknowledged that they were going to die of their advanced disease. Recruited from an outpatient palliative clinic, as opposed to an oncological clinic, and with accumulated disease knowledge, participants may have been more cognizant of their dying than other patient groups. Participants in this study were not necessarily “in denial” of their approaching death, a term often employed in the psychosocial oncology literature (Zimmermann). Moreover, for certain participants, the acknowledgement of death was not necessarily synonymous with coming to terms with the closeness of death.

The recognition of death did not exclude individuals from the search for life-extension, but at times intensified their sense of desperation to locate more effective treatments and further contributed to their sense of ambiguity. Participants often downplayed the likelihood that their current line of treatment would not work, although participants occasionally hinted at it during the interviews. Both patients and family members felt reassured by the perceived availability of more and more treatments: the next clinical trial, new medical scientific developments, or a trip to another country to receive biomedical treatments not available in Canada. Even though participants in this study acknowledged death, there was a sense of open-endedness and unease about the unclear end point of one’s search for life-extension.

42.3 Time and the Emergent Form of Life

Because of their location between living and dying, participants representing the form of life described in this study experienced time in a distinctive way. Biomedicine often forces a self-
calculation about how much time is left in relation to disease status, leading those with the poorest status to ponder a future with shortened horizons (Kaufman, 2010). Those with advanced cancer are often presented with a difficult temporal bind offered by biomedicine: to imagine one’s own death, which is an extremely daunting prospect, or to imagine a longer life, which often involves risky oncological interventions (Kaufman). Generating productive forms of patient subjectivities, the experience of time became increasingly constrained for individuals in this study who were forced to use time efficiently before it ran out. For instance, participants enrolled in clinical trials were preoccupied with the estimated time left in the consent forms and this often shaped their sense of time in their everyday lives. Amplifying the intensity of their quest to realize a cure or significantly extend life before the end, time was experienced by patients and family members in an almost frantic and sped up way. With this limited experience of time, participants, for instance, often described living from treatment to treatment or clinical trial to clinical trial.

The results of this study illuminate that the amount of time left is increasingly viewed as something that lies within one’s control and is dependent on the quality and level of commitment to one’s individual health practices. This rationalization of time may be part of a larger social expectation to control a phenomenon like cancer that ultimately may not be controllable (Willig, 2011). The current perception of death as a seemingly controllable event is a relatively new phenomenon in the cultural history of the West (Kaufman, 2010). Timmermans (2010) suggests that the modern era gave rise to both the practice of isolating the dying and the frantic search to postpone the time of death, a cultural preoccupation that is reflected in this study. As a result of the technological developments in treating life-threatening disease and the encroachment of biomedicine in the aspects of everyday life, contemporary attempts to broker death are simultaneously a professional endeavour and a project of daily life (Timmermans). Confirming this notion, the results of this study suggest that both biomedical therapies and other self-curative prospects offer intriguing possibilities to potentially extend one’s life in the everyday, thus giving rise to new forms of patient subjectivities. Another important cultural assumption is that individuals can “add time” through employing various biomedical technologies like pharmaceuticals and surgery (Kaufman). Adding a new perspective to this idea, my study reveals that the notion of “adding time” has now been extended to different technologies of the self
intended to postpone death, such as positive thinking or self-care, that move beyond the limits of biomedicine to engage in the search for life-prolongation as part of everyday practices. These seemingly curative technologies of the self were associated with often demanding expectations to develop knowledge of the self for individuals with late-stage cancer (Foucault, 1988; Packer, 2011). For instance, in order to enact different self-care and self-healing practices, participants were forced to develop self-knowledge of their relationships with caregivers, interpersonal capabilities, abilities to draw on different resources, negative thoughts around suffering, and sense of mortality.

42.4 The Eternal Self and Fighting Cancer

Despite the current abilities of the cancer care system to extend the dying period, life with metastatic cancer cannot be prolonged indefinitely. Taken from the perceptions of patients and family members, this study highlights some of the perceived therapeutic shortcomings of oncological medicine to eliminate certain forms of cancer or reverse a poor prognosis of cancer. At the same time, these assumptions about biomedicine did not preclude the emergent form of life from attempting to prolong his or her life. Based on his sociological analysis, Bauman (1992) argues that one of the fundamental activities in culture is extending lifespan and pushing back the time of death. Making the job of death more difficult, death is then positioned as a matter of significance or concern above the level of the mundane or ordinary (Bauman). The second important cultural activity around death involves the quest for immortality to achieve the so-called “eternal self” that survives well beyond death (Bauman). Through the culturally endorsed search for transcendence over death, death is partially denied its uncomfortable finality (Bauman).

The results of this study also argue that by enacting certain types of subjectivities, some patient participants sought to realize a kind of eternal self that would be fondly remembered long after death. For instance, by ensuring some form of financial and social security for their family members, some participants described their wish to be remembered as a responsible parent or a loving sibling after they had passed away. Whereas certain participants were concerned about being remembered after their death, other participants were more preoccupied about the
transcendence of death while they still were alive. Despite the diagnosis of terminal cancer, this study highlights the ambiguity about when life really ends at this point in history. Death from advanced cancer often remains open and unresolved for many individuals, which may complicate the delivery of palliative care. Participants’ acknowledgement of death somehow did not exclude them from the quest to achieve the eternal self. By reassuring themselves of their own abilities to expertly navigate the cancer system or their own self-curative skills, this emergent form of life actively resists dying. The perception of biomedical science as cutting edge and its seeming inexhaustibility (for instance, the assurance of the next experimental trial and the next) meant participants had increasingly open access to tools that could help them possibly transcend death. Yet, the realization that life with advanced cancer could not significantly be lengthened was still a potent reality in individuals’ lives. Participants in this study simultaneously held subjectivities that could actively seek life-extension and yet acknowledging the painful realization of the limitations of life prolongation.

The eternal self is also inextricably linked to the valorized self that is engaged in the enduring battle to fight cancer. The individualized fight against cancer is often inscribed with broader cultural expectations to battle cancer by any means necessary and until the enemy is thoroughly defeated (Willig, 2011). Those who fully engage in this battle are often heroized and sometimes soothed by the perception that one can successfully fight cancer through the effort of will (Seale, 2002; Good et al., 1990). A culturally endorsed way to address the uncomfortable taboos of cancer as a “ruthless, secret invasion” (Sontag, 1989 p. 5), the war on cancer metaphor is inscribed with broader perceptions that those with cancer must become fully engaged in ridding themselves of disease. Based on a discourse analysis of the popularization of scientific articles in the mass media, Camus (2009) located intriguing metaphors of cancer as a scientific puzzle or riddle simply waiting to be solved. By reinforcing an optimistic cultural belief in the continuous progress of medical science and that a cure for cancer will likely be discovered (Willig), Camus’ study suggests that the discourse of experimental scientific is inscribed with notions of a fight, and more importantly to this study, a powerful perception that this fight can legitimately be won.

By doing “what it takes” to prolong life, employing different strategizes in the clinical encounter, and by taking up different practices of self-care, participants in this study searched for life-extension in such a determined, persistent, and aggressive manner as to resemble a fight.
Through determination one is made to believe that one can generate curative possibilities. A prevalent theme in the data, both patients and family members seemed caught up in the idea that one can will their way to a cure by maintaining the strength of one’s resolve. Moreover, the positive thinking subject was often valorized for remaining upbeat in the fight against death. At the same time, the process of fighting cancer was much more nuanced in this study than the literature on this topic sometimes suggests, for example, the war on cancer as described by Sontag (1989). For instance, the fight for participants was not an “all out battle”, but rather comprised a nuanced and calculated, but still intense, process of maximizing the most effective therapeutic effects. In doing so, participants actively participated in a contemporary form of biopower under which individuals worked on their identities and bodies in order to revitalize life (Rabinow & Rose, 1996), but were not willing to eradicate themselves in the process.

43 Section Two: Power/Knowledge Relations in Advanced Cancer

43.1 Shifting Power/Knowledge Relations in the Clinical Encounter

The results of this study call attention to the shifting power/knowledge relationships between patients and healthcare providers in the current cancer care system. Although biomedicine was still a dominant discourse, the power/knowledge practices of participants were supported by a newfound cultural permission to both monitor and challenge the treatment plans and knowledge claims of healthcare providers. Some individuals felt that taking on more assertive political identities in the clinical encounter and circumventing traditional routes to access treatment was in fact necessary in order to obtain further treatment. These findings thus problematize traditional social constructions of terminally ill cancer patients as passive, absolved of certain self-care responsibilities, and exclusively adopting a traditional sick role in order to obtain care (Frank, 2013). Rather, patient and family members in this study negotiated power relations with healthcare providers by the taking on decidedly more active subjectivities: the cancer expert, proactive, and mistrusting subjects. Even the model patient subject, who was willing to work
within the mainstream hierarchy of biomedicine, manipulated power/knowledge relations to their advantage in a sophisticated way.

Previous descriptions of this active type of patients in the health sciences have focused on the single aspects or traits of individuals (for instance, personality types) (Heldal & Tjora, 2009). Generating a more one-dimensional and binary view of power in relationship with providers, this limited perspective often categorizes individuals as either passive and powerless or active and powerful (Heldal & Tjora). Rather than perpetuate this static view of power, this study offers a different perspective on how individuals take up assertive forms of subjectivity through navigating the multiple social interactions within the cancer care system. This study also exemplifies the poststructural concept of power as continually exercised and negotiated within relationships, as opposed to power being monopolized by one governing body (Foucault, 1976). For example, although biomedicine was shown to be an authoritative and at times dominating force in the gate keeping of treatment, the prestige of biomedicine was found to be very fragile within the context of meeting participants’ expectations for a cure. The self-governing expectations that individuals must extend their lives despite having advanced cancer not only originated within the discourse of biomedicine, but also wider neoliberal discourses about self-care and self-healing that sometimes are antagonistic to biomedicine.

This study calls attention to the shifting hierarchy in how bio-scientific knowledge about cancer treatment is presently located, manipulated, and utilized in the search for life-extension. Medicalised understandings of disease only ever produce a partial understanding of the reality of disease and the dominance of biomedical knowledge has become increasingly subject to distrust and cynicism (Youll & Meekosha, 2011; Lupton, 1997). Although information from healthcare providers was perceived as essential, knowledge obtained from a wider assemblage of sources (for instance, one’s own body, self-navigation of cancer research, informal social networks, and the mass media) was also viewed with a certain level of importance. An emerging arrangement of knowledge in the 21st century, participants did not necessarily view the knowledge obtained from healthcare professionals as inherently more credible, but rather often used self-obtained understandings to compare, confirm, and sometimes discredit the knowledge obtained in the clinical encounter. In a similar way, Broom (2009) found that cancer patients often pieced together embodied knowledge, intuition, and formalized scientific expertise to come to terms
with treatment options. However, the participants in my study appeared to be decidedly more critical of biomedicine than in the study by Broom and were more likely to translate knowledge into different resistant forms of health practices (for instance, working around their appointed oncologist to obtain treatment). Whereas Broom sampled from a wider cross section of individuals with different cancer acuities, the poorer prognosis of my participants may have generated the discursive conditions for a harsher critique of biomedicine.

The changing power/knowledge relationships generated by the search for cancer therapies led to new and intriguing forms of patient resistance against the discourse of biomedicine. Previous qualitative studies in oncology have examined patient led resistance against longer treatment wait times in cancer care institutions (Mulcahy, Parry, & Glover, 2010) and discourses of risk in cervical cancer screening (Armstrong, 2005). The results of my study suggest that the urgent need of advanced cancer patients to access biomedical treatment seemed to intensify the level of resistance in power/knowledge relationships with providers.

The resistance of participants took place in various densities and occurred in an irregular and sometimes unexpected fashion (Foucault, 1976). For example, although the mistrusting patient subject resisted medical authority by challenging the knowledge claims of physicians, utilizing assertive communication techniques in the clinical encounter, and evading traditional routes of accessing treatment, the formation of the model patient subject also comprised a kind of resistance, although it was more nuanced. This subjectivity often came prepared with their own biomedical records, engendering the sympathies and sometimes admiration of healthcare providers, and subtly redirected appointments to their own advantage. The model patient subject simultaneously resisted the power claims of clinicians to direct care and acted on their own suspicions that professionals should not have any more power over treatments as the patients themselves. These findings problematize the arguably simplistic view that patient resistance is necessarily as a rejection of professional advice and interventions that is sometimes portrayed in current poststructural health science research (Armstrong & Murphy, 2011). Certain participants in this study did not necessarily resist biomedical authority outright, but rather carefully mediated how power/knowledge was exercised, more forcibly exercising power in certain contexts and relinquishing power in other contexts.
43.2 The Negotiation of Cancer Expertise

Rose (1993) views “expertise” as a modern method to govern individuals that is distinguished from past techniques of governance. The authority of medical expertise as a claim to legitimized knowledge is grounded in its claims to scientific validity, objectivity, efficacy, and a constructed sense of neutrality (Rose; Armstrong, 2007). Authorities often mobilize expertise in distinctive ways so as to produce new relationships between knowledge and the government of individuals, thereby directing the capacities of certain subjectivities (Rose). Though this may be, this study highlighted the present instability of expertise from the perspective of individuals with advanced cancer. One of the major ways that power/knowledge was continually negotiated was through the shifting perception of who is an expert in the current system. Both patients and family members viewed certain traditional experts as inadequate in certain regards and sought to become experts themselves in order to close this perceived gap. To receive a particular level of care, individuals had to undertake a process of moulding the self in order to appropriate new subjectivities. Given the high level of medical scientific sophistication needed to understand the intricacies of advanced cancer, the constitution of the patient expert subject as a form of resistance to traditional expert roles is a fascinating finding.

Although participants did not have formal medical training, they drew on other forms of expertise (for instance, the ability to self-advocate) to justify their claims of cancer expertise. In a qualitative case study, Heldal and Tjora (2009) found three main contributing factors to patients’ sense of expertise in myeloma: being well informed, becoming highly involved in their own treatment, and having third-party health professionals as allies. Similar to Heldal and Tjora, participants in this study utilized an individualized process to develop their perceived expertise: relying on intuition, drawing on interpersonal skills developed in their careers, and utilizing research savvy to search for experimental treatments. The proactive patient subject also relied on local social networks to drive their sense of expertise: using numerous oncologists and clinical scientists as resources, getting second opinions from family members or friends, and obtaining mass media materials about experimental treatments from friends. The results of this study
suggest a broad assemblage of both individual and local social processes in the constitution of the patient expert and the overall search for life-extension.

### 43.3 Shifting Power/Knowledge Relations and Healthcare Providers

The shift towards the proactive, expert, and mistrusting forms of patient subjectivities led to particular social tensions for healthcare professionals. Professionals found themselves in many difficult positions when dealing with this emergent type of patient in the clinical setting. Constrained by their role as the conscious gatekeepers of biomedicine, the subjectivities of healthcare providers were found to be very challenging when clinically dealing with patients who search for life-extension. For instance, providers had to compassionately assist patients to mediate the aggressive nature of disease and the possibilities of death, yet simultaneously manage their occasionally aggressive demands for further treatment. Providers also had to arbitrate the knowledge claims of patients as apparent cancer experts, yet articulate their own professional biomedical knowledge. Constrained by the current limits of oncological medicine, physicians often could not meet the seemingly unreasonable demands of certain patients to eliminate aggressive forms of cancer and significantly extend life. These tensions highlight the wider matrix of interconnected relationships and subjectivities between healthcare providers and patients and family members.

This study found that the clinical encounter was characterized by the ongoing oscillation between the trust and mistrust of healthcare providers. Although certain individuals trusted their oncologist more than others, each participant outlined different interpersonal and knowledge strategies to monitor oncologists in case some aspect of care was missed or another treatment option might be more efficacious. Because they played a stronger role in symptom management and less of a role in the gatekeeping of more potent anti-cancer therapies like high dose chemotherapy, palliative care physicians seemed to engender more trust than oncologists from patients and family members.
These findings diverge from a recent qualitative study by Hillen et al. (2012) that found a high level of patient trust in oncologists (described by participants as fidelity, competence, and honesty) because the severe and urgent nature of their disease necessitated that patients quickly establish a trust alliance. The study by Hillen et al., however, had a more heterogeneous patient sample, as opposed to a focus on individuals with progressive disease. Instead, the sense of mistrust located in my study is consistent with sociological research on the contemporary changes in clinical relations between professionals and providers. Much of this research suggests a shift towards the physician-patient “encounter” away from the physician-patient “relationship” in the Western world (Potter & McKinlay, 2005). The increasing view of healthcare as a financial commodity and the increasing corporatization of institutions has lead to the lost of social status for physicians towards the end of the 20th century (Potter & McKinlay; Lupton, 1997). This transition made the paternalistic approach of physicians obsolete, along with patients’ sometimes assumed and uncritical trust of physicians, in place of a consumerist framing of the clinical encounter (Potter & McKinlay).

Similar to purchasing goods in a retail store, interactions with physicians now serve as a commercialized space where individuals act as savvy consumers, consider different health options, feel entitled to have every option presented to them, and eventually “purchase” biomedical treatment (Potter & McKinlay, 2005; Lupton, 1997). Although the present study took place in the publically funded Canadian healthcare system, patients and family members often appropriated these consumerist rationales in the negotiation of power/knowledge relations with professionals. Participants in this study tended to heavily invest in their self-capacities to advocate for, understand, and access treatment. For instance, some participants felt they distinguished themselves from other patients by their willingness to do “what it takes” to improve their disease status. In this individualistic framing of the personal responsibility for health, one’s social location that may limit one’s capacity for personal responsibility for one’s disease is downplayed. Through this process, the importance of trusting healthcare providers to heal one’s cancer is also simultaneously downplayed.

Healthcare professionals, who often enact the discourse of biomedicine through various care practices, are implicated in the production of patient subjectivities, yet often cannot handle the intensity of this new form of life. Although most professionals in this study were careful not to
negatively depict patients and family in interviews, certain participants in this study were indirectly labeled troublesome and “problem patients”. Similar to a previous study by Stacey, Henderson, MacArthur, and Dohan (2009), the present study found that the knowledge claims of patients, which were gathered through Internet blog sites or in the mass media, generated the most difficult tensions for physicians when conducting the work of biomedicine. In particular, individuals came with the expectation that physicians review and validate information gathered online, some of which suggested a different treatment approach than standard treatment protocols or altogether diverged from data presented by professionals (Stacey et al.).

Physicians in this study described similar challenges in both screening and mediating the information patients presented to them, which was often articulated as part of their professional role. Given their extensive formal training, the elite nature of the work, and the experience gained through immersion in clinical practice, the tendency of certain physicians to reclaim their authority in the negotiation of power/knowledge relations is understandable. In addition to patients and family members, healthcare providers were equally constrained by the discourse of biomedicine to employ the “correct” form of knowledge. An earlier study by Broom (2005) found that oncologists often employed disciplinary strategies, such as discrediting the information presented in the consultation, to reinforce traditional patient roles and to occasionally alienate individuals who employed the Internet as a central information source (Broom, 2005). Although a similar power struggle occurred in this study, physicians did not describe their own assertion of professional knowledge necessarily as domineering, but rather as a well-intended attempt to direct treatment toward more appropriate therapeutic routes. The findings of this study suggest divergent perspectives between physicians and patients around lay-obtained knowledge. Patients and family members described how self-obtained knowledge empowered them, thereby allowing them to feel more in control, whereas physicians reinforced biomedical discourse’s claim to the “truth” by viewing these kind lay assertions of expertise with caution.

The social consequences for individuals that threaten the conventional arrangements of biomedical knowledge resemble Holmes, Murray, Perron, and Rail (2006)’s critique of the “regimes of truth” (p. 180) of evidence-based health science. Supported by the unchallenged authority of institutional medicine, the evidence-based movement in the health sciences is often
exclusionary and normative with regards to scientific knowledge (Holmes et al.). The appropriation of scientific data by individuals with advanced cancer comprises a subjugated form of knowledge because it may lie outside of accepted parameters. According to Holmes et al. these subjugated forms of knowledge often “arise from below” (p. 183) in contrast to the top-down approach that “characterises the hegemonic thrust” (p. 183) of traditional evidence based healthcare. An institutional subject who is presumed to know the truth of disease and possess the intellectual capacity to prescribe treatment, physicians not only often shape the realm of the therapeutically possible, but also close off other avenues (Holmes et al.). Given this well entrenched structure of knowledge and expertise, it is no wonder that the opposition to physicians by patients comes with certain social consequences.

An unexpected clinical phenomenon discovered in this study, the open availability of electronic medical charts to patients and family members generated new challenges in the negotiation of power/knowledge relations. Although this was an unusual institutional feature of the study setting, patient-accessible electronic charting systems could potentially become more widespread in various cancer clinics and hospitals (Jha et al., 2009). Previous research on this topic has focused on the institutional value of electronic health records in promoting patient safety, tracking the effectiveness of health interventions, and promoting high quality care (Miriovsky, Shulman, & Abernethy, 2012; Shachak & Jadad, 2010). Although I do not dispute the intentions of this trend, my study suggests one of the effects is that patient-provider relations have become further constrained. Generating certain tensions in the clinical setting, healthcare professionals had to contend with patients’ expectations that physicians therapeutically act on certain chart findings (for example, higher prostate antigen levels), even though they may not be clinically significant.

At the same time, the electronic chart system encouraged participants to continually revisit the clinical data that demonstrated their advanced disease status, partly absolving professionals from the difficult work of reinforcing poor prognosis during clinical consultations. Historically, the medical chart has been a highly politicized site where multiple and interoperable stories about the performances of patients’ bodies, the clinic, and professionals are documented, interpreted, and processed (Berg & Bowker, 1997). This study suggests that the medical chart is now a site with disciplinary effects for healthcare providers. Constraining textual discussions about the
complicated work of dealing with patients and family at the end of life, online charting forced professionals to closely monitor what they wrote about individuals with cancer in their medical notes. Despite the hard work of dealing with so-called demanding patients and family members, the medical chart became one less institutional space for healthcare providers to debrief about the complexity of these clinical challenges.

43.4 Power/Knowledge and the Social Location of Participants

The results of the study highlight how the privileged social location of patients and family members allowed them to exercise power/knowledge relations in more confident ways. Participants’ relatively privileged social location permitted them to draw on certain social and informational recourses in the search for treatment. As biomedicine still retained a powerful and authoritative role in oncology care, one must have a high level of confidence to challenge both the knowledge and skills of healthcare professionals. Not every individual with advanced cancer may be able to evenly participate in the forms of resistance or the mediation of power/knowledge relations described in this study. Other groups of individuals with different social locations, for instance those who do not have formal education or are economically and socially marginalized, may be excluded from these forms of subjectivities. Even adopting the model patient subjectivities necessitated that individuals understand the social milieu of the clinical world in a sophisticated way. Individuals with less socially advantages might navigate the search for life-extension in an altogether different way.

Interestingly, the importance of social location was reflected in which types of patients that were recruited to the study. Although moves were made to sample a variety of participants, clinic physicians tended to refer participants that they perceived could coherently speak to the subject matter on a sophisticated level. As they may have personally identified with certain patients over others, physicians sometimes reported that they referred participants that they closely empathized with or enjoyed treating in the clinic. For instance, Achmed’s (Case Five) referring physician described how he was a favourite patient. In this unique instance, this physician’s affection for Achmed may partly stem from their similar levels of educational and economic status.
These findings are consistent with a well-cited Canadian study by Dunlop, Coyte, and McIsaac (2000) that examined the link between physician utilization and the socioeconomic status of patients. Based on a large population based survey, Dunlop et al. determined that higher income and education levels were associated with both being referred to and being seen by a medical specialist. Despite the promise of equal access in Canada’s publically funded healthcare system, less educated or poorer individuals may not be able to as readily express their preferences or expectations for care in comparison to those who are more affluent (Dunlop et al.; Asada & Kephart, 2007), particularly in highly specialized care like oncological medicine. Understanding the effects of social location on the treatment seeking practices in severe cancer is important, as there is mounting evidence that suggests social disparities greatly impact cancer incidence, mortality, and survival (Ward et al., 2004). As previously discussed in the literature review, higher levels of education is often associated with receiving cancer treatment close to death (Earle et al., 2008; Randen et al., 2013). My study illuminated how advanced cancer patients with a higher socioeconomic status may be more confident and employ sophisticated social strategies in order to access healthcare resources at the end of life.

44 Section Three: Care of the Self

44.1 Subjectivity and Shaping the Self

The search for life-extension in this study became more than simply procuring an experimental chemotherapy or an extra round of radiation, but also became a deeper process of transforming the self in order to become a kind of subject that achieves life-extension (Foucault, 2001). By adopting multiple techniques on the body, rules of conduct, and ways of being, participants in this study became a particular kind of aesthetical self that embodied certain stylistic characteristics associated with accessing biomedical therapies and subverting the biological destiny of advanced cancer (Foucault, 1988). From the perspective of participants with cancer, these stylistic traits included determination, assertiveness, shrewdness, intelligence, persistence, and a sense of invulnerability. Though this may be, participants in this study did not undergo the shaping of the self in isolation as an autonomous process, but rather the process was often
constituted through the interplay of power/knowledge relationships within the broader discourses of biomedicine, palliative care, self-care, and self-healing (Foucault, 1976).

Similar to other poststructural research on practices of the self in the early detection of prostate cancer (Kampf, 2010), complementary and alternative medicine (Broom, 2009), lifestyle modification, and cancer prevention (Bell, 2010), this study further highlights the increasing possibilities in contemporary society to shape the self that is afflicted with cancer. The tools for shaping the self are not only more socially prevalent, but are also increasingly accessible to those with serious forms of cancer. For instance, participants in this study drew on multiple devices to shape the self: the wider availability of bio-scientific knowledge, the increased dialogue about clinical drugs trials, self-healing in popular culture, and positive thinking techniques. Participants described their ultimate personal goals for the process of self-formation: regenerating the possibilities for life in a body that was previously cast as dying. By undertaking different techniques for self-formation and various practices of the self, the subjectivities of patients in this study were largely shaped by the quest to cultivate an inner biological and psychological environment that was both hostile to cancer and could maximize the body’s capacity to heal itself.

The formation of the self was simultaneously a productive and problematic practice for participants in this study. On one hand, the process of shaping the self to achieve life-extension encouraged individuals to mobilize the various personal skills, social networks, and curative resources at their disposal. These kinds of transformative practices of the self allowed individuals to develop self-mastery over illness and to reclaim their own bodily healing potential from the appropriation of biomedicine (Frank, 1998). Many patients and family members reported a positive sense of hope, comfort, and ownership through taking up different self-healing techniques such as developing research skills, positive thinking, becoming informed about broader treatment options, or modifying their health behaviours. Through adopting multiple subjectivities, individuals in this study often resisted the dominance of the discourse of biomedicine and at times forcibly made the clinical encounter more meaningful based on their own values and concerns. By reconstituting the self into individuals who are assertive, able to advocate for themselves, and understand the nuances of the cancer care system, individuals in
this study were able to get key pieces of information (for instance, prognostic estimates) that otherwise might have been withheld (Stacey et al., 2009).

On the other hand, the various practices of the care of the self uncovered in my analysis were intended to ultimately extend one’s life from advanced cancer, which seemed like a daunting and likely unobtainable task for many participants. Although care of the self is a never-ending and elusive task according to poststructural thought (McNeill, 1998; Flaming, 2006), patients and family members described their fierce determination to stop advanced cancer and in some cases fully eliminate the disease from the body. The poor prognosis of individuals seemed to accelerate and intensify this process. Care of the self in this study was thus developed within the cultural milieu of biomedicine in North America that stresses longevity by any means and at any cost (Kaufman, 2010).

By marshalling the concept of self-responsibility and individual responsibility, care of the self is an example of how the operations of power in everyday life can incite governance of the self according to expert ideas about success and morality (Rimke, 2000). Since cancer is often constructed as a cultural sign of inner physical or emotional weakness, high levels of vigilance and responsible behaviour are often expected from patients (Willig, 2011; Stacey, 1997). As an object of self-governance, individuals immersed in the process of self-care are often rendered partially responsible for their successes as well as their failures in treating their own disease (Rimke; Rose, 1993; 1999; Frank & Jones, 2003). Leading to the suffering subject described in this study, the drive to shape the self into a robust type of subjectivity that resists death coexists with the immense suffering of having metastatic cancer. This generated a powerful struggle for participants who were simultaneously expected to both strive for life-extension and prepare for death.

### 44.2 Positive Thinking as Care of the Self

The study findings illuminate how participants with advanced cancer utilized positive thinking practices as a culturally endorsed technology of self-care, but not without certain consequences. Similar to an earlier qualitative study by McGrath, Montgomery, White, and Kerridge (2006),
patients with terminal cancer were positioned within the challenging location between hoping for a cure and mediating the reality of death. As demonstrated by the wide array of document data in this study, participants drew on the growing proliferation of books, websites, and self help courses that endorse positive thinking as a way to deal with and increasingly cure cancer (Ehrenreich, 2009). Similar to a previous study by Youll and Meekosha (2011), individuals in this study used positive thinking techniques to gain agency, control, and power over their perceived helplessness of having cancer. Because of the assumption that individuals may play a role in the causation of their cancer (Sontag, 1989; Willig, 2011), there may be stronger a cultural preoccupation with curing cancer by emphasizing a positive mental attitude than in other fatal diseases (Ehrenreich). For instance, one participant described a link between positive thinking and the miracles of spontaneous remission in metastatic cancer that was located in a popular self-help book, but also endorsed by her informal social network.

Unlike what is sometimes suggested in the broader scientific discourse on this topic (Ehrenreich, 2009), individuals in this study did not exclusively employ positive thinking to deny death. Rather, participants employed positive thinking both as a curative technique and also as a part of an ethos of the self that motivated their search for further biomedical treatment (Foucault, 1997). As certain negative thoughts were viewed as detrimental to cultivating an inner environment that resists cancer, some individuals disciplined themselves to think positively whenever possible. This often came out in the research process as a type of social performance (Atkinson & Delamont, 2005), where individuals tried to demonstrate an emotional robustness afforded to them through positive thinking. The findings of this study align with earlier work by De Raeve (1997) that considered how the negative feelings of those with cancer are often marginalized in the interest of preserving a positive disposition and inner environment of healing. Leading to a sense of “moral oppression” (p. 249), De Raeve described how individuals might interpret the failure of positive thinking to reverse a poor prognosis of cancer as moral failure for not trying hard enough. Although individuals in my study did not refer to “failure” per se, some described how the belief in positive thinking made it challenging to even consider the possibilities of relinquishing the search for life-extension and letting go in the belief of a cure, despite how elusive this may be. Because of the pressures to redirect one’s way of thinking towards positive
thoughts, the positive thinking subject was also a disciplinary subject because of its firm expectations to maintain pre-specified parameters.

44.3 The Search for Life-extension as a Neoliberal Project of the Self

The search for life-extension despite life-threatening cancer is presently being constituted as a neoliberal project of the self because it is constituted by the crystallization of neoliberal values like assertiveness, responsibility, and accountability (Moore, 2004). As demonstrated in this study, the search for potentially life-extending biomedicine spawned emergent and multiple forms of subjectivity (for instance, the proactive self) that preserves neoliberalism as a governing force (Gordon, 1991; Rose & Miller, 1992). Facilitated by present discourses of active citizenship, this contemporary figure moves away from being a passive recipient of biomedicine towards being an active consumer with the capacity for rational health choices (Moore; Rose, 2007). As with participants in this study, patients in the current time and place often actively choose and consume biomedicine, pharmaceuticals, alternative medicine, and self-psychology in order to maximize and enhance vitality of life (Rose, 2007). Immersed in neoliberalism, the present self acts in a calculated manner to engage in a project of self-improvement (Lupton, 1997). Rose notes that in this present bio-political climate, health is understood as an imperative for the self in order to “maximize the vital forces and potentialities of the living body” (p. 23). Whereas Rose’s analysis tends to focus on well bodies of the general population, this study examined the maximization of health potential for bodies heavily afflicted by metastatic cancer. A seemingly impossible and arguably futile task, this neoliberal project of the self involves rejuvenating or injecting life into a diseased body that is, in effect, actively dying. The results of the study point out the creativity and resourcefulness of individuals needed to engage in the current venture of life-prolongation. Through the project of the self, the cancerous body in this study becomes recast as a productive, subjected, and thus politicized body (Foucault, 1975).

Many poststructural scholars have provided a harsh critique of the role of neoliberalism in health as method of governmentality that polices individuals at a distance (Rose & Miller, 1992; Moore, 2004). Institutional healthcare’s move to “empower” patients through the promotion of
autonomy may be viewed as an attempt by authorities to reduce dissent and resistance in society through shaping both the personal identities and rules of conduct of individuals (McDonald et al., 2007). The emergence of the institutional practice to keep patients informed of their biomedical status calls attention to how the cancer care system constructs so called autonomous individuals. As a result of neoliberalism, institutions of authority often shift what has traditionally been seen as responsibilities of the state onto individuals through transforming them into so called responsible citizens (McDonald et al.). According to this perspective, biomedicine partially relinquishes the responsibility for treating incurable forms of metastatic cancers and defers this seemingly impossible task to patients, who then take up this ambitious project in their daily lives. Within this study, healthcare providers described how certain patients made their clinical work easier by coming prepared with current and sophisticated knowledge of their current cancer status. In addition, participants described the necessity of acting as their own physicians through adopting different self care roles. In response, participants developed certain practices of self-care in reaction to the perceived therapeutic, informational, and at times emotional shortcomings of healthcare professionals and the wider cancer care system.

Other poststructural scholars have considered the productive role of care of the self, neoliberalism, and an increased sense of self-responsibility in resisting certain forms of biomedical rule as part of many broader political movements in the West (Rose, 2007; Rabinow, 1996). Rose examines the rise of “biological citizenship” (p. 131) in the late 20th century to describe how patients increasingly define their citizenship in terms of their rights and obligations to life, health, and cure (Rabinow & Rose, 2006). Through different collective patient movements, individuals sought to gain better lay access to biomedical knowledge, end stigma, gain access to services, and develop a sense of their rights as patients (Rose). The cancer survivorship movement, particularly survivorship of women with breast cancer (Kaiser, 2008), is a potent example of patients’ collective political mobilization and an articulation of their right to more effective and less toxic cancer treatments.

The results of this study suggest that the project of self-care is simultaneously shaped by both the governing forces of biomedicine and broader social discourses about patients’ rights to better treatments that often lie beyond the cancer care system. As highlighted in my study, Rose (2007) suggests that some of these movements remain anti-medical, whereas others operate in a manner
that remains open to established biomedical knowledge and expertise. For instance, some participants drew on self-care resources from peer support groups that intersect with mainstream oncology institutions, whereas others participants drew on the more radical anti-establishment views of care of the self. Despite these diverse sources of knowledge, the overall study findings suggest that the present curative project of the self is occurring both within and outside the authority of healthcare professionals.

44.4 The Ethical and Moral Self

The findings of this study recast how the provision of biomedical treatment in advanced disease is thought of as a morally problematic health practice. As discussed in the literature review, treating incurable disease is sometimes thought of as medically futile or overly aggressive care because it generates moral dilemmas for clinicians who are concerned with the negative effects of invasive therapies on vulnerable patients (Damrosch et al., 1993; Kuuppelomaki & Lauri, 1998). Concerned with good and “ethically sound” treatment practices, both the concepts of medically futility and treatment aggressiveness originate within normative ethical principles (Mohammed & Peter, 2009). With the exception of one oncologist, the terms futility and aggressiveness were not used by any other of the participants in this study, including healthcare providers. Rather, it appeared that individuals with cancer were able to mediate their own sense of futility or aggressiveness around treatments. For instance, individuals attempted to maximize their own therapeutic benefits by refusing treatment that they felt would lead to more harm than good.

As opposed to using normative ethics to problematize the moral suitability of life extending treatment, this study employed Foucauldian ethics to open up a new understanding of the ethical self in advanced cancer (Foucault, 2001). Participants hinted that their search for life-extension might ultimately be in vain, conceding at certain moments during data collection that their current treatment approach may in fact not delay death or reverse a poor prognosis. Although the provision of invasive biomedical treatments in late-stage cancers may be futile in terms of biomedical criteria, this practice had important value to participants in terms of their ethical relation to themselves. Patients and family members seemed less morally concerned with
disrupting the cancer care system with their behaviours and actions. Fortified by a sense of confidence and, at times, entitlement to care, these individuals seemed less troubled with fulfilling the ethical expectations that define a morally good patient that is satisfied with standard care and passively wait for treatment. Despite the challenges they posed to the cancer care system, participants often viewed their individual treatment practices as a way to constitute themselves as ethical subjects according to their own personal ethos (Bernauer & Mahon, 1994). By shaping themselves into persons who instantiate certain values (Prado, 2003), individuals were able to transgress the limits of the self within the normalizing social forces and imbalanced power relations that are sometimes constructed by the healthcare system (Lamb, 1995; Holmes, O’Byrne, & Gastaldo, 2006).

Participants had to navigate multiple relationships in order to be shaped into ethical individuals that could resist advanced cancer (Foucault, 1997; Prado, 2003). From the perspectives of participants with cancer and their relatives, one becomes a good patient if one takes up certain subjectivities that support this search (for instance, by becoming the productive or proactive subject). The practice of an ethics of the self often describes different techniques for resisting imbalanced power relationships (Lamb, 1995). Even the act of challenging the authority of healthcare professionals was viewed as an ethical practice for some participants (for example, the mistrusting subject), because individuals were transformed into active, assertive, and knowledgeable beings. For other types of subjects (for example, the model patient subject), care of the self was bounded by the need to manage disease, yet not aggravate the physicians or disrupt the traditional power relations of biomedicine. At the same time, by coming prepared with detailed biomedical records to consultations and capitalize on the sympathies of providers, the model patient subject transcended the normalizing social forces of biomedicine that claim that healthcare professionals exclusively manage and manipulate disease data.

The ethical relationships that individuals developed with themselves were shaped by broader moral responsibilities of what it currently means to be a cancer patient. Contemporary healthcare is inscribed with ethical responsibilities for patients to the rest of society, including obligations to the general population, other patients, and healthcare providers (Civaner & Arda, 2008). Through interactions with professionals, patients are called upon to use healthcare resources in an efficient, appropriate, and rationale way (Civaner & Arda). Similarly, participants in this study
articulated an ethical relationship with themselves to simultaneously receive biomedical intervention, yet retain enough functionality to not become a burden and to meaningfully contribute to society through participation family life and also in experimental treatments (for instance, through the productive subject). The vulnerability of patients did not necessarily exclude them from the drive to be productive. For example, certain participants enrolled in clinical trials described the simultaneous meaning of utilizing the trial to gain longevity and the sense of fulfilling social responsibility. In doing so, participants appropriated broader social forces of biopower that focuses on integrating individual human bodies into institutional and often efficient systems, such as experimental biomedical science (Rabinow & Rose, 2006).

45 Conclusion to Discussion

In this chapter, I discussed the study findings on the search for life-extension in advanced cancer. Through using various Foucauldian theoretical concepts, as well the broader scientific and broader theoretical literature on dying, illness, and biomedicine, I placed the findings of this study within a wider scholarly perspective in this discussion chapter. This chapter was divided in three main sections: (1) An Emergent Form of Life, (2) Power/Knowledge Relations, and (3) Care of the Self.

In this first section, I described how participants who seek life-extension through biomedical treatment comprise an “emergent form of life” as a result of the competing discourses in operation and the conflicting subjectivities that arise from these discourses. In developing a characterization of this figure, I described a new category of the chronically dying that is able to more actively participate in the politics of fighting cancer, the negotiation of treatment with physicians, and the utilization of bio-scientific knowledge. I then described how the results of this study shed light on the impossibility of holding the multiple selves generated by the struggle for life-extension. Next, I described how the acknowledgement of death for participants was simultaneously held with the possibility of life-extension, leading to a sense of ambiguity. I also described how this emergent form of life was compelled to experience time in an efficient and sometimes constrained way. To conclude this section, I described the search for further treatment and the notion of the eternal self.
In the second section, I described the shifting power/knowledge relationships in the current cancer care system, where participants felt that being more politically assertive in the clinical encounter was necessary in order to obtain further therapies. I also explored the shifting hierarchy in how bio-scientific knowledge is presently located, manipulated, and utilized in participants’ search for life-extension. I discussed how healthcare practitioners, who often enact the discourse of biomedicine through various care practices, are implicated in the production of active patient subjectivities, yet often cannot handle the intensity of this new form of life. In particular, I interrogated the growing role of consumerism in promoting the mistrust of healthcare providers and how the open availability of electronic medical charts often redistributed the power dynamics between patients and clinicians.

In this final section of the discussion chapter, I described how the search for life-extension became more than simply obtaining biomedical treatment, but involved a process of transforming the self in order to become a kind of subject that achieves life-extension. I called attention to the increasing possibilities in contemporary society to shape the self that is afflicted with cancer. I then focused on the expanding and increasingly culturally endorsed discourse of positive thinking, a technique of the self that is designed to help individuals gain agency, control, and power over the perceived helplessness of having cancer. Next, I examined how the present search for life-extension is constituted as a neoliberal project of the self because it is often formed by neoliberal values like assertiveness, responsibility, and accountability. To conclude this section, I considered the ethical relationships individuals developed with themselves through the process of self-constitution and how these relationships were shaped by broader moral responsibilities of what it currently means to be a good patient.
Chapter 8
Conclusion

In this chapter, I conclude this thesis by first presenting a summary of the key ideas from this study. I then outline some of the methodological and theoretical limitations of this research. Next, I move on to explore the important empirical and theoretical contributions of the study findings to the body of knowledge in advanced cancer, clinical practice in oncology, education in the health sciences, and health policy. In doing so, I reflect on how the understandings generated by this work might ultimately help patients with advanced disease, family members, and healthcare providers in oncology. I end this chapter by proposing directions for future research in this area and by drawing some overall assertions about seeking life-extension despite life-threatening cancer in the 21st century.

46 Summary of the Key Ideas from this Study

Although invasive types of therapies provided to eradicate cancer may lead to harsh physical side effects and may even hasten death late in the disease trajectory (Weeks et al., 1998; Emanuel et al., 2003), approximately 16 percent to 32 percent of advanced cancer patients continue to receive these types of treatments within a month to two weeks of death (Barbera et al., 2006; Randen et al., 2013). This study examined patient and family members’ search for life-extension through biomedical treatment and other self-instituted treatment ventures.

As discussed in the literature review, multiple studies have previously examined the particular views of advanced cancer patients toward their disease and treatment (Slevin et al., 1990; Donovan et al., 2002; Sahm et al., 2005; Hirose et al., 2005; Voogt et al., 2005; Chen at al., 2013; Chow et al., 2001; Penson et al., 2004; Weeks et al., 1998; Kass et al., 2010; Meropol et al., 2003; Sulmasy et al., 2010; Godskesen et al., 2013; Tattersall et al., 2002; Chochinov et al., 2000; Hancock et al., 2007; Quirt et al., 1999). While much is known about how the rationales of individuals might influence their willingness to pursue potentially life-extending treatment, less is known about how this search is shaped by wider spheres of understanding such as the biomedical control of disease, the lay usage of bio-scientific knowledge, patient responsibilities
about generating their own health, and dying and death. By offering new ways of understanding this issue, this study challenged the current literature that often portrays advanced cancer patients who search for treatment as uninformed of their poor prognosis and passively dependent on healthcare professionals. By examining the perspectives of different social actors involved in this phenomenon, I reconsidered how individuals draw on their local social relations, utilize disease knowledge from both the cancer system and beyond, and reshape their identities to become active agents in the search for life-extension. Drawing upon Foucault’s (1972) concept of discourses as a set of principles that leads to the formation of knowledge, the first objective of this study was to explore the discourses in operation when individuals with advanced cancer seek life-extension through biomedical treatments. The second purpose was to characterize the types of subjectivities that are produced by these discourses.

The overall results suggest that there are often multiple discourses and subjectivities at play in the search for life-extension despite advanced cancer. The tensions generated by the conflicts between discourses and subjectivities, along with the ambiguities generated by the prolonged dying process, lead to what I characterize as an “emergent form of life”. This form of life actively participates in the contemporary politics of obtaining biomedical treatments and exercises assertive power/knowledge relations in an unprecedented way within the cancer care system. Ultimately, this form of life is governed by wider discourses that enforce the expectation that individuals control disease processes that may lie beyond control, yet must do so in a manner that does not disrupt the cancer care system.

The results of the data analysis suggest that the search for life-extension is not exclusively formed by a single discourse, but rather is constituted by the complex interrelation of numerous discourses in fractured, uneven, and sometimes antagonistic ways. Existing as practices that constitute the discourse from which they are derived from (Foucault, 1972), discourses also shaped the conduct and perspectives of the different social actors in this study. Four major discourses were at play in this phenomenon (Figure 1: Discourses). A dominant discourse in operation, (1) the discourse of biomedicine was implicated in the monopolization of cancer knowledge and the gatekeeping of treatment. At the same time, the prestige of the discourse of biomedicine was threatened by an encroaching sense of uncertainty with medical care, which was characterized by patients’ uneasy perception that their disease was at times uncertainly
managed by physicians. Evolving as a response to the discourse of biomedicine, (2) the narrative of self-care was characterized by the belief that one had to subvert the hierarchies of biomedicine in order to gather treatment information and to sometimes access the actual therapy. An emergent discourse, the discourse of self-care shaped certain intriguing patient practices such as the subversion of the traditional hierarchies in the healthcare system and the lay utilization of bio-scientific knowledge. A way of thinking about the supportive care of the dying, (3) the narrative of palliative care generated tensions for some participants because of its perceived passivity and its assumed incompatibility with the discourses of self-care that encouraged the active search for life-extension. Although this study initially focused on biomedical treatment, (4) the narrative of self-healing emerged as a way for individuals to maximize their own curative potential outside of the limitations of traditional biomedical discourse.

Building on my discussion of discourses, I then identified and characterized eight types of subjectivities that were currently in circulation. Moving beyond a merely informed patient, (1) the cancer expert subject assumed an expert role in appropriating disease knowledge and adopting certain valued skills in the drive for treatment, such as research knowhow and the record keeping of personal health data. (2) The proactive subject creatively mobilized whatever therapeutic resources were immediately available and often sought out new and unexpected resources proactively. (3) The productive subject was concerned with being productive in the face of incapacitating disease, in particular with making a wider social contribution to science by, for example, becoming a perpetual subject of experimental biomedicine. Focusing on discussions and materials that questioned the dominance of biomedicine, (4) the mistrusting subject tended to invest in his or her own capacities to generate the possibilities of life-extension, thereby downplaying the importance of trusting relationships with physicians. In contrast, (5) the model patient subject aligned him or herself with the privileged social location of healthcare providers and sought to preserve traditional power relations between patients and clinicians as a strategic approach in order to access cancer therapies. (6) The positive thinking subject not only addressed the symptoms of cancer through thinking positively, he or she also sought a cure by limiting one’s harmful and negative thoughts about suffering. Characterized by a fragmented and contradictory sense of self, (7) the suffering subject existed as the result of the conflicts between the different subjectivities regarding cancer treatment and death. The final subjectivity identified
in this study, (8) the challenged clinician subject, focused on the difficult positions of healthcare providers who clinically care for patients that assertively seek life-extension, while retaining a sense of doing what is best for their patients.

Although epidemiological research over the last ten years suggest that individuals are living longer with advanced cancer (CCS, 2013; ACS, 2013; Lage & Crombet, 2011; Ferris et al., 2009), few studies have considered how the chronicity of dying moulds how individuals renegotiate their partnerships with healthcare providers, their usage of disease knowledge, and their relationships with themselves (Nissim et al., 2012). This study opened up a new understanding of how the increased duration of advanced cancer generated certain tensions for advanced cancer patients who searched for life-extension, leading to the rise of an “emergent form of life”. This form of life was caught between simultaneously pushing for life-extension and coming to terms with the terminal nature of their disease.

Participants were not necessarily uninformed of their serious prognosis or in denial of death, which is often suggested in the current literature as a contributing factor to the search for further biomedical treatment (Zimmermann, 2004). Rather, the process was highly nuanced; the acknowledgement of death was simultaneously held with the belief that one could generate life-extension through managing disease information and engaging in a variety of potentially life-extending health practices. At the same time, the uneasiness about dying was not necessarily dissipated by the search for life-extension. Consistent with previous studies about the anxiety of impending death (Grumann & Speigal, 2003; Sand & Strang, 2006), the fear of mortality was part of the everyday milieu for patients and family members.

Although the physical pain of cancer is part of the everyday in clinical practice and the existential or emotional suffering of having advanced cancer is well studied (Wilson et al., 2007; Boston et al., 2011; Karlsson et al.2012), this study made a contribution to understanding how the process of searching for biomedical treatment late in the disease trajectory generates its own category of suffering. The analysis of the data highlighted how new forms of subjectivity, in particular the suffering subject, resulted from the challenges of not being able to sit with the multiple and conflicted selves generated by the struggle for life-extension. The irreconcilabilities
between the self who is permitted to die and the self that holds onto the possibilities of extending life became particularly difficult for participants to endure.

Although previous Foucauldian informed research has focused on cancer and practices of the self (Kampf, 2010; Broom, 2009; Bell, 2010), this study made a contribution to understanding how the search for life-prolonging treatment was informed by current subjectivities. Drawing on Foucault’s (2001) notions of care of the self, I described how the search for life-extension became more than simply obtaining additional drugs or radiation, but also became a deeper process of shaping the self in order to become an assertive, knowledgeable, and robust subject that actively resists death. Yet, participants did not undergo self-formation in isolation as an autonomous and individualistic process (Foucault, 1976), but rather the process was often constituted through the interplay of power/knowledge relationships with local social relations and broader social discourses. As evidenced by the discourses described in this study that call for manoeuvring around oncology professionals, appropriating bio-scientific knowledge, and realizing self-healing, there may be more possibilities than ever before in contemporary society to shape the self that is afflicted with terminal cancer. At the same time, the process of transforming the self was both a productive and problematic practice for participants. Shaping the self encouraged a self-mobilization of various skills and resources, yet individuals simultaneously were called upon to participate in the elusive task of extending one’s life despite having forms of disease that previously did not respond to therapy.

These active forms of subjectivity often yielded shifts in the local power/knowledge relationships between patients and clinicians. Although previous research suggests that cancer patients are generally trusting of oncologists (Hillen, et al., 2011; Seetharamu et al., 2007), this study developed a new understanding of how the desperation to extend life encouraged participants to be more aggressive and circumvent the conventional ways patients access further biomedical treatments. Coupled with exercising power/knowledge relations in a more assertive way, resistant forms of patient subjectivities were constituted in reaction to the growing discourses of mistrust of healthcare providers that corresponds with previous scholarly work (Lupton, 1997). At the same time, the findings suggest that these emergent forms of subjectivity are nuanced; not all study participants were mistrusting of healthcare professionals in an outright way. By coming prepared with self-compiled biomedical data and engendering the sympathies of medical
practitioners, the model patient subject employed a sophisticated strategy of resistance against the authority of physicians to direct care and control treatment. The findings of this study problematize the arguably simplistic view that patient resistance is necessarily a rejection of professional advice and interventions as it is sometimes portrayed in poststructural research (Armstrong & Murphy, 2011). The participants exercised power relations when negotiating for cancer treatment in a savvy way, asserting their own sense of authority in certain contexts and relinquishing power in other contexts.

Highlighting the wider matrix of interconnected subjectivities, the findings of this study also provide a novel understanding of the particular social tensions for clinicians who are increasingly called upon to address these more assertive forms of patient subjectivity. Healthcare providers had to compassionately assist patients to mediate the aggressive nature of disease and the possibilities of death, yet simultaneously manage their demands for potentially life-extending therapies. Physicians, in particular, had to arbitrate the knowledge claims of participants as apparent cancer experts, yet articulate their own professional biomedical knowledge. Constrained by the current limits of oncological medicine, physicians could not meet the demands of certain participants to eliminate aggressive forms of cancer and significantly extend life. Although clinicians and their various care practices are implicated in the production of these subjectivities, they often could not handle the intensity that these individuals brought to the system. Even through most healthcare professionals were careful not to negatively depict patients and their relatives in interviews, certain participants in this study were indirectly labeled troublesome or “problem patients”. This problematizing of certain patient subjectivities by clinicians illuminates some of the social consequences of the search for life-extension.

47 Contributions to Knowledge

Randall and Downie (2006) note that end of life care is often immune from a critical approach because of the sensitive nature of death and the idealization of the supportive treatment of the dying by palliative care. Because of the cultural associations of cancer as the paradigmatic illness (Sontag, 1989), the safeguarding of cancer patients as they die may be especially idealized as a care practice. As a consequence of this absence of critique, there is a lack of a deeper reflection
on the current models of care and a lack of understanding of the social effects generated by the treatment of the terminally ill (Randall & Downie). By drawing on poststructuralism to better understand biomedical treatment in advanced cancer, this study pointed to new ways to understand this complex phenomenon.

Although earlier Foucauldian based research on cancer has been conducted on screening, alternative medicine, and cancer prevention, (Vahabi & Gastaldo, 2003; Kampf, 2010; Broom, 2009; Bell, 2010), few previous poststructural studies have considered the biomedicine and self-initiated treatment of advanced disease (Youll & Meekosha, 2013). This study was one of the first in the health sciences to employ a Foucauldian framework to examine how individuals with advanced cancer actively search for biomedical treatments and also assertively realize other curative possibilities. Although previous conceptual work using poststructuralism has problematized the neoliberal framing of medical treatment choices (Marta, 1998), this was also one of the first studies informed by a Foucauldian framework to lend empirical data from the diverse perspectives of different social groups to understand this phenomenon in an innovative way. By moving beyond the existing scientific discourse that narrowly frames this issue from rationalistic, individualistic, and autonomous perspectives, this study contributed new knowledge of the broader discursive conditions that facilitative the search for life-extension and the multiple subjectivities that result from these discourses.

Rather than focus on one type of discourse or subjectivity, this study was responsive to the complexities of the research phenomenon and the dispersed influences on the self that come from both within and outside the health care system. This study considered several types of discourses and subjectivities, as well as the interrelationships, fragilities, and antagonisms between these concepts. The wider analytical scope of this study ultimately led to its contribution to new knowledge in this field. In contrast to the more comprehensive scope of this study, the present scientific literature on this topic tends to accentuate biomedicine and privileges the knowledge and authority of healthcare providers to act as gatekeepers of further treatment. This study did not locate power/knowledge relations within a single governing institution, thereby encouraging the examination of sometimes unexpected discursive areas.
As discussed in the literature review, the current health science literature on this issue sometimes positions patients and family members as uninformed subjects that are sometimes unaware of their impending death (Tattersall et al., 2002; Chochinov et al., 2000; Hancock et al., 2007; Quirt et al., 1999). Based on this perspective, patients are sometimes unwillingly located between certain conceptual binaries: informed or uninformed, rational or irrational, and accepting of death or denying of death (Marta, 1998). By highlighting the multiple subjectivities generated by the wider discursive forces in operation, this study problematizes this categorical view of the self in advanced cancer. An important contribution, this study described the complexity of individuals who seek life-extension in advanced disease as multidimensional, complicated, interconnected, and conflicted selves. This conflicted self was conceptually described in this study through mapping the emergent “form of life” to characterize individuals who seek life-extension at this point in history.

This study also contributed a deeper understanding of how this emergent form of life brought a sense of intensity and conflict into the clinical encounter. Clinicians often found it challenging to exercise their own authority by directing cancer treatments in the “best interests” of their patients, yet contend with the assertive demands of individuals for cutting edge biomedical treatment, access to the most current disease knowledge, and to have their own lay forms of cancer expertise acknowledged.

A contribution to theoretical knowledge, this study illuminated how the intense search for life-extension forced individuals to understand themselves in particular ways and to shape the unique relationships individuals had with themselves in the disruptive context of terminal illness. The search for life-extension was more than simply obtaining treatment, but also became a deeper process of self-knowledge and the transformation of the self in order to become a kind of subject that achieves life-extension. By adopting multiple techniques on the body, rules of conduct, and ways of being, participants in this study became a particular kind of aesthetical self that embodied certain stylistic characteristics associated with accessing biomedical therapies and subverting the biological destiny of advanced cancer.

Finally, an additional contribution of this study was the deeper understanding of the increasing chronicity of the dying process in advanced cancer, which is an expanding issue in oncology.
practice. Although a previous study by Nissim et al. (2012) has examined this topic, this study contributed a new theoretical understanding of how the prolonged period of dying previously generated certain forms of discourses and yielded new and intriguing forms of subjectivities. Rather than dispute the advancement of oncological medicine in extending the life span of those with metastatic cancer, this study calls attention to the discursive tensions and conflicting subjectivities in operation.

48 Methodological Contributions

The current methodological literature offers divergent perspectives about the ethical acceptability of research participation for the terminally ill because exploring sensitive topics could be distressing, intrusive, time consuming, and could divert individuals from other important activities (Gysels, Shipman, & Higginson, 2008a). Given their need for symptom control and other crucial services, palliative care patients may be highly reliant on healthcare providers, thus generating the concern with coercion during recruitment (Addington-Hall, 2002). Because terminally ill participants may not derive long-term benefits, some scholars have called attention to the ethical appropriateness of burdening this vulnerable group (Gysels, Shipman, & Higginson, 2008b). Offering a different perspective on these assumptions, I found that the enactment of certain subjectivities motivated individuals to participate in this study. Their sense of activeness and the drive of active subjectivities pushed participants to assertively tell their stories, articulate their sense of discontentment, or describe how they obtained care. The functional abilities of this patient group, who were at the end of life, yet not incapacitated or imminently dying, also permitted them to actively participate. Distinctive from other terminally ill groups, the nature of this study population allowed them to become deeply engaged in the research process, such as multiple and longer interviews. In fact, with certain cases, I had to restrict the amount of document data referred to me and respectfully terminate the research relationship because some participants felt very compelled to contribute.

Despite the vigour with which participants told their stories, this study also highlights the methodological skills needed to navigate the emotional, political, and ethical complexities of cancer treatments at the end of life. In many instances, my own positionality and skill as a nurse
was an asset to conducting the interviews. I had to expertly balance the need for individuals to display the robustness of their subjectivities with the sensitive nature of dying. Despite crying, one participant and his spouse commanded me to ask even more probing questions about funeral planning and ensured me that they could both “take it”. Instead, I paused the interview, assessed the situation, provided emotional comfort, and only continued with their permission and when I determined it was appropriate. In addition to methodological skills, competently dealing with the human emotions of others was critical in this research.

Although an asset overall, my nursing background also led to certain challenges around maintaining research boundaries. Speaking to me as if I was a colleague, the natural healer (Case One) not only wanted to discuss Isabel’s case, but also wanted to explore additional cases by using photocopies of other individuals’ personal health records. In response, I quickly paused the interview and reminded this participant about confidentiality because many of these records had identifying information. The natural healer also wanted to show me graphic photos of cancerous body parts that were treated with topical herbal creams. Because some were intimate photos of the natural healer being interviewed, I felt embarrassed and quickly redirected the discussion back to Isabel’s case. My experience resonated with the study by Dickson-Swift et al. (2007), who suggest that acknowledging one’s own vulnerability and discomforts is vital when researching sensitive topics. I sought the support of my research committee to reflect on this incident.

Another methodological consideration of this study was the challenge to recruit participants with cancer because of the initial gatekeeping of physicians at the study setting. As discussed in the methodology chapter, cases in this study were classified as radical or atypical case studies (Flyvberg, 2006; Baxter & Jack, 2008; Stake, 2000) in the sense that the care these patients were receiving may call attention to individuals’ discontentment with the system and difficult relationships with healthcare professionals. In addition to this concern, some clinic physicians were also apprehensive about burdening their patients because they felt that participation in this study with its many components (multiple interviews, etc.) was too demanding. My experience is consistent with Addition-Hall (2002)’s claim that healthcare staff are often protective of patients that they perceive to be the sickest and the most distressed. During a staff meeting at the clinic, I presented my experiences of the first two participants and also emphasised my sense that
individuals derived personal meaning from participation. This attempt to build the trust of the clinic staff was helpful. By acknowledging the circumstances of individuals’ lives and respecting their limitations, it appeared that the participants themselves were able to decide the extent of their own participation. My experience as a researcher corresponds to a study of terminally ill research subjects by Gysels et al. (2008) that suggested that palliative care patients and their family carers were capable of deciding to participate in interviews and negotiating how they wanted this process to unfold.

This study illustrates the usefulness of qualitative case study methodology in the study of advanced cancer and calls attention to the transferability of this approach to the study of other serious diseases. Having a variety of empirical data sources from different social actors led to a better understanding of the social dynamics that surround this phenomenon. This study also highlighted the methodological value of examining radical or atypical case studies (Flyvberg, 2006; Baxter & Jack, 2008; Stake, 2000). Cases collected in this study were radical in the sense that they had either caused clinical challenges or were idealized by the healthcare team, involved often non-conventional treatment practices, and generated certain tensions for participants. Because they involved social effects that were not immediately obvious to an outside viewer and activated deeper mechanisms in the study phenomenon (Flyvberg, 2011), the radical cases examined in this study revealed a rich understanding of how knowledge impacts the power relations between patients and healthcare providers that extends beyond the confines of the actual cases (Baxter & Jack, 2008).

Moreover, this study illuminates the need for researchers to be sensitive to the limitations of snowball sampling when compiling cases. Once again, the enactment of certain subjectivities geared to achieve life-extension generated challenges when developing certain cases. Some participants were hesitant to refer any healthcare providers to their case because of a concern with destabilizing their existing social arrangements that supported their access to cancer treatment. Appearing almost afraid or angry that I wanted to speak to other clinicians involved in their care, these participants were very careful not to depict their oncologist in a negative light during their interviews, but rather expressed their concerns with their care through speaking about the system in general. As it was difficult to recruit each of the influential social actors around all seven participants with cancer, compiling rich cases was sometimes challenging. Yet,
for other participants, I was able to compose a case that had a variety of participants and documents. A strong point of this work, the complexity of certain cases paralleled the complexity of the research topic.

49 Implications for Clinical Practice

This study emphasized the difficult social and relational roles of family members in the search for life-extension. While simultaneously having to prepare for the eventuality of their loved one becoming incapacitated or dying, family members in this study were vital allies in the search for life-extension through engaging in information seeking practices, supporting loved ones in their decisions, assertively advocating for information in the clinical encounter, and participating in self-healing ventures. Like previous research in this area (Oh et al., 2004; Burns et. al, 2003), family members in this study often favoured the use of potentially life-extending biomedical therapies late in the cancer trajectory. In a key example from this study, when a particular patient became increasingly ill and unable to self-advocate, family took ownership over the search for life-extension by frantically pursuing experimental radiotherapy. Although the participant had seemingly come to terms with the eventuality of her death, the family endured much unease and suffering because they were unable to let go. This particular example calls attention to the importance of supporting family members through this process as a part of clinical practice.

Another key practice implication is that both individual clinicians and the overall cancer system were unable to acknowledge the type of suffering endured by the emergent form of life. This may be understandable, as conceptualizing this issue in its complexity is difficult work and also requires a deep understanding of the social effects of these subjectivities. Considering the robustness and assertiveness with which participants pushed for treatment, their vulnerabilities and fragilities may have been concealed to healthcare providers. Confirming previous research about the biomedical priorities of oncologists (DelVecchio Good, 1990), the study findings suggest that the clinical consultation in oncology is sometimes focused on the exchange of biomedical data, as opposed to assisting patients and family members work through the suffering at the end of life. Despite the prevalence of “patient centred care” as a broad approach to valuing the personhood of individuals (Edgman-Levitan, Daley, & Delbanco, 1993; Oates, Weston, &
and the increased emphasis on promoting quality of life in palliative care (Peerson, 1995; Pastrana et al., 2008), the suffering of individuals often remained unaddressed. Even though most participants reported supportive relationships with their palliative care physicians and oncology nurses, these bonds did not seem to mitigate the overwhelming sense of suffering endured by participants.

Interestingly, both healthcare professionals and patients made their own contributions to the constrained nature of these meetings. For instance, the proactive patient subject often viewed healthcare providers as curative resources to be both stockpiled and employed to one’s own ends, whereas the challenged clinician subject was troubled by patients’ assertive demands and sometimes interpersonal approach. By describing troubled forms of subjectivity, this study suggests that the search for life-extension is not without certain costs. Rather than simply disappearing or dissipating, the conflicts generated by the demand for biomedical treatment continually surfaced and resurfaced in the research process. This study points to the need for healthcare professionals to help patients and family members ameliorate the unique kind of suffering that is generated by the continued attempts to extend life.

The findings of this study revitalize the seminal work by Kleinman (1988) on suffering and illness. Kleinman suggests that using a medical or scientific perspective often does not mitigate the problem of suffering in contemporary biomedicine, which often positions the pain of individuals as extrinsic to the human condition. Rather, healthcare professionals are often orientated to treat suffering as a problem of “mechanical breakdown requiring a technical fix” (Kleinman, p. 28). As discussed earlier, DelVecchio Good (1990) described how oncologists often equated good care with offering additional curative technologies. A poignant example, one oncologist from this study described his or her perception that it was sometimes easier to simply prescribe additional rounds of chemotherapy at his or her computer at a distance, rather than have an uncomfortable in-person discussion with a patient and their family about relinquishing treatment. In place of a meaningful moral or existential response to suffering, biomedicine occasionally tends to focus on manipulating disease related factors (Kleinman). This study highlights the significant consequences of exclusively offering further biomedical treatment as an antidote to the suffering of advanced cancer. Participants in this study often described the constraints of this approach, as they desperately moved from treatment to treatment in order to
keep themselves alive. When biomedical interventions are presented as the only therapeutic option, patients’ subjectivities are shaped by these discourses in order to maximize their therapeutic benefits.

Using postmodern deconstruction as a framework, Zimmermann and Wennberg (2008) problematized some of the conceptual dichotomies that limit the integration of palliative care into curative medical practice. In particular, Zimmermann and Wennberg critique the notion that a definitive choice needs to be made between a peaceful death and a “painful heroic fight to the end” (p. 256). Moreover, they call attention to the opposition between accepting death (sometimes in order to receive palliative services) and the effort to resist death through technological intervention. As individuals receiving invasive therapies or those who are not ready to accept their death may benefit the most from palliative care, these dichotomies may not only be a conceptual oversimplification, but also may be detrimental to care (Zimmermann & Wennberg). At the same time, patients in this study were already been followed by palliative care, yet this conflict of the self persisted. In this study, I do not dispute the value of palliative care, but rather use empirical data to shed new light on the complicated social effects of this type of care within wider discourses that often resist death. If anything, this study described how individuals with advanced cancer had mostly positive relationships with palliative care physicians, valued their ongoing emotional support, and recognized their medical expertise in alleviating serious physical symptoms.

At the same time, the suffering of patients and family members did not seem easily resolvable by one overarching approach to their care, including the provision of palliative care intended to support those with severe disease to die a “good death” (McNamara, 2004). By calling attention to the social costs of this issue, this study offered a new perspective on the growing literature on the integration of palliative care into oncological medicine that was introduced in the literature review (Smith et al., 2012; Hauser et al., 2011; Gaertner, et al., 2011; Bruera & Hui, 2010). Although the previous research has noted that the integration of these two types of healthcare results in improved length of survival and quality of life for patients (Temel et al., 2010; Meyers et al., 2011; Bakitas et al., 2009), this study suggested that individuals were often in a state of conflict as a result of simultaneously generating their own curative possibilities, yet hesitantly preparing for death. In particular, this study shed new light on the highly cited study by Temel et
al. (2010) by suggesting that although an integrated approach is ultimately a productive shift in terms of improving the lives of the terminally ill, there are important but hidden social consequences of this approach to care.

In a recent clinician opinion statement, the American Society of Clinical Oncology (ASCO), a professional organization for oncology physicians, advocated for the uncoupling of palliative care from its historical association with the end of life care of individuals (Smith et al., 2012). Instead, the ASCO’s new definition recasts palliative care as specialized medical treatment that should provide seriously ill patients with relief from the symptoms, pain, and stress that is provided “at any stage in a serious illness, and can be provided together with curative treatment” (Smith et al., p. 881). Despite this move to expand palliative care beyond its original focus as care of the terminally ill, the perspectives of participant in this study suggest that this care may still be negatively associated with passively waiting for death, in contrast to more the active forms of subjectivity that were prized by participants.

Given the larger public debate about alleviating suffering for those with incurable disease and about the promotion personal control at the end of life (Boston et al., 2011; Karlsson et al., 2011; McNamara, 2004), addressing the suffering caused by searching for, and not just receiving, biomedical treatments needs to be addressed in oncology practice. Amplified by the controversial opening up the euthanasia debate in 2009 by the College of Physicians of Quebec (Assemblee Nationale Quebec, 2010), euthanasia is a high profile and divisive issue. Even though participants in this study did not mention euthanasia in their interviews, previous work by Karlsson et al. suggests that the possible legalization of euthanasia was perceived by some with advanced cancer as increasing patient control over one’s personal decisions about mortality and promoting individual autonomy for those who are suffering (Karlsson et al., 2011).

Although the search for life-extension and the move to allow self-determination at the end of life are different clinical matters, it is important to consider the interrelatedness of these two issues. Both topics highlight the importance of understanding the prolonged period of dying and the need for those with terminal illnesses to control death in one form or another. For those hesitant to permit euthanasia, there is a moral concern with allowing patients too much control over their dying and the insistence that biomedicine needs to retain a certain amount of authority in order to
safeguard individuals against making decisions against their best interests (Ferreira, 2007). The search for life-extension despite advanced cancer provokes the same concerns about the limits of personal control over the dying process: when is too much control over receiving invasive treatment too much, what are the limits, and does too much control over treatment without a sense of professional guidance lead to suffering? For example, the suffering subject characterized in this study described the challenges of wanting to feel like one was in control over death, yet concurrently dealing with the realization that the biomedical destiny of advanced cancer could not really be controlled. Both the search for life-extension and the euthanasia debate may be related to not having a sympathetic location to place contemporary suffering at the end of life. The alleviation of intolerable suffering of the dying is sometimes used to morally justify the role of euthanasia as a humane practice (Ferreira). In a similar way, fully participating in the search for further treatment may be a way advanced cancer patients and families deal with the suffering of the end of life, although not without several social and individual costs. In an important way, both the search for life-extension and euthanasia ultimately call attention to the contemporary politicization of the dying process in the 21st century.

Another clinical implication of this study is the development of a richer understanding of how power/knowledge relations have transitioned in the current mediation of treatment and the social effects of this shift in the clinical environment. Patients’ at times strong reaction to biomedicine as a conscious gatekeeper of treatment should prompt healthcare professionals to fully acknowledge the power they yield when dealing with the intensity of individuals who are desperate to locate a cure. By developing a more complete understanding of the wider social discourses that support the confidence of individuals to self-advocate, the findings of this study might encourage clinicians to better empathize with the more aggressive interpersonal style of certain patients and family members.

This study thus points to the clinical value of suspending the judgement of patients and family members who reflect certain subjectivities that may be problematic to the cancer care system. The findings of this study describe how the shaping of the self through the search for life-extension is ultimately an aesthetical and creative endeavour (Foucault, 2001). Participants became a particular kind of aesthetical self that embodied certain stylistic characteristics associated with subverting the biological destiny of advanced cancer (Foucault, 1998). Thought
this may be, this study suggests that the healthcare system is not necessarily open to the emergence of certain aesthetics of the self. Rather, certain non-traditional subjectivities were viewed as problematic and at times disruptive to the work of biomedicine. By developing a better understanding of the unique bind of patients, this study may elicit a stronger sense of empathy for those immersed in this search. For example, patients are called upon to be informed of their disease status and actively participate in the planning of their treatment, yet are reprimanded when they exercise the cancer expert, proactive, and mistrusting subjectivities. Given the desperate circumstances of patients and families, moderating these more assertive forms of subjectivities may be a difficult endeavour.

Finally, this study draws attention to the depth and complexity of clinical skills needed to support individuals with incurable disease who are actively searching for life-extension. Part of the contemporary experience of having cancer, patients and family members must contend with an almost overwhelming number of therapeutic possibilities related to their treatment: locate a clinical drug trial, get a second or third opinion from a different oncologist, try alternative therapies, attempt a new treatment in another country, and so forth. In order to assist patients navigate these different options and eventually help patients mediate the closeness of death, healthcare professionals will need to have in-depth and sensitive conversations about the end of life alongside the provision of these potentially life-extending treatment.

50 Implications for Nursing

While only two oncology clinical nurses were recruited as part of the cases, as opposed to five physicians, the viewpoints of participants with cancer and their family suggest that the role of nursing seemed to be obscured in the search for life-extension. Only three participants could remember the names of specific nurses in order to refer them to be recruited. Other participants claimed that although clinic nurses were pleasant and generally helpful as an overall group, they often played more of an administrative role (i.e. organizing appointments) or acted almost as an assistant (i.e. collecting health information) to their oncologist, who ultimately made the decisions about treatment. Nursing work on the outpatient clinics at the study institution was organized in such a way that patients and family members dealt with several different nurses
from day to day. The professional role of nurses in the setting of this study seems to be less prominent than the study by McCullough et al. (2010). In McCullough et al.’s study, nurses described being present with patients in treatment consultations and then later being asked by patients for clarification and their expert views about treatment. Nurses recruited to my study did not describe this more relational facet of practice, but rather focused on the exchange of disease knowledge in order to meet patients’ informational demands. Composed of nurses that work in inpatient units, the community, and ambulatory clinics, the diversity of sample interviewed by McCullough et al. may have led to dissimilar findings. Nurses from both my study and McCullough et al., however, tended to defer the responsibilities of clarifying the goals of treatment to physicians.

As evidenced by the inability of participants to recognize the professional role of nurses, this study suggests that one of the unforeseen effects of the search for life-extension is that clinic nurses tend to have less social prestige. Oncologists, who have the authority, knowledge, and ability to prescribe potentially life-extending therapies, played a more prominent role in this phenomenon from the perspectives of participants. Though this may be, the findings of this study suggest that the privilege of biomedicine in the context of advanced cancer is inherently fragile because it exists as a proxy of a cure for cancer that in fact may not exist. As discussed in the methodological chapter, the workflow of nursing in an outpatient ambulatory clinic might constrain the abilities to nurses to engage in relational practices with patients, thus impeding their influence in the negotiation of treatment. The study findings call attention to the limited role of oncology clinic nursing in assisting patients to examine the reasons they might accept treatment or explore other possibilities. Rather than simply engage in the exchange of personal health data and the scheduling of biomedical tests, I call for an expanded and relational nursing practice in the clinic that is focused on helping patients mediate the suffering that is generated by simultaneously being close to death, having progressive disease, and pushing for life-extension. This more multifaceted nursing practice might encourage oncology nurses to realize a more complete level of nursing practice that is in keeping with professional expectation to be well versed in the biomedical, but also appreciate the circumstances of the patient, employ therapeutic relationships, and understand the current complexities of dying.
51 Implications for Education in the Health Sciences

The results of this study also have important implications for the education of health professionals from multiple disciplines. The knowledge generated by this work can be used to educate care providers in oncology so they can be better prepared for the complexity of their role in caring for individuals at the end of life. Rather than simply blame physicians or other healthcare professionals, this study called attention to the nuanced pressures clinicians experienced in practice as part of a wider social network. Providers had to compassionately assist patients to mediate the aggressive nature of disease, simultaneously manage their occasionally aggressive demands for treatment, and yet gently guide them towards death. Providers also had to arbitrate the knowledge claims of patients as apparent cancer experts, yet articulate their own professional knowledge. Constrained by the current limits of oncological medicine, providers could not meet patient demands to eliminate aggressive forms of cancer and significantly extend life. Educating new oncology clinicians about this wider matrix of interconnected relationships and subjectivities between clinicians, patients, and family members may help to develop a better appreciation for the sensitivity and tact required in practice.

52 Implications to Policy

In June 2012 Prime Minister Stephen Harper issued a one-time three million dollar federal investment in palliative services for Canadians and a new policy document entitled, The Way Forward: Moving Toward Community-Integrated Palliative Care in Canada (Health Canada, 2012). This policy focused on healthcare measures that encouraged the integrated delivery of palliative care in a multitude of care settings, such as hospitals, long-term care facilities, and the primary sites of data collection for this study, outpatient clinics, and the home. Although providing higher quality patient care was a stated goal, improving the economic efficiency of palliative care is a prominent focus of this policy. In particular, the document claims that people tend to use more healthcare resources (and incur more costs) at the end of life than any other period in their lives (Health Canada). The policy also suggests that greater costs are often incurred because of unwanted or ineffective interventions at the end of life. A subsequent federal policy document that outlines a national framework (The Way Forward National Framework) for
Palliative care in Canada describes how these expensive procedures often do not prolong life and sometimes cause suffering or even hasten death (Canadian Hospice Palliative Care Association [CHPCA], 2013). Although this policy document outlines the negative implications of these forms of treatments, the palliative care framework then goes on to describe the centrality of patient autonomy, promoting personal control for the dying, and aligning the intention of biomedical treatment with a patient’s individual goals (CHPCA, 2013).

By articulating the nuances of how palliative care is taken up by terminally ill patients who seek curative forms of treatment, the study findings contribute a new perspective that can deepen a national framework that seeks to better integrate a palliative approach across a wider spectrum of healthcare. Future policy endeavours need to consider an understanding of how the discourse of palliative care concomitantly exists with other competing and culturally endorsed discourses that support the active struggle to resist death (for example, discourses of self-care and self-healing). Moreover, participants, including physicians and nurses, did not discuss the associations between expensive biomedical therapies at the end of life and the financial implications of these practices to the broader healthcare system. In fact, patients and family members often articulated a sense of entitlement and their right to be offered a myriad of technological therapeutic options, as opposed to reporting the resource costs to the system as part of their rationale. In fact, participants often reframed their search for further treatment by calling attending to the contribution they perceived they were making to biomedical science through being subjects of experimental medicine. Future policies around palliative care will have to address the complicated discrepancies between the “effective” use of healthcare resources articulated by the system and that of the actual users of the system.

Palliative care policies that claim to endorse the promotion of control and autonomy might need to be sensitive to contemporary social expectations of those who are dying to shape themselves as robust, invulnerable, and active entrepreneurs in the search for treatment. Intended to promote life-extension, these particular aesthetical values may be antithetical to how certain individuals with cancer think about palliative care in their fight to resist death. Future palliative care policies may need to be more sensitive to the escalating tensions of what it means to die of a chronic disease at this point in history and the increasingly widespread availability of tools that make one believe death can be regulated through everyday health practices.
In addition to palliative care policies, the study findings have important policy implications in the field of self-care in chronic diseases (also called patient self-management), which is quickly becoming a high profile approach in the Canadian healthcare system. In 2007, the Ontario Ministry of Health and Long-Term Care ([MOHLTC], 2007) published a framework entitled *Preventing and Managing Chronic Disease* that describes policy measures to support chronically ill clients to be “self-mangers of their conditions” (p. 14). Similar discipline-specific policies, such as the nursing best practice guideline, *Strategies to Support Self Management in Chronic Conditions* by the Registered Nurses Association of Ontario ([RNAO], 2010), exemplify the increasingly pervasive concern with self-management. The duties of patients who are responsible self-managers include partnering with the healthcare system, following recommended treatment protocols, and managing the impact of chronic conditions on one’s emotional life and functional ability (MOHLTC; RNAO). The provincial framework encouraged healthcare professionals to “take on the role of expert coaches” (MOHLTC, p. 14) by fulfilling their own facilitative role in supporting the capacity of patients to self-manage. These supportive duties include providing information and education about the disease, counselling, and supportive services to help patients learn to emotionally cope with their circumstances.

The findings of this study complicate how a self-management policy might be designed and implemented if the healthcare system aspires to improve the circumstances of those who assertively seek life-extension. As evidenced by the proactive, productive, and cancer expert subjectivities, the study findings lend intriguing knowledge of how individuals with advanced disease already employ their own practices of self-management around their cancer treatments that often operate outside of the level of a governmental policy. More research on this specific area is needed. As highlighted in this study, these practices of the self stem from within the cancer system, but also are constituted by broader social discourses about self-generating curative possibilities that lie outside the jurisdiction of biomedicine.

Future policies in self-management need to consider what individuals are already doing to self-manage their treatment and illness, particularly for those who are desperate to survive their disease. The process of care of the self was in part a productive practice for participants. The process of shaping the self to achieve life-extension encouraged individuals to mobilize the various personal skills, social networks, and curative resources at their disposal. Many patients
and family members reported a positive sense of hope, comfort, and ownership through taking up different self-healing practices such as positive thinking, becoming informed about non-biomedical treatment options, or changing everyday bodily practices. Whether these various techniques of the self can be harnessed by formalized self-management measures to improve the health conditions for those with advanced cancer remains an important area for future consideration.

On the other hand, harnessing the self-care practices of patients by healthcare institutions raises concerns about whether this move will duplicate disciplinary power/knowledge relations and encourage individuals to participate in their own governance. By marshalling the neoliberal concept of individual responsibility, care of the self practiced by patients that seek life-extension was found to incite governance of the self according to certain culturally endorsed ideas about success, morality, and taking on active subjectivities (Rimke, 2000). Participants that were immersed in the process of self-care were often rendered partially responsible for their own successes, as well as their own failures in treating a disease with a very poor prognostic outcome. By developing health policy that seeks to formalize or institutionalize certain practices of self-care, these practices will inevitably be reshaped or removed from their original meanings in individuals’ lives.

53 Directions for Future Research

Although this study provided a new understanding of how certain forms of subjectivity generated the possibilities for life-extension, further research is needed to investigate the numerous ways in which individuals actively self-manage other areas of living with advanced cancer. Future studies need to explore how individuals mediate the increasing chronicity of having advanced cancer, such as dealing with symptoms and managing the emotional effects of nearing death, that often originate outside the authority of biomedicine. New knowledge about this under-researched, but rising issue may assist the healthcare system to complement what patients and family members already do to manage their advanced disease.
The findings also draw attention to the clinical challenges faced by healthcare professionals when dealing with certain forms of assertive and “demanding” subjectivities. This study also highlighted the unexpected role of openly available electronic medical charts in increasing the confidence of individuals to advocate for themselves in the clinical encounter and to reshape their expectations for reasonable therapeutic action. Although a novel feature in the study setting, the unsupervised access to personal medical information has the potential to become a commonplace practice in health care institutions in the future (Jha et al., 2009). With the acceleration of information technologies employed in everyday life, even more sophisticated ways to access bio-scientific knowledge of one’s disease will likely emerge in the future. The open access to medical charts and how it might transform the negotiation of end of life treatments will form an important area of research in the next few years.

Upcoming studies need to examine the relational, educational, and arbitrational work that health professionals already conduct in the everyday milieu of clinical practice to address the requests of individuals who are desperate to extend their survival. This study initiated a discussion of this particular issue that should be furthered in later studies. Since only two nurses were interviewed in this study, future studies also need to examine the specific roles that oncology, palliative, or clinical trials nursing play in mediating this search. If nursing is relegated to play only a minor role, which the study findings hinted at, future consideration is needed to conceptualize the structural or social reasons nursing tends to be obscured. Despite the multifaceted role that oncology nurses play and the perception from participants that nurses were highly supportive in general, patients and family members seemed to greatly emphasize the role of oncologists in the search for life-extension.

One of the considerations in employing a poststructuralist approach is that it allows the researcher a vehicle to examine a set of discourses and subjectivities within a particular historical time and place. Among the many contextual locations that impacted the research findings, this study occurred in a cancer hospital that was tertiary, academically based, ran scientific trials, was well resourced, and was located in a large North American city. As it would likely generate a different set of discursive practices and alternative ways individuals might shape to the self in order to access treatment, it would be intriguing to duplicate this present study in a different cancer care institution that may not have the same resources. Employing a similar
methodological and theoretical approach, upcoming studies could also focus on the drive to receive biomedical interventions in other chronic but equally severe diseases, such as end-stage renal or long-term cardiovascular disease. This type of scholarly endeavour may point to certain discursive commonalities related to dying of disease in the 21st century, but may alternatively point to the particularities of how the culturally endorsed “war on cancer” impacts the pursuit for survival.

Finally, future studies need to consider how social location might impact the abilities of individuals to access cancer treatments in ways that both the healthcare system might view as problematic. As mentioned in the discussion chapter, this study illuminated how advanced cancer patients with a higher level of socioeconomic status may be more confident and employ more sophisticated social strategies in order to access healthcare resources at the end of life. Individuals who endure certain social inequalities, for example those with lower income, less educated, or have decreased status, may not be able to as readily express their preferences or expectations in comparison to those who are more affluent (Dunlop et al.; Asada & Kephart, 2007). A specialized form of care, oncological medicine may be particularly challenging for patients and family members to understand, let alone research and present disease knowledge to physicians. Future studies on individuals with lower social status that seek further treatment, or are unable to seek life-extension, may uncover altogether different forms of subjectivities.

54 Seeking Life-Extension from Advanced Cancer in the 21st Century

In light of the present study and the wider implications outlined in this final chapter, I conclude this thesis by drawing some overall assertions about the search for life-extension in advanced cancer in the 21st century. Considering the different understandings generated by this study, I also venture about what advanced cancer, death and dying, and the ongoing quest to locate potentially life-extending biomedical treatment (and beyond) might resemble in the future in the interest of orientating further directions of thought.
As this thesis draws to a close, it becomes worthwhile to reiterate the emergent types of discourses and active subjectivities described in this study and speculate on the types of discourses and subjectivities yet to come. Bolstered by the emerging discourses of self-care and self-healing, this contemporary form of life is positioned away from a passive recipient of biomedicine towards a proactive entrepreneur who takes control over their individual health (Moore, 2004; Rose, 2007), despite having advanced cancer, which Western culture often constructs as the quintessential deadly disease (Sontag, 1989). As the likely duration of having very progressive disease increases and more and more individuals in the future will go through multiple rounds of remission and reoccurrence (CCS, 2013; ACS, 2013), the line between who is dying and who is not dying from cancer will be further blurred. What constitutes “advanced” disease, as a biomedical category, might not fit with how cancer patients define themselves, their social value, or their right to access certain forms of curative therapies. Yet, people will still continue to die of this disease. The increasingly chronicity of what it means to die from cancer will of course lead to new discourses and forms of subjectivities for both patients and health care providers that have not yet been created, but will likely be the focus of new public dialogues.

As the ethical responsibilities of what it means to be a cancer patient are increasingly drawn and redrawn, more individuals with the necessary social conditions to do so may adopt these more assertive types of subjectivities in the future. How far upcoming cancer patients will go in becoming “their own doctors” (Eva, Case Four, Interview One) might look radically different from the descriptions in this study. Although this may be ultimately a productive move in the interest of promoting additional curative possibilities for individuals outside the realm of biomedicine, this trend generated certain tensions in oncology practice that will likely propagate in the years to come. The findings suggest that the current healthcare system was not necessarily open to the emergence of a certain kind of aesthetical self that embodied characteristics associated with accessing therapy. If the system hopes to mediate conflicts for those who are dying, it must adopt a better sense of inclusivity to these emergent forms of the self. How this will be accomplished in the future is open to debate, although this study did initiate an empirical and theoretical understanding of this contentious issue.

The search for life-extension in advanced cancer will likely be placed within an increasingly widespread economic framework that calls for the austere use of health care resources,
particularly at the end of life. The new Canadian framework on palliative care already cautions against the over use of certain expensive technological procedures that cause suffering and often do not prolong life (CHPCA, 2013). Whether the specific biomedical interventions that participants were receiving in this study were “futile” or not in terms of a medical sense was not the focus of the analysis. Yet, these types of policies envision a clinical world where the healthcare system actively discourage or flat out refuse patients’ requests for additional rounds of cancer treatment without consideration for the intricate social contexts that surround this issue. This prospect leads to an intriguing question for the future: In a system that will likely devote fewer technological resources to the dying, how might healthcare institutions mediate the intense drive of individuals to extend their life? The restricted distribution of certain forms of biomedical treatment in advanced cancer is one foreseeable direction.

The findings of this study also point to another possible direction, where patients with advanced cancer will have even wider access to cancer treatment options, similar to a menu at a restaurant. The future will witness the accelerated development of new oncological treatments, such as personalized and genomic medicine, that will be coupled with the more sophisticated dissemination of clinical research to lay audiences through the mass media. With patients’ increasing expectations for a cure, the commercialization of health, and emphasis on providing the terminally ill with as much control over the dying process as possible, individuals with a certain level of social privilege may push for new ways to access treatment in the future (for example, paying for services or seeking options outside of the country). Individuals with different social locations (for instance, low income or less educated) may be excluded from these practices, which may perpetuate existing inequalities. Leading to new forms of discourse and subjectivity, conflicts, and practices of resistance, this increased demand for treatment may coexist with institutional boundaries regarding who can access biomedical therapies that may be more restrictive than today. The only certainty is that death from advanced cancer, and the move to resist death, will be shaped and reshaped by these new developments. New types of figures that will be constituted by discourses and subjectivities yet to come will eventually replace the form of life characterized by this study.
References


Tattersall, M., Gattellari, M., Voigt, K., & Butow, P. (2002). When the treatment goal is not cure: are patients informed adequately? *Supportive Care Cancer, 10*, 314-321.


# Appendices

Table 2: The Composition of Cases

<table>
<thead>
<tr>
<th>Cases</th>
<th>Case Details</th>
<th>List of Data Sources</th>
</tr>
</thead>
</table>
| Case Three: Todd | Factory Manager in a food-processing factory.  
College educated.  
Approximately mid 40’s.  
Married, Teenaged Children.  
Born in Canada.  
Metastatic prostate cancer.  
Receiving radiation therapy.  
Enrolled in experimental chemotherapy drug trial. | Joint interview with wife Nancy.  
Follow up interview with Todd.  
Interview with Medical Oncologist.  
Interview with Radiation Oncologist.  
Interview with Palliative Care Physician.  
Book: *The Healing Journey* by Dr. Alastair Cunningham.  
Book: *Life Lessons* by Dr. E Kubler-Ross and David Kessler.  
Book: *Anticancer: A New Way of Life* by Dr. David Servan-Schreiber.  
Pamphlets from the electronic chart system from cancer institution. |
|---|---|
| Case Four: Eva | Retired Business Consultant.  
University educated.  
Approximately early 70’s  
Divorced, No children.  
Born in Belgium.  
Metastatic breast cancer.  
Receiving chemotherapy. | Joint interview with sister Madga.  
Follow up interview with Eva.  
Interview with Registered Nurse from oncology clinic. |

| Previously received chemotherapy. | Website: “John Hopkins Medicine: Cancer Clinical Trials” (http://www.hopkinsmedicine.org/kimmel_cancer_center/research_clinical_trials/clinical_trials/)

| Husband seeking experimental radiation. | Website: “The University of Texas, MD Anderson Center”. (http://www.mdanderson.org/) |
Appendix A: Information Sheet for Physicians regarding Patient Characteristics

**Patient Inclusion Criteria**

Patients will be potentially eligible for this study if they meet all of the following inclusion criteria:

<table>
<thead>
<tr>
<th>Study Inclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Has advanced (stage 3 or 4), metastatic, and/or recurrent cancer of any type. Disease has a poor prognostic outcome.</td>
</tr>
<tr>
<td>2. Is receiving or has made a request to receive further medical treatment (e.g. third or fourth line chemotherapy, clinical trials).</td>
</tr>
<tr>
<td>3. Appears relatively stable in their overall condition. For instance, the individual lives at home and is able to ambulate.</td>
</tr>
<tr>
<td>4. Appears cognitively stable and able to provide informed consent.</td>
</tr>
<tr>
<td>5. Able to speak and read English.</td>
</tr>
</tbody>
</table>

Patients who **fulfil all of the inclusion criteria will be approached** for the study.

**Patient Characteristics**

This study seeks to find patients from a variety of demographic backgrounds. Efforts will be made to recruit patients that have a variety of these characteristics.

<table>
<thead>
<tr>
<th>Patient Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Age group (over 65 and under 65)</td>
</tr>
<tr>
<td>• Gender</td>
</tr>
<tr>
<td>• Cultural background</td>
</tr>
<tr>
<td>• Religious background</td>
</tr>
<tr>
<td>• Family composition</td>
</tr>
<tr>
<td>• Educational level</td>
</tr>
<tr>
<td>• Type of cancer</td>
</tr>
<tr>
<td>• Length of illness</td>
</tr>
<tr>
<td>• Number of treatment attempts</td>
</tr>
<tr>
<td>• Invasiveness of cancer</td>
</tr>
</tbody>
</table>
Appendix B: Study Introduction Script to be used by Physicians

There is a PhD student from the Faculty of Nursing at the University of Toronto who is conducting research about what influences people with advanced cancer to continue to receive medical treatment. This study is about how people think about their disease and what makes them want to receive treatment of their cancer. If you agree to participate, you will be asked to do a one-hour interview, with the chance of a follow up interview, about your experiences making treatment choices. The interview will take place at a time of your choice and may take place at the hospital, at your home, or the researcher's office. The researcher may also ask your permission to speak to a family member, friend, or other caregiver. In addition, the researcher may come with you to appointments or meetings about your treatment. You will be given a gift card from Shopper’s Drug Mart for your time and be compensated for your transportation costs.

Can we give you an information package about the study? All of the questions that you will be asked in the interviews will be in the package as well as other information. Agreeing to get this package does not mean that you are going to be in the study. The research ethics boards at the University of Toronto and (Name of Cancer Hospital) have approved this study.

If the PhD student were on site, would you like to speak to him in person to explain the study in more detail? If not, would it be all right if he followed up with you in a couple of days to see if you have any questions.
Appendix C: Email to Patients regarding Study Introduction and Invitation to Participate

My name is Shan Mohammed, a PhD candidate from the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto. I am conducting a research project, under the supervision of the primary investigator Dr. (Name of Researcher) at (Name of Cancer Hospital), about what influences people with advanced cancer to continue to receive medical treatment. This study is about how people think about their disease and what makes them want to receive treatment of their cancer.

If you agree to participate, you will be asked to do a one-hour interview, with the chance of a follow up interview, about your experiences making treatment choices. The interview will take place at a time of your choice and may take place at the hospital, at your home, or the researcher’s office. If needed, there is a chance of a follow up interview. The researcher may also ask your permission to speak to a family member, friend, or other caregiver. In addition, the researcher may come with you to appointments or meetings about your treatment. You will be given a “thank you” gift card from Shopper’s Drug Mart and have some of your transportation costs covered.

Can I give you an information package about the study? All of the questions that you will be asked in the interviews will be in the package as well as other information. Agreeing to get this package does not mean that you are going to be in the study. The research ethics boards at the University of Toronto and (Name of Cancer Hospital) Centre have approved this study. Please let me know your address so I can forward the package to you or whether you want me to email it to you.

Thank you.
Appendix D: Email to Family regarding Study Introduction and Invitation to Participate

My name is Shan Mohammed, a PhD candidate from the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto. I am conducting a research project, under the supervision of the primary investigator Dr. (Name of Researcher) at (Name of Cancer Hospital), about what influences people with advanced cancer to continue to receive medical treatment. This study is about how people think about their disease and what makes them want to receive treatment of their cancer. As part of this study, I will be interviewing individuals who may influence patient’s treatment decisions. I recently interviewed one of your family members/friends (name of patient) and he/she suggested that I contact you.

If you agree to participate, you will be asked to do a one-hour interview, with the chance of a follow up interview, about your role in influencing (name of patient)’s treatment choices, and experiences making treatment choices. The interview will take place at a time of your choice and may take place at the hospital, at your home, or the researcher’s office. If needed, there is a chance of a follow up interview. In addition, the researcher might observe appointments or meetings with you and (name of patient) related to their medical treatment in the clinic or elsewhere. You will be given a “thank you” gift card from Shopper’s Drug Mart and have some of your transportation costs covered.

Can I give you an information package about the study? All of the questions that you will be asked in the interviews will be in the package as well as other information. Agreeing to get this package does not mean that you are going to be in the study. The research ethics boards at the University of Toronto and (Name of Cancer Hospital), Centre have approved this study. Please let me know your address so I can forward the package to you or whether you want me to email it to you.

Thank you.
Appendix E: Email to Healthcare Workers regarding Study Introduction and Invitation to Participate

My name is Shan Mohammed, a PhD candidate from the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto. I am conducting a research project, under the supervision of the primary investigator Dr. (Name of Researcher) at (Name of Cancer Hospital), about what influences people with advanced cancer to continue to receive medical treatment. This study about how individuals choose to receive treatment of their disease, their motivations, and about how they think about their disease and medical treatment. As part of this study, I will be interviewing individuals who may influence patient’s treatment decisions, including healthcare workers. I recently interviewed an individual who you interacted with in clinical practice, (name of patient), and he/she suggested that I contact you.

In this study, you will be asked to do a one hour interview about your clinical experiences interacting with patients with advanced cancer who continue to receive further medical treatment and your role in influencing treatment choices. The interview will take place at a time of your convenience and will occur at the hospital or the office of the researcher. In addition, the researcher might observe appointments or meetings with the particular patient related to medical treatment in the clinic or elsewhere. You will be compensated for your time with a gift card from Chapters Indigo and reimbursed some of your transportation costs.

Can I provide you an information package about the study? All of the questions that you will be asked in the interviews will be in the package as well as other information. Agreeing to get this package does not mean that you are going to be in the study. The research ethics boards at the University of Toronto and (Name of Cancer Hospital) have approved this study. Please let me know your address so I can forward the package to you or whether you want me to email an electronic copy to you.

Thank you.
Appendix F: Palliative Performance Scale

<table>
<thead>
<tr>
<th>PPS Level</th>
<th>Ambulation</th>
<th>Activity &amp; Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>50%</td>
<td>Full</td>
<td>Normal activity &amp; work</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>50%</td>
<td>Full</td>
<td>Normal activity with Effort</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>70%</td>
<td>Reduced</td>
<td>Unable normal Job/Work</td>
<td>Full</td>
<td>Normal or reduced</td>
<td>Full</td>
</tr>
<tr>
<td>60%</td>
<td>Reduced</td>
<td>Unable heavy/labor work</td>
<td>Occasional assistance needed</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>50%</td>
<td>Mainly sit/Lie</td>
<td>Unable to do any work</td>
<td>Considerable assistance required</td>
<td>Normal or reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>40%</td>
<td>Many in Bed</td>
<td>Unable to do most activity</td>
<td>Mainly assistance</td>
<td>Normal or reduced</td>
<td>Full or Drowsy or Confusion</td>
</tr>
<tr>
<td>30%</td>
<td>Totally bed bound</td>
<td>Unable to do any activity</td>
<td>Total care</td>
<td>Normal or reduced</td>
<td>Full or Drowsy or Confusion</td>
</tr>
<tr>
<td>20%</td>
<td>Totally bed bound</td>
<td>Unable to do any activity</td>
<td>Total care</td>
<td>Minimally responsive</td>
<td>Full or Drowsy or Confusion</td>
</tr>
<tr>
<td>10%</td>
<td>Totally bed bound</td>
<td>Unable to do any activity</td>
<td>Total care</td>
<td>Minimal care only</td>
<td>Emergency or Cortical Coma</td>
</tr>
<tr>
<td>0%</td>
<td>Death</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Used with permission Victoria Hospice Society, 2006

Palliative Performance Scale Aug 25, 2003

(Victoria Hospice Society, 2006)
Appendix G: Short Orientation Memory Concentration Test

**SHORT ORIENTATION-MEMORY-CONCENTRATION TEST**

**Patient Name:**

**Kater Name:**

**Date:**

**Instruction**

Score 1 error for each incorrect response, to maximum for each item.

<table>
<thead>
<tr>
<th>No.</th>
<th>Question</th>
<th>Maximum error</th>
<th>Score x</th>
<th>Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>What year is it now?</td>
<td>1</td>
<td>____ x 4</td>
<td>=______</td>
</tr>
<tr>
<td>2.</td>
<td>What month is it now?</td>
<td>1</td>
<td>____ x 3</td>
<td>=______</td>
</tr>
<tr>
<td>3.</td>
<td>About what time is it? (within one hour)</td>
<td>1</td>
<td>____ x 3</td>
<td>=______</td>
</tr>
<tr>
<td>4.</td>
<td>Count backwards 21 to 1</td>
<td>2</td>
<td>____ x 2</td>
<td>=______</td>
</tr>
<tr>
<td>5.</td>
<td>Say the months in reverse order</td>
<td>2</td>
<td>____ x 2</td>
<td>=______</td>
</tr>
<tr>
<td>6.</td>
<td>Repeat the phrase just given</td>
<td>5</td>
<td>____ x 2</td>
<td>=______</td>
</tr>
</tbody>
</table>

*Total error score = ____/28*

Reference


Comment

A well-studied test, which is (so far) little used. It has been validated against neuropsychology, and was derived from the longer Blessed scale. Reliability not formally tested. The score correlates highly ($r = 0.52$) with the full scale and it was almost as sensitive as the longer test. Any error score of 0-6 is within normal limits.

Scoring is difficult as originally devised and as shown, and it is more easily understood if scored positively, subtracting from maximum for item for each error. This gives a 0-28 score with a higher being better, scores over 20 being 'normal', as shown below.

(Katzman et al., 1983)
Appendix H: Detailed Description of the Cases

Case One: Isabel

Isabel is a woman with metastatic breast cancer in her late thirties. She is Caucasian, born in Canada, married to her husband James, has one child, is university educated, and worked professionally with computers. She was receiving hormonal treatment for her cancer and was also taking various self-directed alternative therapies.

The interview occurred in a boardroom of the main cancer hospital. She was approximately 20 minutes late to the interview because she had to complete her blood work before the meeting. Isabel and husband were annoyed that they could not find the interview room and called me to meet them at the front information desk. Isabel seemed bubbly and happy to see me, but James seemed hesitant.

Isabel was wearing glasses, slacks, sandals, and a wildly patterned blue blouse. Her hair was pulled back into a ponytail. Her makeup was very colourful and eccentric. Both Isabel and James seemed hesitant to sign the consent form and meticulously read every page before signing the document.

During the interview, I felt that I had to ask very few questions. Despite her discussions of emotionally laden topics, such as cancer causing her infertility, she did not appear to be in distress. Sometimes she made eye contact with me, other times she stared at the audio recorder. James provided answers more as a supplement to Isabel’s responses. He wasn’t interested in discussing his own experiences or initiating his own stories. At times when Isabel was speaking, James appeared bored and sleepy, yawning and looking off into space. The interview lasted approximately an hour. They both agreed to a follow up interview, although James seemed hesitant.

I called Isabel to arrange a follow up interview and she informed me that she would prefer to be emailed a list of questions. Although the second interview was located in the same room, Isabel was again 20 minutes late. She was carrying a large Tupperware juice container full of a thick, green drink that looked like vegetable juice. I later learned that the juice was an enzymatic herbal therapy. She was also carrying her small laptop in a black shoulder bag. Isabel came by herself because James had to work. Before the interview, she plugged in her laptop and opened the document that I had emailed to her two days earlier. The document appeared to have fairly extensive notes below each questions and she often referred to the document during the interview. The interview lasted approximately one and a half hours. In this interview, she mentioned the financial challenges in paying for her alternative treatments, something she did not mention in the first interview. Before we left she said she would email me a list of resources that she compiled.

In the month that followed our last interview, Isabel sent me an extensively researched typed response to the interview questions that I sent to her. In the list, she referred me to several websites and books that were influential to her. I also interviewed Isabel’s unlicensed natural healer. In addition to this individual, I interviewed Isabel’s palliative care physician.
Case Two: Daniel

Daniel is a man with metastatic prostate cancer in his mid to late sixties. He is originally from Korea, married, and has adult children. He is university educated and is an insurance agent. He was enrolled in a chemotherapy drug trial at the time of the interview.

When I called Daniel he seemed very enthusiastic and was waiting for my telephone call. He suggested that we conduct the interview in a large public café. As the café was moderately busy and music was playing overhead, I was concerned about hearing each other.

Daniel was wearing thick glasses with large black square frames, a blue chequered shirt, khaki pants, and was carrying a beat up looking yellow grocery bag with various documents in them. He had some limitations in his ability to ambulate related to his disease process, but did not need an assistive device.

Daniel appeared comfortable during the interview. He took pauses to get more coffee and also to use the bathroom. The interview took about an hour and a half.

When I asked Daniel about other individuals I could possibly speak to about this issue, his mood and tone changed slightly. He said I could contact the palliative care team, but that the clinical trial doctors and nurses were often really busy. He seemed hesitant about me contacting certain individuals for purposes of the study. He mentioned that he would speak to his wife about participation, but warned me that she might get upset during the interview. In the end, she was not interested. When discussing the support group he accessed, he mentioned that I might want to contact the director of the group. The director did not respond to my emails.

After the interview, he seemed pleased and said I could email him if I needed assistance. Although I declined his offered me a ride to the subway in his car.

Daniel mentioned a patient run organization for individuals with cancer that offers a variety of services such as peer support groups and information sessions. I incorporated their website and other links into the case. This organization offers information sessions in the evenings for prostate cancer patients and their families. About three days after our interview, Daniel emailed me an e-flyer advertising a public information session about the psychological impacts of making treatment decisions. Although he informed me that he would not be attending, I thought that it would be useful to observe the meeting. Daniel informed me that he would only be interested in attending information sessions about new clinical trials. The speaker was a psychologist from a large downtown cancer hospital. Much of the discourse and patient directed questions were medically focused. He openly discussed how patients should question their oncologist and get second opinions about their prognosis. In addition to observing this session, I interviewed Daniel’s palliative care physician in his office at the cancer hospital.
Case Three: Todd

Todd is a man with metastatic prostate cancer in his early forties. He is Caucasian, born in Canada, married to his wife Nancy, and had several children. He is college educated and works as a factory manager in a food processing plant. At the time of his first interview he was receiving radiation treatment and contemplating whether to enrol in a clinical trial. He and Nancy eventually decided to enrol and we discussed this in our second interview.

When I called him on the telephone Todd seemed open, friendly, and eager to participate. He suggested I conduct the interview in his home in a smaller town. When we met in person, Todd was dressed casually in jeans, plaid shirt, and jean jacket. He was had a Prostate cancer support pin pinned to his jacket.

The décor of Todd’s home was inviting and seemed recently renovated. He invited me to sit in his large well-lit kitchen while his wife was getting ready. While we were waiting I commented about the box of new ceramic tiles in the corner of their kitchen. He informed me that he has been renovating his home over the last few weeks in order to leave something of financial value for his wife and kids.

His wife Nancy was equally friendly. She was also in her early forties and was dressed casually in a dark sweat suit. I sat at the kitchen table with Todd and Nancy sat across from me. We all shared coffee during the interview. One of their children came down the stairs and left the house. Nancy asked if I also wanted to interview her as well and I informed her I could only adults could participate in the study.

I conducted the interview with both of them together, but occasionally I received the impression that Nancy wanted to have a separate interview alone. She openly shared her anxieties about Todd’s illness and seemed that she had other things she wanted to share. At times, the interview was awkward because they seemed emotionally distraught. It was scattered with uncomfortable silences and they became teary at times. Todd kept on saying, “Ask us anything; we can handle it”. The interview lasted about an hour and a half. Todd said that he was meeting some friends from work later.

We arranged a follow-up interview via email. Todd had shared in his email that he was thinking about enrolling in a clinical trial and wanted to share his experiences during the second interview. For our second interview, Todd seemed more physically robust than our first meeting. He was wearing a sweatshirt and pyjama pants. He his feet were bare and seemed somewhat swollen. Although it was about 11:00 am, he had recently awakened from a nap. He was at home alone.

The second interview went smoother than the first because he seemed more at ease. For example, he felt comfortable enough to wear his pyjamas and use swear words in his responses. The interview lasted about an hour. He told me that he had often had to play an active role to manage the household and his children while his wife was at work. While I was leaving he was making a list of grocery items that he needed to buy later that day.
During the first interview, Todd and Nancy mentioned several self-help and positive thinking books that helped direct their thinking about cancer treatments. I incorporated several of these data sources into the case. Both two of his oncologists agreed to participate in the study after I introduced the study via email. I interviewed one of Todd’s oncologists in his office. The interview was very challenging to conduct. This oncologist’s answers were to the point and it was very difficult to get a deeper exploration of the subject matter. It was challenging to extend the interview to 30 minutes. Conducted in a public meeting room, the interview with the other oncologist yielded richer a discussion and lasted approximately 45 minutes.

Case Four: Eva

Eva was a woman in her early seventies who had metastatic breast cancer. She was Caucasian, divorced, had no children, university educated, and worked as a business consultant. She was very close to her sister Madga, who she described as her primary caregiver. She was originally from Belgium and often spoke about her Western European heritage. As she was previously diagnosed with breast cancer several years ago, her current diagnosis was her second. Her cancer did not respond to previous rounds of treatment, and was currently receiving chemotherapy.

I interviewed Eva and Madga in my office at the university. Eva appeared friendly, attractive, well put together, and affluent. She was wearing jeans, a blazer, a blouse, and pearls. The interview went very smoothly. Eva and Magda were both very animated and loud during the interview. Magda, however, was more reserved than Eva and seemed to play more of a supportive role. During the interview, Eva conveyed how “in control” she was of her cancer, treatment, and life overall. When the interview was over, I forget to give both her and her sister their gift card. Eva rushed back to my office to make sure that she had them and commented about how “sharp” she was. Eva agreed to a follow-up interview after the holidays.

I called Eva to arrange a second interview. She said that her medications were recently changed and that she had not been feeling well over the past few weeks. She requested that I interview her at her apartment in an up-scale section of the city. When Eva greeted me at the door, she appeared more subdued than our first meeting, but still friendly and welcoming. She looked physically well, but more tired than our first meeting. She was dressed much more casually in a tracksuit and house slippers. Eva mentioned that Madga was not feeling well and could not make it to this interview.

Her apartment was elaborately decorated. Although it appeared comfortable and relatively upscale, there was an “old fashioned” quality about how it was decorated. She had jazz music playing lightly in the background. We sat down on the sofa together and had a cup of tea. The interview went well and similar to the first interview, she took the lead with her answers.

Eva’s case was distinctive in that she did not mention any documents that were influential in how she understood her cancer treatment. I also interviewed her nurse from the medical oncology clinic.
Case Five: Achmed

Achmed is a man with metastatic multiple myeloma, a type of cancer of the lymphatic system. He has a long history of receiving chemotherapy, transplantation, and a rare experimental anti-myeloma drug. He is approximately in his late-fifties, originally from Iran, married to his wife Fatima, and has adult aged children. He is university educated with a graduate degree and works in a scientific field.

Achmed’s referring physician described him as articulate and a favourite patient. On the telephone, Achmed seemed very eager to participate. We agreed to conduct the interview at his home located in a small town. Achmed’s house was large and well appointed. His wife, Fatima greeted me at the door. She was friendly, appeared in her early fifties, and was attractively dressed. Achmed was waiting for me on the patio set in the backyard, where the interview was conducted. Achmed came outside to greet me. He was wearing glasses, grey slacks, and a long sleeve grey plaid shirt. Achmed, Fatima, and myself shared tea during the interview.

Achmed seemed very engaged to tell his story, particularly around the medical aspects of his cancer. He brought a binder with colour charts that he had prepared himself to the interview. These charts graphed his essential lab values of his ongoing treatment. The interview lasted about two hours, although it seemed that he had more to share. We had a follow up interview on the telephone about a month later. That interview lasted approximately 45 minutes and covered similar content to the first interview.

In addition to the interview data, Achmed emailed me newsletters from various myeloma organizations and an article about a famous hockey player (Mario Lemieux) who had a similar type of cancer. I also interviewed an oncology clinic nurse who both Achmed and Fatima mentioned that was influential in their cancer treatment.

Case Six: Krishna

Krishna is a man with metastatic multiple leukemia. He is currently enrolled in a clinical trial that he feels is unsuccessfully treating his cancer. He previously received chemotherapy to slow his metastases. He is approximately in his mid-sixties, originally from Nepal, is a practicing Hindu, married, and has adult children. He is university educated and owns a business.

I first introduced the study to Krishna on the telephone. For our first meeting he invited me to sit with him while he was waiting for his clinic appointment. If we had time, he agreed to conduct an interview. I scheduled a meeting room for later in the afternoon. We met in the lobby of the cancer hospital to sign the consent, which he did without any concerns. Krishna was wearing a plaid shirt, grey slacks, and sandals. He had some difficulties ambulating. My first impression was that he seemed grouchy and not that happy to see me. He was somewhat bossy in his approach with me and suggested that I follow him from appointment to appointment around the clinic.
His first appointment was to see his oncologist. It was a busy day with almost every seat full. Krishna mentioned that he had other appointments after this one and asked if I could begin the tape-recording the interview in the waiting room. He seemed irritated when I expressed concerns about confidentiality, but continued on to discuss his treatment and disease.

Krishna mentioned that when he comes to the clinic, he sticks to himself and does not speak to other patients. He says that he does not want to hear about anyone’s negative feeling that could bring him down and demotivate him. He talked about his motivations for being on multiple lines of chemotherapy and for enrolling in a clinical trial. Krishna said that he does his own research on drugs and treatment. His principle approach is to remain positive and also not to burden anyone. Krishna mentioned that he didn’t like alternative therapies and thinks that they are a “joke.” Rather, he claimed that he puts his faith in clinical trials. He said that he knew he was going to die, but that he still wanted to continue on in his current approach. We agreed to meet two weeks after our first meeting for a formal interview.

Krishna was half an hour late to our scheduled interview in a meeting room at the cancer institution. As I only had the room until noon, the interview seemed rushed. Krishna seemed angry and agitated during the interview; he would not make eye contact and seemed irritated. With only had ten minutes remaining, I suggested the option of a follow up interview. He angrily snapped at me and said I had to be very selective about my remaining questions. His answers were rather short and “to the point”. At times, my questions seemed to annoy him. Interestingly, he did not want me to speak to anyone about his case. In an overt way, he expressed his unwillingness for me to speak to his nurses, physicians, and his family. There was a sense that he wanted to retain a sense of control and dictate how the interview process unfolded. The interview ended because the next meeting began at noon. Despite his annoyance with me, he said that we could find a place to sit and talk some more.

We did find a place in a relatively secluded area to sit and talk. After about 20 minutes, Krishna mentioned that we could go down to the chemotherapy day unit in the basement. Again, he mentioned that he wanted to “finish” with me today and suggested that we pause so I could compose additional questions. As we got off the elevator, Krishna ran into a fellow patient that he knew from before. Krishna’s demeanour changed when encountering him. He seemed very happy to see his man and greeted him in a very warm manner. Krishna called me over to meet him. The man asked if I was Krishna’s son. Krishna introduced me as “his friend”. I left them to finish their conversation. When I sat down Krishna gruffly mentioned that he was trying to get me another participant and that I had just walked away.

Since he was about an hour before getting his chemotherapy, Krishna invited me for tea in the cafeteria. He said that as a “young man”, I could wait in line for the tea while he got a seat. He also insisted that he pay for his own drink. He seemed to relax somewhat during our tea together and asked started ask me about my personal life. He also opened up about the strain his cancer posed on his family and how he wished he could return to Nepal one more time before his death. It was challenging to end the tea. I often ended the encounter after he mentioned that if I had things to do that I could leave. Despite his hostility to me, he mentioned that I could call him on the phone if I needed any follow up information.
Case Seven: Krystal

Krystal is a woman with advanced prostate cancer who was diagnosed approximately a few months before our interview. She previously received chemotherapy that was unsuccessful at stopping her cancer. Her husband Mark was actively seeking experimental radiation treatment that was only available in the United States. Krystal was Caucasian, born in Canada, approximately in her mid-sixties, and has adult children. She is university educated and is a part-time sales clerk.

When I spoke to Krystal on the telephone, she was willing to participate, but had very direct questions. She wanted to know about my background, how long participation would take, and what the information would be used for. However, she seemed to soften her tone by the end of the interview.

Krystal’s home was in an affluent location in a large urban area. When she answered the door, she immediately apologized because she was not feeling well. Although I encouraged her to reschedule, she wanted to do the interview that day. Krystal was dressed casually with a casual white top and pyjama like pants. We sat in her sitting room during the interview.

The consent process was fairly straightforward. She very quickly read the consent and she did not want to keep her copy. During the first part of the interview, she seemed somewhat standoffish and only offered very short responses. She would then stare at me with very wide eyes and wait for me to ask her the next question. It was not until the second half of interview until she seemed to soften her response to me.

The interview with Krystal proceeded well, although once again she seemed somewhat guarded in her answers. She seemed to be suffering emotionally and at times I found it difficult to probe deeper with her. In particular, when she seemed distressed when she discussed her family and how they often encouraged her to look for treatment. The interview lasted about 45 minutes.

I asked if I could interview Mark about how he researches her treatments. He seemed to be the main driving force in her search for treatment. Before his interview started, she warned me to please “tread lightly” because he gets very upset when asked to speak about her disease. When I interviewed Mark he appeared calm, but there was an undercurrent of distress that often bubbled up to the surface. I wanted to keep his interview short (about twenty minutes).

Mark mentioned several websites that he consulted to research experimental radiation treatment. In addition, I interviewed Krystal’s palliative care physician in the boardroom of the cancer hospital.
Appendix I: Interview Guide for Patients

1. Tell me a little about your life before you were diagnosed. (Probes: What did you do for work? What was your family life and/or friendships like? What was most important to you in your life?)

2. When you were first diagnosed with cancer, what was that like?

3. What choices about your disease and/or treatment have you made up to this point?

4. Describe what kind of treatments or care you are currently receiving. (Probes: Where are you getting treatment? How often are you getting this treatment? Which healthcare providers are involved and what are their roles?)

5. What motivates you to choose your current cancer treatment? (Probe: How do you approach your life and/or disease? Tell me about symbol, image, slogan, or object that you brought in and what it means to you.)

6. Walk me through how you make choices about your treatment and disease?

7. Where do you get information about cancer and your treatment from?

8. Who do you talk to when you make choices about your disease and treatment? (Probe: May I speak to some of these individuals? Can we list the names of some of these individuals?).

9. How do you compare what you received in your treatment to what you would have liked to have?

10. If you could things differently in your life and/or disease, what would it be and why?
Appendix J: Interview Guide for Healthcare Providers

1. Tell me about your education and previous work experiences.

2. What made you choose oncology/palliative care as a speciality?

3. Tell me about the history of the patient in question and how it came to be that they received further treatment? (Probe: Or can you discuss another clinical example of a cancer patient who received further medical treatment in advanced disease?)

4. Either for this patient or patients in general, what factors do you feel promote continued treatment? (Probe: For example, how do factors related to the healthcare system, diagnosis, prognosis, and/or disclosure to patients and families influence this issue?)

5. What sources of information (for example, educational materials, guidelines, or protocols) inform your thoughts about this practice?

6. Either for this patient or patients in general, what are the implications or benefits of this kind of treatment?

7. Is there a difference between you and other healthcare workers in how you think about this issue? Is there a difference between you and other members of the healthcare team? (Probe: What are the similarities between you and other team members?)

8. How does this affect your work with this patient or patients in general? (Probe: How does this practice impact your relationships with patients, family caregivers, and/or other healthcare professionals?)
Appendix K: Interview Guide for Family and Informal Caregivers

1. Tell me about your relationship with your family member/friend before he or she had cancer? (Probes: Did you live together? How much time did you spend together?)

2. When your family member/friend was first diagnosed, what was that like for you?

3. Who currently cares for the person and what do they do? (Probe: What is your role in their care? What is your role in their choices about their disease and treatment?)

4. What choices have you made about the treatment of your family member/friend’s cancer up to this point?

5. Describe what kind of treatments or care your family member/friend is currently receiving. (Probes: Where are they getting treatment? How often are they getting this treatment? Which healthcare providers are involved and what are their roles?)

6. What motivates you to choose the current cancer treatment for your family member/friend? (Probe: How do you approach your family member/friend’s disease? Tell me about symbol, image, slogan, or object that you brought in and what it means to you.)

7. Walk me through how you make choices about your treatment and disease?

8. Where do you get information about cancer and treatment? (Probe: Who do you talk to when you make choices about your disease and treatment?)

9. How do you compare what treatments your family member/friend received to what you want them to have had?
Appendix L: Recruitment of Personal Artifacts for Patients and Family and Informal Caregivers

In order to help us talk about your experiences of cancer and what influences your choices around treatment, it would be helpful if you brought any of the following to the interview:

- A symbol that is important to you (for example, a flower, a logo, a religious symbol).
- An image that is important to you (for example, a landscape, a photo, a poster, an ad, a painting).
- A slogan that is important to you (for example a prayer, lyrics of music, a sentence, a phrase, a motto).
- A physical object that is important to you (for example clothing, jewellery, an assistive device like a cane).
- A document that is important to you (for example, a book, a magazine, a medical report).

During the interview, we may discuss the symbol, image, slogan, object, or document that you brought in, what it means to you and how it might influence your choices about treatment. This part of the study is optional.
Appendix M: Research Ethics Board Approval

PROTOCOL REFERENCE # 26114

March 3, 2011

Dr. Elizabeth Peter
Lawrence S. Bloomberg Faculty of Nursing
University of Toronto
155 College St.
Toronto, ON M5T 1P8

Mr. Shan Mohammed
Lawrence S. Bloomberg Faculty of Nursing
University of Toronto
155 College St.
Toronto, ON M5T 1P8

Dear Dr. Peter and Mr. Mohammed:

Re: Your research protocol entitled, “A Foucauldian examination of patient subjectivity: A case study of patients with advanced cancer receiving further medical treatment”

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<th>ETHICS APPROVAL</th>
<th>Original Approval Date: March 3, 2011</th>
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<td>Expiry Date: March 2, 2012</td>
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<td>Continuing Review Level: 2</td>
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We are writing to advise you that the Health Sciences Research Ethics Board has granted approval to the above-named research study, for a period of one year. Ongoing projects must be renewed prior to the expiry date.

All your most recently submitted documents have been approved for use in this study.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible.

Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your study. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry, as per federal and international policies.

If your research has funding attached, please contact the relevant Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your project.

Yours sincerely,

Daniel Gyewu
Research Ethics Board Manager- Health Sciences
Appendix N: Informed Consent Form of Patients

CONSENT TO PARTICIPATE IN A RESEARCH STUDY


Principal Investigator: (Name of Researcher)

Study Contact: Shan Darrel Mohammed, RN, MN, PhD Candidate

Lawrence S. Bloomberg Faculty of Nursing, University of Toronto

155 College Street West, Toronto, Ontario M5T 1P8

shan.mohammed@utoronto.ca

Telephone: 1-416-818-6904

Sponsor: Social Science and Humanities Research Council of Canada

Informed Consent

- You are being asked to consider participating in a research study. A research study is a way of gathering information to answer a question that is not well understood.
- The form explains the purpose of this research study, provides information about the study procedures, possible risks and benefits, and the rights of participants.
- Please read this form carefully and ask any question you may have. You may take as much time as you wish to decide whether or not to participate. Feel free to discuss it with your friends, family, healthcare provider, or anyone else.
- Please ask the study staff or one of the investigators to clarify anything you do not understand or would like to know more about.
- Make sure all your questions are answered to your satisfaction before deciding whether to participate in this research study.

Introduction

- You are being asked to consider participating in this study because you have advanced cancer and your choices to seek out or continue to receive additional medical treatment for your disease.
- The investigators are doing this study to understand how people think about their disease, what makes them want to receive treatment of their cancer, and what influences people with advanced cancer to continue to receive medical treatment.
- There is not much known about this topic from the viewpoint of patients, their family, their friends, and other caregivers. Also, there is not much known about the influence of
what people read and hear about, their relationships, and their own thoughts on additional medical treatment.

- This study may help healthcare providers develop ways to support future patients and families/friends as they make choices about their cancer treatment.

**Why is this Study being done?**

- The investigators think that patient’s choices for medical treatment is influenced by their relationships, what information they are exposed to, and how they understand their disease.
- This research is supposed to demonstrate how relationships with others affect the choices that patients make, look at the information people are accessing, and study how individuals understand their disease.
- This will accomplished through a case study. A case study is a way of gathering information by using more than one way to collect data about a case. In this case study, investigators will interview individuals, observe certain interactions, and examine what individuals are reading or viewing to inform their treatment choices.
- The patient and their treatment choices are the main focus of each of the cases.

**What will happen during this Study?**

- I will be interviewing patients in this study.
- During the interview you will be asked to discuss: (1) your past disease experiences, (2) influences on your current treatment choices, and (3) what keeps you going in your current treatment.
- You also will be asked to bring in a symbol, image, slogan, physical object, and/or document that are important to you. You can bring one of any item or none at all to the interview. The investigators will discuss this item(s) in the interview, what it means to you, and how it might influence your treatment choices.
- The investigators will also be interviewing your family members and/or friends, and healthcare providers.
- To locate family members or friends and healthcare providers, the investigators will be asking you in the interview to name people that influence how you make treatment choices. For example, you might name your spouse, children, friend, doctor, nurse, personal support worker, or naturopath.
- You also will be asked permission by the researchers to contact these people. If you agree, the investigators will be contacting these individuals to invite them to consider participating in this research.
- In addition to the interview, investigators may accompany you to appointments, events, and/or meetings that are related to how you make treatment choices about cancer. For example, investigators might accompany you to a clinic appointment, information session about disease, a visit with your naturopath, or a walk in the park.

**How many people will take part in this study?**

- This study will involve four to six cases.
- It is anticipated that about 20 to 30 individuals will participate in this study.
• The length of this study for participants is a single interview that will take about one hour. You have the option of having a second follow up interview that also will take about an hour.

• If you choose to have an investigator observe your appointments or meetings, the length of this observation will vary but will be a maximum of three hours. If you choose, investigators can observe a maximum of three events with you.

• The entire study is expected to take about one year to complete and the results should be known in about one and a half years.

**What are the responsibilities of study participants?**

**Eligibility**

• You are not eligible for this study if you are receiving medical treatment for cancer for the first time or are not able to speak English.

• To participate, you must be well enough to take part in the interview and understand the consent process.

• To assess your eligibility, we will administer two quick tests: (1) the Palliative Performance Scale, that determines if you are well enough to participate, and (2) the Short Orientation Memory Test, that determines if you have the mental ability to participate.

• Depending on the results of the two tests, there is a chance that you will not be eligible to participate in the study.

**Time Commitment/Number of Visits**

• The total time commitment for participation varies from about one hour (one interview) to about 10 hours (spread out over a few interviews and observations).

• The total number of contacts with investigators varies from about one contact to about five contacts.

• The interview will take about one hour. If you feel tired or upset during the interview, we can stop and try again later or another day. You have the choice of a second follow up interview if you find one hour is not enough time.

• Observations will take about one hour to a maximum of about three hours.

• The first interview will occur at a time and date that you choose. It may take place in your home, the office of the investigators at the University of Toronto, or at (Name of Cancer Hospital). The second follow up interview, if needed, may take place at the same location or on the telephone.

• Observations will occur at a time, date, and an event that you choose.

**During the Interview/Observation**

• Your interview will be tape recorded to help the investigators look at what you said more closely. It is expected that all interviews for this study will be taped recorded; however, you have the right to have parts of your interview not recorded.

• You will not be asked to identify your name, the hospital, or any other identifying information during the interview. You have the option of adopting a pseudonym (i.e. fake name) during the interview.
• You may choose to provide the names of family members or friends and healthcare providers in order for the investigators to invite them to consider participating. In this instance, we will not tape record their names or contact information.
• The interview tapes will not be labelled with your name or any other identifying information. Tapes will be erased following transcription.
• Observations will not be taped or video recorded. Rather, the investigator will make notes about what he or she observes following the end of the event.
• During observations of meetings or appointments, the investigator will not participate in the situation. For example, the investigator will not interrupt or ask questions about the situation.

Stopping Participation
• Participation in this study is fully voluntary and will not affect your care at the clinic.
• You may refuse to participate in this study without any negative effects.
• If you do agree to participate, you may decline to answer any question or decline to participate in any parts of the study. For example, you may choose to participate in the interview, but choose not to have the investigator observe you.
• You may withdraw from this study at any time, including stopping the interview or observation at any point. You will still be eligible for financial compensation if you withdraw at any point.
• If the presence of the investigator during the observations is bothering you, please let him or her know and he or she will leave immediately.
• You can withdraw what you said and what investigators observed in the study up to one month after you finish.

What are the risks or harms of participating in this study?
• There are no medical risks to you from participating in this study. However, when talking about your experiences with disease there is a possibility that you could feel uncomfortable or upset.
• You may refuse to answer questions or stop the interview at any time if you experience discomfort.
• To minimize this risk, a registered nurse who has six years of experience caring for patients with cancer will conduct the interviews and observations.
• If you become really upset, you will be referred to your physician and/or primary nurse and the investigators will follow up with you to see how you are doing.

What are the benefits of participating in this study?
• You may or may not benefit from directly participating in this study.
• The interview may provide you a chance to talk openly and honestly about your experiences.
• Your participating may or may not help those with advanced cancer who are making treatment choices in the future.
• There are no medical benefits to you taking part in this study.
Can participation in this study end early?
• The investigators may decide to remove you from this study without your consent if you are unable or unwilling to follow the study procedures.
• If you are removed from this study, the investigators will discuss the reasons with you.
• You can also choose to end your participation at any time. If you withdraw voluntarily from the study, you are encouraged to contact Shan Mohammed, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, shan.mohammed@utoronto, Telephone:
• If you leave the study, the information that was collected before you left may still be used. No new information about you will be collected without your permission.

What are the costs of participating in this study?
• Participating in this study may result in added costs for such as parking or transportation.

Are study participants paid to participate in this study?
• If you decide to participate in this study and the research will take place outside your home, you will be reimbursed $20.00 for your travel costs such as parking or public transit.
• To compensate you for your participating, you will receive a $30.00 gift card from Shopper’s Drug Mart after finishing the study. If you choose to leave the study early, you will still receive the gift card.

Do the investigators have any conflicts of interest?
• There are no conflicts of interest to declare related to this study.

What are the rights of participants in a research study?
All participants in a research study have the following rights:

1. You have the right to have this form and all information concerning this study explained to you and if you wish translated into your preferred language.

2. Participating in this study is your choice (voluntary). You have the right to choose not to participate, or to stop participating in this study at any time without having to provide a reason. If you choose to withdraw, your choice will not have any effect on your current or future medical treatment or health care. Should you choose to withdraw from the study you are encouraged to contact Shan Mohammed, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, shan.mohammed@utoronto, Telephone:

3. You have the right to receive all significant information that could help you make a decision about participating in this study. You also have the right to ask questions about this study and your rights as a research participant, and to have them answered to your satisfaction, before you make any decision. You also have the right to ask questions and to receive answers throughout this study. If you have any questions about this study you may contact the person in charge of this study, (Name of Researcher).
If you have questions about your rights as a research participant or any ethical issues related to this study that you wish to discuss with someone not directly involved with the study, you may call (Name of Cancer Hospital).

4. You have the right to have any information about you and your health that is collected, used or disclosed for this research study to be handled in a confidential manner.

If you decide to participate in this study, the investigator(s) and study staff will look at your personal health information and collect only the information they need for this study. “Personal health information” is health information about you that could identify you because it includes information such as your:

- Name
- Address
- Telephone number
- New and existing medical records, or
- The types results of various tests and procedures

The following people may come to the hospital to look at your personal health information to check that the information collected for the study is correct and to make sure the study followed the required laws and guidelines:

- Representatives of the (Name of Cancer Hospital), who oversee the ethical conduct of research studies at (Name of Cancer Hospital).

Access to your personal health information will take place under the supervision of the Principal Investigator.

In addition, any study data about you that is sent outside of the hospital will have a code and will not contain your name or address, or any information that directly identifies you. “Study data” is information about you that is collected for the research study, but that does not directly identify you.

Study data that is sent outside of the hospital will be used for the research purposes explained in this consent form.

The investigator(s), study staff and the other people listed above will keep the information they see or receive about you confidential, to the extent permitted by applicable laws. Even though the risk of identifying you from the study data is very small, it can never be completely eliminated.

When the results of this study are published, your identity will not be disclosed.

The Principal Investigator will keep any personal information about you in a secure and confidential location for seven years and then destroyed as required by (Name of Cancer Hospital) policy.
5. By signing this consent form, you do not give up any of your legal rights.

6. You have the right to receive a copy of this signed and dated informed consent form before participating in this study.

7. You have the right to be told about any new information that might reasonably affect your willingness to continue to participate in this study as soon as the information becomes available to the study staff.

8. You have the right to access, review and request changes to your personal health information.

9. You have the right to be informed of the results of this study once the entire study is complete. If you would like to be informed of the results of this study, please provide your name, address and telephone number to Shan Mohammed, Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, shan.mohammed@utoronto, Telephone:
DOCUMENTATION OF INFORMED CONSENT

Full Study Title: A Foucauldian examination of patient subjectivity: A case study of patient with advanced cancer receiving further medical treatment.

Name of Participant: _______________________________________

Participant

By signing this form, I confirm that:

• This research study has been fully explained to me and all of my questions answered to my satisfaction
• I understand the requirements of participating in this research study
• I have been informed of the risks and benefits, if any, of participating in this research study
• I have been informed of any alternatives to participating in this research study
• I have been informed of the rights of research participants
• I have read each page of this form
• I authorize access to my personal information, and research study data as explained in this form
• I have agreed to participate in this study or agree to allow the person I am responsible for to participate in this study

__________________________________________________________
Name of participant (print)                           Signature                           Date

Person obtaining consent

By signing this form, I confirm that:

• This study and its purpose has been explained to the participant named above
• All questions asked by the participant have been answered
• I will give a copy of this signed and dated document to the participant
ASSISTANCE DECLARATION □ (check here if not applicable)

The participant/substitute decision-maker was assisted during the consent process as follows:

☒ The consent form was read to the participant/substitute decision-maker, and the person signing below attests that the study was accurately explained to, and apparently understood by, the participant/substitute decision-maker.

☒ The person signing below acted as a translator for the participant/substitute decision-maker during the consent process. He/she attests that they have accurately translated the information for the participant/substitute decision-maker, and believe that that participant/substitute decision-maker has understood the information translated.