The clinical practice of embodied care: 
A phenomenological examination of physician-family interactions in oncological treatment

by

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Abstract

The purpose of this study was to explore family caregivers’ interactions with physicians as they accompanied their loved ones through cancer treatment. Increasingly, family caregivers have assumed caregiving duties that were once the domain of medical professionals. It is natural, therefore, that family caregivers should seek guidance from the attending physicians in carrying out the multiple and complex responsibilities of cancer caregiving. Yet these interactions serve not just to communicate information and guide care-giving actions. They can be seen to be integral to the quality of care provided by virtue of the manner in which the physicians engage with the family members as a matter of course and in the most telling circumstances of cancer treatment. My aim has been to document how and to what extent the interactions between physicians and caregivers are conducive to a compassionately extended framework of cancer care.

This hermeneutic phenomenological study is based on in-depth interviews with five caregivers. Five major themes emerged from the participants’ stories: seeking presence–finding absence; feeling bereft–turning away; turning towards–gestures of presence; to give; and words from the family–a practice of embodied care. The interview data comprising this study has been composed as an extended narrative of how gestures, intonations, facial expressions and stances can be perceived as being crucial to helping family members feel integral to their loved ones’ cancer treatment. They spoke of the power of small, everyday, gestures to create a space of presence. While the participants also spoke of many neglects and indifferences, they also identified physicians who unceasingly gave of their time to be physically and emotionally available to family caregivers of their cancer patients. These physicians were seen to offer the gift of compassionate presence which sustained caregivers and physicians alike throughout the cancer journey.

This study holds recommendations for how the space of medical care can be more compassionately defined and where the suffering of the patient, the accompanying family, and the physician can be recognized. Suggestions for transformational healing practices for physicians, allied health professionals, and the family caregivers themselves are discussed.
Keywords: Lived experience; Family caregiver-physician interactions; cancer; compassion; Hermeneutic phenomenology
Dedication

To those who suffer and those who suffer with them
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Chapter 1.

Introduction

When the cancer came to us, it came in the form of a phone call as a distant voice. He says he is the oncologist. He tells me that my husband must be at the Bone Marrow Clinic the next day. He has been diagnosed with Acute Myeloid Leukemia. And so my husband and I, and our two adult children arrive at this place of illness. Dressed in his professional attire, a gestureless doctor introduces himself as the oncologist in charge. He takes us to a room filled with boxes and papers. He sits across from us, our seats placed uncomfortably far away from his desk. The physician explains in a matter of fact voice that the disease is cancer of the myeloid cells. He informs us there is a “disease trajectory” and that “initial treatment requires total hospitalization.” It is to begin the next day. “Induction,” he goes on to say, “is a 7 x 3 standard regimen of cytogenetic drugs.” These are words of a language I hardly comprehend. A cytogenetic analysis is necessary and has already been ordered. The “genetic analysis,” we are told, is also critical to determine whether post-remission therapy will be one of “consolidation,” or “one of salvage,” that is, “the administration of supporting drugs until death.” I feel a darkness already forming at the edges of my awareness. As the doctor continues his talk, I cannot stop wondering about my husband and my children. I try to listen to the medical terminology but my attention begins to drift away. I see the patients and their families who pass us in the halls. I wonder about their everyday life experiences at the leukemia ward. I wonder what they might tell me of their illness, their pain. I again hear the doctor’s voice as he reassumes his biomedical talk of leucocytes, lymphocytes, blasts, allogeneic stem cells, irradiated platelets and immune-phenotyping. Together with my husband and my children we sit and listen to the medical facts in this hospital office. Despite this frightening discourse, no one asks us how we are feeling or if we need anything, even if it is just some time alone.
Today I sit in silence in the ICU. Time seems frozen. Fear, powerlessness, and dread engulf me. The room is large, and in the centre my husband's body lies upon a hospital bed. His body, now hooked to machines, is desperately struggling to sustain each breath. Beside his broken body, there is nothing else but high-tech machinery in the room. When the physician arrives on his rounds he does not once look at me or at my husband. The physician’s head moves up and down, his gaze fixed on the numbers displayed on the computer screen. I sit there thinking about what is to come, whether my husband will come home, or if death will arrive too soon. The doctor enters this space but he does not offer a smile, a glance, a supporting touch, or any sense that he understands my vulnerability. Only an objectified gaze and a robotic stance meet me. The physician remains in the room momentarily as he chats with the nurse who gives him a number of printouts from the machines. My husband, his broken body lying on the bed fighting for every breath, is hardly noticed.

I glance through the windows to other rooms where other bodies lie sedated and ventilated, connected to machines. I watch as other family members sit and care for their ill loved ones. Is there a sensitive touch afforded to them, I wonder? Is there a voice speaking caringly to them? Is there a comforting connection? Instead, we sit passively, mutely, bearing witness to the dehumanizing aloneness inhabiting this hospital space. In the darkness, we family members stand by, hoping for hope. These memories haunt me and come back to life as my fingers hit the keyboard. They remain painful memories. Indeed, it is through these poignantly lived experiences that I question the physician and the family caregiver’s interactions as they occur in the day-to-day events of cancer treatment.

The current study developed in significant part through my lived experience as the spouse of a cancer patient. The motivation was the distance and detachment I felt from too many of the physicians I encountered throughout my husband’s cancer treatment. As a practitioner in a large metropolitan hospital I continue to observe such instances and moments of physician distance and detachment. Roter (2000) calls attention to the “increased depersonalization” of medical practices (p. 19) in the current bio-medical hospital environment. Potter and McKinley (2005, p. 465) call it the “non-existent relationship” between those confronting illnesses and the physicians providing treatment. The Committee
on Behavioural and Social Sciences in Medical School Curricula (Cuff & Vanselow, 2004) echo these same concerns. In fact, this health advisory committee has called for the urgent reform of medical school curricula so as to embrace practices that may restore the personhood of the sufferers and thus bring the patient and their family back into the medical encounter. Given that family members are increasingly taking on the role of caregiver in the cancer trajectory (Deshields & Applebaum, 2015; Ekstedt, Stenberg, Olsson, & Ruland, 2014; Northouse, 2012), enhanced relations between physicians and family caregivers has become paramount.

How, then, is the interaction between the patient’s family and the physician(s) experienced by the family member? How is an extended relationality of care established in the highly technical space of the modern hospital? What are the foreground and background considerations that inform the physician’s orientation to the family members who daily accompany the cancer patient? How is the medical encounter lived by the patient’s family? In attempting to understand the desired relationality involving physicians and family members, the guiding question for the present study becomes: How is the physician-family interaction best understood by family members accompanying a loved one through oncological treatment?

Zaner (2015), a world renowned medical ethicist and phenomenologist, posits that the clinical encounter is about a space where real human beings—the patient and the family members who accompany them—meet and interact. It is this clinical encounter and interaction that is at the heart of medicine and medical ethics. In this space of illness, the patient and family often confront a lifeworld of illness where time, space, and relationships are suddenly altered. An unrecognizable lifeworld unfolds where the most basic aspects of daily life are often suddenly interrupted and disrupted. Health, once taken for granted, becomes uncertain. Hopes and dreams of a nearby future are suddenly placed on hold. The threat of death becomes a constant companion for both patient and family (Gordon, 1990; Pusa, Persson, & Sundin, 2012). In this disrupted lifeworld, as Frank (1995) notes, “destinations and maps I had once used to navigate before were no longer useful” (p. 1). A fragmentary lifeworld engulfs the patient and family caregiver(s) who must still attempt to struggle on living through a catastrophic illness (Zaner, 1990). In this crucial time of upheaval
vital contact with the physician tasked with their loved one’s care is sought to navigate the course of the illness (Zaner, 2015).

What Zaner (1990, 2000, 2015) appears to suggest is that a disconnection exists between the vital contact that is sought out by patients and families, and the contact they receive from physicians. For patients and their families, the current biomedical reality of hospital care is one that largely focuses on fixing disease, while overlooking the despair, the challenges, and the richly textured lifeworld of the family caregivers. Disease is viewed primarily in a “medical way” that fundamentally reduces the illness to the biochemistry of enzymes, genes, and molecules. Under such a biological conceptualization, the disease and not the persons afflicted by the illness constitutes the real object of the biomedical gaze and thus of medical practice. Yet what might be needed for cure is not necessarily what might be needed for healing (Zaner, 2000).

What is of concern to patients and their family caregivers is the lifeworld of illness: that is, their existential concerns, their emotional afflictions, their values, historicity, and the lived constraints of coping with cancer. The patient’s concerns, as well as those of their family carers, their struggles, desires, uncertainties, fears, and hopes are often dismissed by a worldview of medicine that regards these as subjective and without practical value. More often than not, how the illness is lived fades from view in the clinical encounter: Real, unique, and concrete illness narratives are replaced by the encoding of “objective” scientific abstractions that are sanctioned as valid and reliable. The lifeworld of illness becomes decontextualized and devoid of personhood (Zaner, 2000).

The present study offers a starting point to a much larger project which is to find a phenomenological opening for reconfiguring the relationality of patient care that involves physicians and the patients’ family caregivers. My aim is to identify these family carers’ needs using their own experiential reports. In so doing, I address current concerns that are increasingly being voiced about the medical practices of the modern scientific hospital that, for many scholars, have eroded the physician-patient relationship (Youngson, 2012). Focusing solely on a reductionist model of biomedicine has created distance and detachment in the
crucial relationships between those who are ill, those who heal, and those who stand alongside their loved ones.

A central tenet of this dissertation is that relationality is critical to the healing experience. Unique illness narratives unfold within the context of medical communications and relations of care that most often follow biomedical prescripts. Thus, in the medical encounter, tension may arise between the biomedical training lived by medical professionals and the expectations of the patients and families they are treating. The knowledge gained from this study also holds important implications for curriculum reform in Canadian medical schools, informing future pedagogical practices that may create a collaborative trust between doctors, patients and patients’ families.

**Statement of the problem**

This study explores the interactions between families and physicians during cancer care from the perspective of family caregivers. Such a focus has been largely ignored by empirical researchers (Bevans & Sternberg, 2012; Burkhalter & Bromberg, 2003; Northouse, 2012). How the face-to-face interaction between family caregivers and physicians is lived and understood by these family caregivers is of great importance. Understanding their concerns regarding physician responsiveness has important implications for those facing catastrophic diseases such as cancer. How family carers navigate the cancer trajectory has important implications for patient health outcomes (Bevans & Sternberg, 2012; Epner & Baile, 2014; Northouse, 2012).

A growing number of scholars, including physicians, ethicists, and medical educators, now maintain that understanding doctor-family caregiver interactions is fundamental to effective oncological treatment, especially where a relationship based on trust may be crucial to overall health outcomes of the patient, the family and the physicians involved in the cancer trajectory (Epner & Baile, 2014; Mitnick, Leffler, & Hood, 2010). According to Northouse, a crucial concept within cancer care is “interdependence” (2012, p. 500). Cancer patients and their family member(s) providing care “have an interdependent relationship. Each person
affects the other” (p. 500). Thus, argues Northouse, it is imperative that current biomedicine recognize the interdependence of cancer patients and the family caregivers accompanying them. Accordingly, in the 21st century, “Healthcare professionals need to treat the patient-caregiver dyad as the unit of care” (2012, p. 500). For Ozanne, Partridge, Moy, Ellis, and Sepucha (2009), a patient focused and family centred model of care, rather than the current disease centred approach, may facilitate decisions at the end-of-life.

Yet, an in depth literature review of two relevant electronic databases PsychINFO and MEDLINE revealed a total of five studies in this area of inquiry. Of those studies, only one explored family-physician interactions, however this study was within the context of palliative/end of life care, and not throughout treatment (Zeliadt et al., 2011). A second study by Waldrop et al. (2012) investigated the timing and nature of family-provider communication but did not examine family carer-physician interactions as lived by these family members. Thus to date the unique experience of family carers remains unexplored and unknown.

**Significance of the study**

Considerable research has focused on examining the physician-patient relation, yet Sandra Pennbrant (2013) asserts that it must now move beyond this dyadic interaction to a family-patient-physician tripartite engagement. Past studies have categorically demonstrated the various facets of family involvement in providing care (Pennbrant, 2013). Moreover, family-physician interactions are likely to occur during cancer treatment and diagnosis. Patients and their families have overwhelmingly expressed the importance of family presence in the medical encounter given the uncertainty and fear brought by a cancer diagnosis (Eggly et al., 2006; Pusa et al., 2012; Shin et al., 2013; Spichiger, 2009). In fact, researchers have shown that in close to 90% of the patient-physician interactions, a family member was present (Eggly et al., 2006; Shin et al., 2013).

An examination of family-physician relational dynamics in cancer treatment may have important implications for patient health outcomes (Adler & Page, 2008; Williams & Bakitas,
2012), for the family (Rabow, Houser, & Adams, 2004), for physicians (Baile, 2015; Bousquet, et al., 2015), for medical school curricula (Baile, 2015; Fallowfield & Jenkins, 2004), and for laying the foundation for an ethical patient-family centered care (Clay & Parsh, 2016; Henneman & Cardin, 2002; Igel, Barrow, & Lerner, 2016). Early research by Kahana and Kahana (2003) showed that family carers not only played a significant role in supporting the cancer patient emotionally and instrumentally but family caregivers also positively influenced their loved ones to engage with and adhere to treatment. Likewise, a significant body of research suggests that the family is a necessary resource in terms of care provision not only by the patient (Ferrel, Hanson, & Grant, 2013) but also by the health care system (Mitnick et al., 2010).

According to Pennbrant (2013), the new millennium has brought about a major shift in health care practices. Most notably, current health care practices have resulted in patients being discharged from the hospital much earlier than ever before. Many cancer treatments have been largely transferred to outpatient care from inpatient settings (Bevans & Sternberg, 2012; Deshields & Applebaum, 2015) with the responsibility of care shifted from the hospital to the family. Family presence has thus become essential within cancer care in recognition of the remarkable physical, emotional, financial, and instrumental contributions made to extended patient care (Girgis, Lambert, Johnson, Walker, & Currow, 2013). While the family is seen as a provider of care, little is known about how the family interacts with the physician (Pennbrant, 2013). Within the family-physician interaction is the physician readily available, sensitive, and empathically responsive? Emerging literature indicates that many physicians may feel uncomfortable when the family is present in the interaction with the patient (Firth, 2006; Meiers & Braeur, 2008). This unease in interactions with family carers creates an ethical dilemma given that how the family navigates the cancer journey has important implications for patient and family health outcomes (Pennbrant, 2013).

This study also relates to medical education and curricula within the realm of oncology (Epner & Baile, 2014). Physicians are immersed in, and are part of, a distinct culture with values, unspoken rules, norms, views, power positions and expectations (Pennbrant, 2013, p. 2). Such cultural values are hierarchical in nature and fuelled by a medical system
“characterized by power and dependency relationships between relatives and physicians; relationships that are asymmetrical” (p. 2). A distinctive feature of how the dynamics of power create the asymmetry of the relationship is the assumption of physicians that they have “power over both patients and relatives” (p. 3). Consequently, the level of family carer participation in the interaction, the conditions under which the family-physician interaction unfolds, how the information is disclosed, as well as the spoken and unspoken rules and norms of communication in the family-physician interactions, are physician-determined and not family need driven. “Medical education emphasizes biomedical knowledge at the expense of relational skills” (Epner & Baile, 2014, p. 1). The lasting result of such cultural power positioning is that “the dialogue, interaction and involvement all suffer, at the expense of both the relative [and] the physician” (Pennbrant, 2013, p. 10) and importantly, at the expense of the patient's healing (Zaner, 2000).

Yet, one may argue that, ethically, building sensitive interactions and new schemas of being with and being together in illness is also the business of medicine. Thus, addressing this relational topic has important implications for bioethical clinical practices (Zaner, 2015). Relational questions include the following: Does the patient’s family caregiver feel recognized by the medical community? Is the family carer and physician interaction experienced as a mutual connection of caring? Is it experienced as a power of turning toward each other and making contact? What are physicians’ ethical stances of listening to, and conveying acceptance, recognition, and acknowledgment of these family members?

Physician well-being is also connected to the strength and quality of the relations that are formed. Physicians can also be impacted when relations are of poor quality or antagonistic (Youngson, 2011). Power differentials fuel detachment and disconnection in the healing human encounter (Pennbrant, 2013) and may have a significant impact on oncologist burnout (Blanchard et al., 2010). Research suggests that the highest incidence of physician burnout occurs within cancer care (Eelen et al., 2014). In one research survey, the rate of burnout among oncologists in the United States was 61.5 % (Allegra, Hall & Yothers, 2005). Increasing empirical evidence shows that physician burnout is related to communicating bad news during diagnosis, treatment outcomes, and/or discussing hospice care with patients and the family.
(Blanchard et al., 2010; Shanafelt & Dyrbye, 2012). More recently, almost 50% of oncologists surveyed reported burnout stemming from delivering bad news (Shanafelt et al., 2014).

A growing body of knowledge has pointed out that physicians have significant difficulties in communicating bad news (Fallowfield & Jenkins, 2004; Friedrichesen & Milberg, 2006). The lack of medical education in terms of delivering bad news has also been highlighted (Epner & Baile, 2014; Orgel, McCarter, & Jacobs, 2010). Consequently, physician detachment may be a response to distress stemming from a lack of training in communicating bad news within already charged emotional interactions (Epner & Baile, 2014; Friedrichesen & Milberg, 2006). More importantly, physician burnout has led to “decreased effectiveness at work” (Shanafelt et al., 2014, p. 1) and thus to an increase in medical errors (Shanafelt et al., 2010). Detachment increases the risk of litigations when mistakes or medical errors do occur (Ambady et al., 2002; Epner & Baile, 2014). It is worth noting that depersonalization of relations may also lead to lower patient and family satisfaction with the attending physician(s) as well as lower treatment compliance (Shanafelt et al., 2014) which may impact the physician-family-patient relationship.

The above reasons underscore that a fuller examination of family-physician relational dynamics in cancer treatment is needed and, moreover, that uncovering how family-physician interactions are lived throughout the cancer journey has important implications for patient health outcomes, the well being of the family, and physician health. These implications extend to medical school curricula and, more generally speaking, lay the foundation for an ethical patient-family-centered-care.

**Choice of methodology**

I seek in this study to understand the experiences of family caregivers interacting with the attending physicians as they accompanied a loved one through cancer treatment. I am interested in uncovering the dynamics of family caregiver and physician interactions and the meanings that these family carers ascribe to these relational dynamics. I follow the advice of van Manen (1990) who says that the research question must guide the method being selected.
In this regard, I am not seeking “possible causal explanations, generalizations, or abstract interpretations” (van Manen, 1990, p. 64) nor to test hypotheses or to draw theory. This dissertation is concerned with intersubjectivity rendered in first-person experiential accounts. My aim is “to explicate the meanings as we live them in our everyday existence” (1990, p. 11).

The present research rejects the positivistic paradigm that assumes reality can be apprehended objectively, free of subjectivity and research biases (Denzin, Lincoln, & Giardina, 2006; Polkinghorne, 2005), and without due consideration of “the context of experience” (Denzin et al., 2006, p. 772). Illness and medical practices are socially and contextually situated (Denzin et al., 2006). As a researcher “one orients to a phenomenon one is approaching with a certain interest” (van Manen, 1990, p. 40). I am part of the research context since the research question of this dissertation arose from my own lived experience of interacting with physicians while accompanying my husband through eighteen months of cancer treatment. Throughout my cancer journey, as I sat daily in the hospital room, I observed other family members who, like me, accompanied their loved ones. I wondered if they also sought out the presence of, and interaction with, the physician. What might it have been like for those family carers to interact with the physician?

“Phenomenology is the study of the lifeworld—the world as we immediately experience it pre-reflectively” (van Manen, 1990, p. 9). “Lived experience is the starting point and end point of phenomenological research,” (p. 36). Such research begins in “using personal experience” and then one wonders if “one’s own experiences are also the possible experiences of others” (p. 54). As I lived the interaction with my husband’s attending physician, I often thought of what it was like for other family members to interact with the physician providing care. What did the experience mean for these family carers? In this time and space where vulnerability engulfed my being, what did interacting with the physician reveal to these carers? How did this experience appear to them? What was said in their meetings? How was the physician’s physical and emotive presence experienced by the family carer? Were family carers seen? Were their voices heard? Was their pain understood? If so, how? Were physicians attuned to their needs and expectations? As van Manen (1991) asks: What subtle gestures, postures, glances and expressions conveyed “sympathetic understanding”? (p. 97).
I chose hermeneutic phenomenology because, as van Manen posits, hermeneutic phenomenology is concerned with deeply understanding “from the inside” (1990, p. 8) the significance “of the human being” (p. 9) and what is it to be-in-the-world with others.

**Thesis Organization**

This dissertation is comprised of nine chapters. In the next chapter, chapter two, I offer a literature review of studies that have pointed to the family caregiving cancer experience. I discuss briefly the current literature on the financial, instrumental, physical, social, psychological, and emotional impacts of cancer on caregivers and the present empirical research findings on family-physician interaction during cancer treatment. My goal is to identify current gaps and biases of the available literature that point to the need for the present study. The next chapter, chapter three, describes the method used in this dissertation. In this chapter I present the descriptive, analytical method and discuss the interview and data analysis techniques. I also introduce some of the philosophical work that guides the interpretive aspects to this inquiry. A brief introduction of the five family caregivers who volunteered to participate in this study is also included in chapter three. Chapters four to eight comprise the body of this dissertation in bringing the family carers’ experiences of relational care to the foreground. Their interactions with physicians while accompanying their loved ones through treatment are described and analysed in the five chapters titled: Seeking presence–Finding absence; Feeling bereft–Turning away; Turning towards–Gestures of presence; To give; and Words’ from the family–A practice of embodied care.

Chapter nine, provides a summary of the findings as well as implications for practice. I hesitate in using the word conclusion. The story is never complete. As Finlay (2014) writes, “the analysis remains tentative, emergent, and incomplete; there is always more to say” (p. 134). My aim is to both understand and have readers of this dissertation appreciate the family carer experience in hopes that a hospitable space can be afforded to all those living the illness.
Chapter 2.

Literature Review

An in-depth literature review shows that little is known about family and physician interactions throughout cancer treatment despite the crucial role that family caregivers play in the cancer trajectory (Ferrel et al., 2013; Gilbar & Gilbar, 2009; Grant et al., 2013; Lund, Ross, Petersen, & Groenvold, 2015; Rabow, Goodman, Chang, Berger, & Folkman, 2010; Rabow et al., 2004). Accordingly, the aim of this phenomenological study is to understand the lived experience of family caregivers when interacting with the physicians providing care. How specifically do they interact with the physician while accompanying their loved one through treatment? What are the qualities of this interaction and what are the particular forms that this interaction takes? And what does this interaction mean to these family members? This dissertation attempts to uncover the lived meaning of family carers and physician interaction.

A key tenet is that cancer is indeed a family illness (Pennbrant, 2013; Pusa et al., 2012). Certainly, a large body of research points out that cancer unfolds within a social milieu (Ekstedt et al., 2014; Rabow et al., 2004; Waldrop et al. 2012) with the family being centrally positioned. Yet as Northouse (2012) points out, there is a dearth of research on family caregivers’ experiences of interacting with physicians and the impact that this can have on positive health outcomes (Lund et al., 2015; Schaefer & Block, 2009). In cancer treatment where the most basic aspects of a family members’ daily life are suddenly interrupted, how do family carers experience their interactions with the attending physicians? Do family members feel listened to and understood by the physician? What do these various interactions, from information-giving to empathic identification, mean to the family living the cancer experience? These questions become all the more important to investigate since families have consistently reported that a lack of communication with the physician continues to be seen as an unmet need (Chen et al., 2016).

In the section below I briefly review literature on cancer and family members’ involvement in cancer care.
Cancer

“Each hour, an estimated 22 people in Canada will be diagnosed with cancer in Canada in 2015” (Canadian Cancer Society’s Advisory Committee on Cancer Statistics, 2015, p. 16) and “each hour, nine people will die” of the disease in Canada (p. 38). “An estimated 196,900 new cases of cancer are expected to be diagnosed in Canada in 2015” (p. 16) with as many as 78,000 people dying of the disease (p. 38). In fact, almost half of all Canadians “2 in 5 will develop cancer in their lifetimes” reports the same government agency (p. 16). Cancer is now the leading cause of death in Canada, having surpassed the death rate of cardiovascular disease.

Family caregivers and cancer

That cancer involves the family of the cancer patient has been acknowledged by empirical researchers (Baider, 2008; Ferrel et al., 2013; Grant et al., 2013; Pusa et al., 2012). They have categorically concluded that families play an integral role in providing care for their loved ones from the initial diagnosis to the treatment that inevitably follows (Baider, 2008; Mosher, Bakas, & Champion, 2013; Northouse, 2012; Rabow et al., 2010; Shin et al., 2013). This large body of research attests to the impact of the family providing formal or informal care to a loved one who has cancer.

Thus far little is known about the family members’ journey through the medicalized environment of the hospital. This is despite the plethora of research that has now documented the vital role that the family plays throughout the cancer journey (Bevans & Sternberg, 2012; Ferrel et al., 2013). “Patients rely on their family caregivers for both emotional and practical support to adhere to their treatment regimen” (Shin et al., 2013, p. 2624). Waldrop et al. (2012) note that the experiences of the family with health care providers and, specifically, with physicians, continues for the most part to be ignored by empirical researchers. “Within the cancer context” research “has largely focused on the dyadic interaction between the patient and the oncologist” (Shin et al., 2013, p. 2624). In a recent report, Shin et al. (2013) assert that in the 21st century the family is still seldom viewed as “an important stakeholder” by the health care system (p. 2624). It is also the case that much of the informal caregiving, with its heavy
and demanding responsibilities, has now been transferred to the family. Yet the unique challenges that the cancer patient’s family must navigate remain mostly unknown and unreported.

Within the last decade, a limited but growing body of knowledge has begun to appear on the family members’ experiences of accompanying their loved ones through treatment. These studies have mainly been carried out within the intensive care unit [ICU] (Gutierrez, 2012, 2013; Lind, Lorem, Nortvedt, & Hevroy, 2011, 2013; Van Cleave et al., 2014), which is a setting that is well known for its reliance on high-tech biomedical science, and where the family presence has largely been restricted, discouraged or excluded altogether (Riley, White, Graham, & Alexandrov, 2014). This exclusion occurs despite the fact that family members in the ICU often act as surrogates for end-of-life decisions (Gutierrez, 2013). These studies have shown for the most part that family members rated interaction and communication with the attending physicians as their most significant need and yet one that continued to be ignored (Gutierrez, 2012, 2013; Lind et al., 2011; Schaefer & Block, 2009).

**Cancer: The family as caregiver**

Over the last two decades a growing body of research has documented how the responsibility for caring for chronically ill patients has increasingly been transferred to the family (Ferrel et al., 2013; Lund et al., 2015; Mosher et al., 2013). Specifically, this research demonstrates the importance of the family in cancer treatment, pointing out that cancer treatment has now shifted from the hospital-inpatient setting to outpatient care where this extended care is to be taken on by family caregivers (Bevans & Stenberg, 2012; Rabow et al., 2004; Speice et al., 2000; Shin et al., 2013). As Bevans and Sternberg note, family caregivers are the “essential partners in the delivery of complex health care services” (2012, p. 399).

Currently in the United States over 40 million American family members provide unpaid caregiving work for their relatives (Duberstein, 2014). Cancer, which is second only to dementia, accounts for the largest proportion of unpaid family caregiving (Bevans & Sternberg, 2012). North of the border, it was estimated in 2012 that over 8 million Canadians
assumed the caregiver role (Statistics Canada, 2013). In Canada, however, cancer is the number one illness and families overwhelmingly assume the role of caregiving (Statistics Canada, 2013). As Bevans and Sternberg (2012) note, an emerging body of evidence points to the intensity of the caregiving job for families caring for a loved one with cancer. These researchers found that one fourth of caregivers spend over 40 hours a week delivering essential and often complex health care services to their loved-ones afflicted with cancer.

Some researchers argue that as treatment advances the family goes on to shoulder tasks that were once carried out by professionals (Duberstein, 2014; Grant et al., 2013; Mosher et al., 2013; Northouse, 2012). For example, a consistent theme in the literature is that as death approaches family caregivers play an essential role in delivering complex treatments such as the management of pain, administrating medications, managing nutritional protocols, managing nausea, and changing dressings among other tasks (Bevans & Sternberg, 2012; Duberstein, 2014; Grant, et al., 2013; van Ryn et al., 2011). Families are asked to handle “medical devices historically restricted to licensed clinicians” (Duberstein, 2014, p. 1216). Furthermore, many cancer patients are now receiving chemotherapy at home which is something that was “unheard of years ago” despite families often feeling unprepared to carry out such tasks (Northouse, 2012, p. 500). Chemotherapy is now often conducted via outpatient settings where the patient is sent home to be cared for by family carers. Cancer care, notes Duberstein (2014), has moved from the hospital to the home in 21st century medicine.

Given the central role of the families’ presence within the health care system and the undeniable transfer of medical care from hospital to families, it is not surprising that some researchers, practitioners, educational scholars, and family members themselves are calling for families to be recognized as crucial stakeholders within the health care system and as an integral part of a patient-family-centred model of care.
Health and autonomy

Some authors argue that the North American emphasis on individualism has led to an emphasis on patient autonomy that focuses solely on the patient-physician interaction while discounting the patient’s family as part of the unit of care (Brand, Pickard, Mack, & Berry, 2016; Clay & Parsh, 2016; Grant et al., 2013; Igel et al., 2016). This is despite the fact that family members are physically, emotionally and instrumentally present throughout treatment (Shin et al., 2013). Firth (2006), an oncologist, asserts that it is not possible to keep discounting the family and focus only on the patient. Patients are born within a family and patients look to their families for “care and support” (p. 500). Firth argues that although most doctors recognize the critical role of the family in cancer care, modern day physicians tend to receive little training in how to communicate with family carers. Thus doctors may feel uncomfortable or ill-prepared to interact with families. Consequently, physicians may tend to ignore or avoid family members.

Pennbrant (2013) suggests that physicians’ discomfort with, and avoidance of, family carers can be traced to the culture of medicine and its values. Such a framework of care excludes the patients’ lifeworld that precede and shape the illness. For Pennbrant, physicians see their role as dealing almost exclusively with disease and providing answers about the disease for the patient, which is much in accord with the cultural values of medicine that are based on explicit and implicit rules and norms that foster asymmetric relationships. In modern day medicine the transmission of information may be seen to reside exclusively within the physicians’ control. Under conditions of active family involvement, however, physician uneasiness in interacting with family carers may be symptomatic of a sense of vulnerability (Firth, 2006). Pennbrant (2013) also speculates that ignoring the family could be the physician’s response to what are perceived as actions beyond the scope of curative medicine.

Duberstein (2014), a professor of psychiatry and family medicine, addresses physicians’ lack of training in interacting with family members. Duberstein proposes that physician apprehension in interacting with the family stems from a culture of medicine still rooted in the 17th century. Cartesian medicine has historically been about curing disease and
“pathophysiology” (p. 1216) to the exclusion of the person, the patient, and the family facing the illness. For Duberstein, seeing the person and not just the disease requires a “culture change” (p. 1216). According to ten Have and Gordijn (2014), internationally renowned bioethicists, a cultural change is now deemed necessary in medicine. For ten Have and Gordijn, the relationality of care is “the primordial phenomenon for the theory and practice of medicine” (p. 169). While uncovering the pathology of the disease is important, it is also the case that medicine is “essentially a relational activity” (p. 169). “The plea for help of someone in need”—the cancer patient and their family carers—“constitutes the enterprise of medicine” (p. 169). For ten Have and Gordijn, relationality of care extends beyond the individual who is ill. Patients are embedded existentially within a contextual web of family relations. Thus physicians need to be attuned to the lifeworld in which health and illness occur.

Cancer: Impact of cancer on patients’ family member caregivers

There is widespread consensus that while caring for a family member may be a rewarding experience, it is also the case that these family members may experience significant emotional, social, psychological, physical, and financial hardships that can affect their well-being and quality of life in a negative manner (Girgis et al., 2013; Grant et al., 2013). Research points to a diagnosis of cancer as representing a situational crisis for patients’ families (Dresser, 2011; Sercekus, Besen, Gunusen, & Edeer, 2014; Waldrop et al., 2012). Upon hearing the word cancer, many family members may feel numb, shocked, confused, uncertain, and fearful (Girgis et al, 2013). Cancer continues to be seen as a catastrophic disease that brings immediate feelings of anguish, terror, uncertainty and hopelessness along with the anticipation of physical deterioration, and death (Gordon, 1990; Sercekus et al. 2014). For patients and their family member caregivers, cancer instantly disrupts and shatters the family’s daily norms (Sercekus et al., 2014). Life is utterly changed. With little knowledge of what is to come, families are often thrown into what is called the “cancer trajectory” where they are more often than not left isolated, unsupported and alienated (Grant et al., 2013).
Emotional psychological consequences

Against the desolate landscape of a cancer diagnosis, many family members see themselves as the main providers of emotional and psychological support for their ill loved ones (Bevans & Sternberg, 2012; Grant et al., 2013; Spichiger, 2009). It follows that as the cancer path unfolds, family members struggle to mask their sadness, anguish, and devastation so as to protect their loved ones (Thomas, Morris, & Harman, 2002). A consistent finding of earlier research by Rabow et al. (2004) as well as more recent research by Sercekus et al. (2014) highlight that a cancer diagnosis and the treatment that follows is often a time of crisis. Family caregivers must carry on with the daily demands of caring while struggling to cope with the emotional burden that cancer brings upon them. Ultimately, such a struggle is likely to take heavy emotional and psychological tolls, leaving these family members in much distress and at high risk for both depression and anxiety (Grant et al., 2013). Statistics Canada (2013) reports that close to 50% of Canadian family caregivers reported emotional and psychological distress such as depression, anxiety, irritability, anger, isolation, sleep disturbances, insomnia, and trauma. This Canadian statistic is in line with empirical findings worldwide (Girgis et al., 2013; Grant et al., 2013).

Physical/body consequences of caregiving

Researchers have documented how the physical health of family caregivers whose loved ones are undertaking cancer treatments can also be negatively affected. For example, fatigue, significant sleep disturbances, insomnia, hypertension, headaches, chronic fatigue, appetite disturbances, weight loss, indigestion, cardiovascular reactivity, and other physical ailments are higher among family caregivers and this is independent of age and gender (Girgis et al., 2013; Rabow et al., 2004; Shin et al., 2013). Poor physical health resulting from the tasks of caregiving may in turn lead to higher morbidity and mortality among these family members of cancer patients (Bevans & Sternberg, 2012; Mosher et al., 2013). Family caregivers of cancer patients experience “physiological effects that are associated with impaired immune system function, coronary heart disease and early death” (Bevans & Sternberg, 2012, p. 399).
Kim, Carver, Shaffer, Gansler, and Cannady (2015) found that family members providing care were significantly more likely to develop heart disease, arthritis and chronic back pain even several years after their loved one's cancer treatment had concluded. These authors noted that these risks were independent of age, gender, sex, and income of the family member providing the care. These authors followed family members two years, five years, and eight years post-cancer diagnosis and treatment. Their findings underscore the long-term costs of caregiving. It is worth noting that The National Profile of Family Caregivers in Canada (Statistics Canada, 2013) reports that 50% of family caregivers have physical health problems stemming from the task of caring for an ill relative or friend. Statistics Canada reported that the higher the intensity of care, the greater the physical health problems that caregivers experienced.

**Daily challenges: The financial cost for the family as caregiver**

As stated above, a large body of research acknowledges that a diagnosis of a life-threatening illness such as cancer is a crisis for the patients’ families (Dresser, 2011; Grant et al., 2013; Peleg-Oren & Sherer, 2001; Sercekus et al., 2014; Waldrop et al., 2012). In addition to the emotional and psychological demands of caregiving, families may suddenly face increased financial challenges associated with their loved ones’ cancer diagnosis, navigating through scenarios of diminished income, and/or loss of employment while at the same time facing increasing expenses (Longo, Fitch, Deber, & Williams, 2006; Timmons, Gooveman-Hill, & Sharp, 2013).

Statistics Canada (2013) recognizes the considerable financial strain experienced by family carers. Caregivers are likely to have decreased income as they reduce work hours, take time off for caregiving duties, or simply leave employment entirely to become fulltime caregivers. Despite a publicly funded medical system, caregivers in Canada are still likely to confront costly and hidden expenses such as parking, lodging, gas, food, childcare, as well as patient-related costs for dental work and medications that may not be included in healthcare coverage. Furthermore, once a patient is discharged to outpatient care, significant drug related expenses that were once covered by the hospital are shifted onto the family to cover. Such
expenses are confronted at a time when families are often facing diminished income. This higher financial burden further negatively impacts the physical, psychological, and emotional health of the family caregivers (Statistics Canada, 2013).

**Cancer in the long-term: consequences for family caregivers**

Family carers of patients with advanced cancer experience considerable social, psychological, financial and physical distress that may even surpass that of the patients (Rabow et al., 2004; Rumpold et al., 2016; Williams, 2014). Isolation, depression, anxiety, insomnia, fatigue, fear, emotional and financial distress, morbidity, and even death are well documented negative outcomes for cancer caregivers (Bevans & Sternberg, 2012; Spichiger, 2009; Williams, 2014). The above negative outcomes may continue long after the cancer treatment has concluded or the patient has died (Rabow et al., 2004). It is also crucial to remember that cancer may re-occur after remission and that the cancer journey may be resumed many times for the patient and the family carers (Baider, 2008; Northouse, 2012).

**Family and the cancer journey**

Scholars are now affirming that within the landscape of life threatening illness such as cancer it is imperative to listen to the voices of families of cancer patients (Lund et al., 2015; Harding et al., 2012; Pennbrant, 2013). These studies question current practices of treating patients as separate from their social-emotional and familial contexts (Clay & Parsh, 2016; Igel et al., 2016; Shin et al., 2013). Ethically and practically, patients can and should no longer be seen in isolation from their family system of relationships (Pennbrant, 2013; Firth, 2006). Patient-centred care, the pinnacle of 21st century biomedical ethics, cannot be patient-centered without the inclusion of the patient’s family (Gutierrez, 2012, 2013; Igel et al., 2016; Riley et al., 2014; Van Cleave et al., 2014). This model of health care is all the more compelling when we consider how the family caregiver living the cancer treatment has the potential to hinder or help patient outcomes. And if the family caregiver becomes ill then patient care will be negatively impacted (Rabow et al., 2004).
In her inaugural speech as the new elected president of the Canadian Medical Association, Dr. Anna Reid (2012) brings awareness to the ‘fleeting’ family-physician interaction as well as physicians’ lack of responsiveness toward their patients’ families. She proposes how such a lack of ethical sensitivity in the family-physician encounter needs to be addressed by drawing upon her experience as a family member interacting with the attending physicians during her father’s illness. Her speech provides a powerful insight into the emotional, psychological, physical, and financial costs when a supportive family is rendered invisible by the medical community. She calls for change and, as Nortvedt (2003) suggested, “an awakening of moral obligation in the encounter with the other person” (p. 223) who is invariably an accompanying family member.

Dr. Reid writes:

I’ve also seen our health care system through the lens of a patient family, and experienced both the best and the worst of patient and family-centred care. These experiences too, underline for me, the possibilities for change.

Last year, after my elderly father, who has Alzheimer’s disease, fell and broke his hip, I travelled across the country to be by his side. During a long hospitalization, despite my daily presence at my father’s bedside, I was only able to speak to a physician on two occasions, and never above a junior resident level. It took one week before my mother and I could even get a physician to sit down with us and discuss my father’s advanced care directives. Despite my best efforts to advocate every day on his behalf, I was unable to relay important information about my father that could have sped his recovery, and saved the system money. In those stressful days, what my family experienced was the antithesis of patient-centred care. Those days were also to be among my mother’s last, as she died a short time later after a brief illness.

I am happy to say that her hospital care was exemplary. She and my family spoke with her physicians often about the course of her illness and the decision to palliate. Her precious last days were spent with her loved ones at her side, and our burden of grief was lightened immeasurably not just by the care and compassion of the hospital staff but also by their capacity to communicate.

The astounding fact about those vastly different experiences—one within a culture of care that is provider-centred; the other within a culture that is patient-centred—is that they took place two floors apart in the same teaching hospital. The patient centred culture cost not a penny more. On the other hand, the lack
of dialogue in my father’s case led to a much longer hospital stay for him.  
(Canadian Medical Association, 2012, Dr. Anna Reid Inaugural Address)

Reid’s speech is echoed by the ethical guidance of the Canadian Medical Association.  
This organization makes clear that patient centred-care must consider both the patient as well as the accompanying family carer.

Care that is truly patient-centred considers patients’ cultural traditions, their personal preferences and values, their family situations, and their lifestyles. It makes patients and their loved ones an integral part of the care team who collaborate with health care professionals in making clinical decisions (Canadian Medical Association, 2007 p. 1).

**Family-physician encounters in ICU**

The experience of the family within the context of intensive care unit [ICU] (Lind et al., 2011, 2013; Van Cleave et al., 2014) highlights the significance of face-to-face interactions with attending physicians (Azoulay, Chaise, Kentish-Barnes, 2014; Gutierrez, 2013; Riley et al., 2014). Families report that such face-to-face interactions seldom occur (Gutierrez 2012, 2013; Van Cleave et al., 2014). Family members are already under conditions of significant stress within the ICU, feeling overwhelmed, shocked, fearful, and facing the prospect of making end-of-life decisions (Azoulay et al., 2014). Thus it is understandable that family members seek face-to-face interaction with the attending physicians in whose hands their loved ones lie (Azoulay et al., 2014; Gutierrez, 2013; Lind et al., 2011).

Gutierrez (2013), who observed and later interviewed ICU doctors and family members, argues that the timing of information is exclusively driven by the physicians’ needs rather than by those of the family. Most times physicians delayed addressing the family, speaking to family members only when they perceived that “things were really declining,” “recovery was highly unlikely” or “death was probable” (pp. 236-237). Their overriding intent was to communicate the need to withdraw treatments (pp. 236-239). Yet Gutierrez contends that family members were observed trying to speak to the doctors on “nearly a daily basis” (p. 239). Gutierrez hypothesized that although many physicians feel uncomfortable with conditions of uncertainty and thus wait “until they reached a perceived threshold of certainty”
(p. 238) “backed up with enough data” (p. 239), family members have stated that a delay in face-to-face communication with the physician increased their sense of powerlessness in what was already seen as a very trying time.

Lind, Lorem, Nortvedt, and Hevroy (2011) examined the experience of family members within the context of medical decision-making within intensive care. Most family members in their study reported that they lived in a constant “wait and see” state with little substantive dialogue with the attending doctor. The majority of family members said that the interaction with the attending ICU physicians was almost ‘non-existent’ despite family members relentlessly seeking out the physicians’ presence. “Physicians often seemed busy, did not keep appointments, and left the family waiting for hours” (p. 1145). When information was made available, it was often perceived as vague or time delayed. A lack of timely and honest communication left them with doubts and unanswered questions, thereby increasing their distress and negatively impacting bereavement. Families also noted that given the little, vague, or late communication, they felt that their role as caregivers went unrecognized (Lind et al., 2011).

It is worth noting that Lind et al.’s (2011) study took place exclusively within the context of end-of-life. Secondly, they did not explore the lived experience of family-physician interactions from the perspective of family members. Their aim was simply to explore whether family members felt included in the decision-making process in the intensive care unit. In addition, this study was conducted in Norway where end-of-life decisions are left almost exclusively in the hands of medical institutions (Lind et al., 2011).

In a recently reported study, Van Cleave et al. (2014) explored the quality of physician-family communication within the context of a paediatric intensive care setting in a major North-American University Hospital. This study is important since it has traditionally been assumed that within paediatric care family presence is recognized, acknowledged and sought out by the attending medical providers. Likewise, it has also been assumed that in situations where there is a critically ill child, the communication between physician and parents would be empathic and inclusive due to the heightened distress of a child’s suffering. Van Cleave et
al. concluded that despite situations involving a sick child, overall family-physician communication continued to be “poor” with physicians speaking on average 75% of the time. Van Cleave et al. also reported that during the family-physician conferences, physicians’ speech lacked empathy and was often complex, relying on biomedical jargon. In terms of decision-making, Van Cleave et al. reported that inclusion of the family within critical care continues to be “meagre” (p. 1513). “Shared decision-making was strikingly infrequent” (p. 1513) and families were informed only 11% of the time about risks or alternative treatments or benefits of treatment. Likewise, informed consent was sought out in only 9% of the cases, despite that 91% of participants were either the mother or the father of the ill minor and thus the legal guardians of the child. The authors contend that a family’s lack of informed consent appeared incompatible with paediatric ethical standards of practice.

Informed consent, the right of disclosure, is the hallmark of bioethics and medical practices (American Academic of Pediatrics, 1995; Kuo et al., 2012). Recognition of, and responsiveness toward, the family supporting the sick child is seen, moreover, as an ethical duty of physicians. According to Jones, Contro, and Koch (2014), physicians must not only include the family at all levels of decision-making but “physicians have an ethical duty to care for the families of children with life-threatening conditions through their illness and bereavement” (p. 8). Yet, as Van Cleave et al.’s study illustrates, such standards continue to be seldom implemented in clinical practices (Kuo et al., 2012).

In line with Van Cleave et al. (2014), Riley et al. (2014) also contend that patient-centred care is now a fundamental principle of biomedical ethics and the emblem of excellence in medical practices. Empirical and professional literature show that patient-centred care is a key value informing medical professionalism, medical education, physicians’ regulatory colleges, hospital boards, and other organizations involved in the provision of medical care (The Joint Commission, 2010). In the 21st century, at the core of an ethical medicine, is patient-centred care, write Riley et al. (2014). Yet they also contend that patient-centred care cannot truly be patient-centred unless it actively includes the family caring for the patient.
Riley et al.’s (2014) study shed light on the differing thoughts of patients’ families and physicians with regards to the family role and presence within institutionalized western biomedicine. These researchers found that family members perceived their presence as critical to the emotional and physical well-being of their loved ones. Family members also thought that their presence had a positive impact on the patients’ health outcomes. Family members indicated that they “knew their ICU family member better than anyone” (p. 318) and, as such, they were in a critical position to notice bodily gestures, noises, movements, and to convey such observations to the medical team. Family members also reported that their presence further enhanced medical treatment as they were in the position to observe subtle changes and to communicate those changes, given that they maintained a constant and vigilant watch over their ill loved ones. Family members overwhelmingly concluded that within the context of serious illness, patient-centred care meant that family “should always be involved” (p. 318).

Physicians in Riley et al.’s (2014) study reported that within the context of critical care, most physicians did not agree with having the physical presence of family carers at the hospital. Physicians did not diminish the importance of family involvement but they saw the role of the family as taking place after “the discharge of the patient from ICU” (2014, p. 318). Riley et al. also found that although patients’ families, and physicians, believed that communication among all key stakeholders was critical in the delivery of a patient-centred care, there was disagreement about how communication should occur. For example, family members reported needing communication that was compassionate and crucially, delivered by the physician. For these families, compassionate care involved having physician communication that was timely and face-to-face. When a face-to-face interaction occurred, family members felt listened to, supported, and even comforted, despite a physician delivering unfavourable news.

In contrast to the family’s wishes for a face-to-face interaction with the attending physician(s), Riley et al. (2014) suggest that doctors did not generally consider face-to-face contact with the family as a priority. This is despite the fact that research has indicated that face-to-face physician-family interaction improves patient outcomes and may facilitate family members’ bereavement (Schaefer & Block, 2009). Most physicians reported that they had no
time to communicate with the family (Riley et al., 2014). Physicians noted that given their time constraints, communication with family members “should be relegated to other members of the health-care team” (p. 319), which may explain why families reported that the family-physician interaction was seldom face-to-face even though doctors had initially told the family they could meet personally. Any family member-physician contact, if it occurred, was largely through a phone call and most often when the patient was close to death. This in turn created a lasting dissatisfaction for family members who wanted to receive the information in person from the doctor. It is worth noting that the studies discussed above did not focus on investigating family member-physician interactions from the perspective of family members. Instead, Riley et al. explored how family members, physicians, and nurses felt about family members being present in the intensive care unit by extending visiting hours in ICU.

While more is now known about the family-physician experiences within intensive care, the above findings may not be generalizable to cancer care (Kim et al., 2015; von Bergwelt-Baildon, Hallek, Shimabukuro-Vornhagen, & Kochanek, 2010). In the section below I distinguish ICU care from cancer care.

**Distinguishing the Cancer Clinic and the Intensive Care Unit**

von Bergwelt-Baildon, Hallek, Shimabukuro-Vornhagen, and Kochanek (2010) argue that “critical care and oncology are frequently two separate worlds” (p. 612). ICU care takes place exclusively in a hospital setting. It is defined as high-tech, state-of-the-art specialized care for patients who are often incapacitated and require sedation and critical medical procedures such as breathing tubes, induced coma, feeding tubes, as well as various life-sustaining therapies and measures (Azoulay et al., 2014). Given the high intensity of crisis care, ICU protocols highly restrict visitation by family members, thus limiting the possibilities of families interacting with the attending physician (Azoulay et al., 2014; von Bergwelt-Baildon et al., 2010). Studies show that family-physician interactions fail to occur in such conditions of extreme medical urgency or restricted visitations (Azoulay et al., 2014; Riley et al., 2014, von Bergwelt-Baildon et al., 2010).
Compared to the ICU where critical care occurs in an exclusively inpatient setting with little contact between families and patients, cancer care involves short hospitalizations with studies showing that cancer treatment is mainly conducted via outpatient settings where the family takes on a prominent role in caregiving tasks (Kim at al., 2015). Furthermore, whether cancer care is delivered though the hospital or in an outpatient setting, the family is expected to assume responsibility for the patients’ physical, practical, and emotional support (Lund et al., 2015; Rabow et al., 2010). Families often assist with tasks such as moving or lifting patients, medication management, pain management, nutritional management, and handling other complex tasks previously done by trained medical staff (Bevans & Stenberg, 2012). Regardless of cancer care setting, therefore, there is little restriction to family presence. As a result, the family and the attending physicians often share the physical space of cancer care (Iconomou, Vagenakis, & Kalofonos, 2001; Lund et al., 2015; von Bergwelt-Baildon et al. 2010). Thus the physician has ample opportunity to interact with family caregivers and to “intervene” in supporting them (Bevans & Sternberg, 2012, p. 398).

In contrast to ICU which by definition is of acute onset and resolution of illness, cancer has largely become a chronic disease (Azoulay et al., 2014; Bevans & Sternberg, 2012, Grant et al., 2013) with multiple recurrences (Kim et al., 2015). According to Kim et al. cancer is characterized by a unique trajectory. Its treatment may be of long duration lasting several months or years thus increasing the frequency of the family-physician interactions. Kim et al. highlight how cancer caregivers “often move in and out of caregiving” (p. 303) as the cancer re-occurs. Interaction with the physician can last for months or years (Limon et al., 2015; von Bergwelt-Baildon et al., 2010) thereby making positive family-physician encounters central to patient care and health outcomes.

Additionally, most families accompany the patient from the first diagnosis onwards (Eggy et al., 2006; Gilbar & Gilbar, 2009; Shin et al., 2013). As such, the possibilities for physicians to create open spaces of genuine contact unfold early in the cancer trajectory. In intensive care, by contrast, patients are likely to be admitted to ICU from the trauma/emergency department or under a rapid deterioration of a life-threatening illness.
(Azoulay et al., 2014). Given the urgency of the intensive care, family-physician contact may be non-existent from the initial admission (von Bergwelt-Baildon et al., 2010).

While many of the above studies have examined family member experiences within the context of ICU/critical care, a small number of researchers have now begun to address the experiences of family members within cancer care. In the next section I explore current research that has examined family-physician encounters within cancer care.

**Cancer: Research on family-physician interactions**

Evidence points out that family carers should be acknowledged as an essential part of the health care team (Dresser, 2011; Rabow et al., 2010; Waldrop et al., 2012). The existing literature emphasizes, however, that family member-physician interactions continue to be overlooked within oncology (Rabow et al., 2010; Waldrop et al., 2012). Scholars are now calling into question the lack of research in the area of family member–physician interactions (Kahana & Kahana, 2003; Zeliadt et al., 2011). Cherlin et al. (2005) posit that research in this area is virtually non-existent despite the plethora of studies pointing out that cancer is not only a family illness but that family-physician interaction is identified as a top unmet need by family caregivers (Grant et al., 2013; Shin et al., 2013).

As highlighted previously, a limited literature has now begun to include the family caregivers’ communications with health care providers. But these studies have focused on end-of-life or prior to end-of-life treatment (Zeliadt et al., 2011; Cherlin et al., 2005). The experience of family carers in their interactions with physicians during treatment continues to be unexplored (Rabow et al., 2010). For example, Cherlin et al. (2005) examined physician-family communication within the context of end-of-life care. Family caregivers (n: 206) responded to a survey in terms of the timing of information provision, hospice enrollment discussions and life expectancy. A small number of caregivers also participated in an interview. Participants were mostly patients’ children (51.4%) and spouses (30.6%) of cancer patients. These researchers looked at three different variables of information provision: when the family member was told by the physician that cancer was incurable; whether family carers were told
about their loved ones’ life expectancy; and when family carers learned about the need of hospice care. Findings underscored that provision of timely, clear, and honest information in terms of disease status, life expectancy, and hospice care fulfilled an essential need of the family members.

In Cherlin et al.’s (2005) study, families noted the importance of having such information provided as early as treatment begins. The large majority of patients’ family carers saw physicians’ communication as crucial in order for them to understand the course of the illness and to make informed decisions. Most family carers reported that they wanted to know the truth about their loved ones’ conditions. Family caregivers also reported they would have liked to receive information about hospice. Physicians’ open, clear and timely communication also facilitated enrolment in hospice which in turn benefitted both the patient and the supportive family carer (Cherlin et al., 2005). Timely communication allowed the family and the patient to have an opportunity to say good-bye and to make the necessary financial and funereal arrangements. This in turn facilitated the grieving process. Family carers indicated the provision of information by the physician in a manner that was truthful and timely should be a “mandatory” standard of medical care.

Yet, in Cherlin et al.’s study, a significant number of family carers said that information coming from the physicians was “limited and delayed” (2005, p. 1184). Over one-third of patients’ family caregivers reported that physicians never discussed the illness becoming incurable. Likewise, over one-third of family carers indicated that physicians never suggested hospice as a possibility. Among those family carers who were informed that the disease was deemed incurable, the majority reported that these conversations came too late, in some cases a week or two before death. Half of the family caregivers stated that physicians never discussed potential life expectancies and that family carers were left uninformed about whether the disease was curable or not. It is important to add that trust in the physicians was also affected. Several family carers reported becoming “suspicious that physicians knew more than they communicated, withholding potential useful information from the caregiver” (p. 1185). More importantly, some family caregivers indicated that had they known the truth about their loved-
ones’ illness they, themselves, as well as the patient, might not have continued on with treatment.

It is important to differentiate Cherlin et al.’s (2005) study from the present phenomenological study. Cherlin et al. examined family caregiver-physician communication exclusively within the context of end-of-life. Participants were family caregivers of cancer patients whose loved one was enrolled in hospice care and thus no longer receiving cancer treatment. The present phenomenological dissertation focuses on physician-family interactions as lived by family caregivers throughout the entire cancer treatment. This study uses a phenomenological hermeneutic analysis aimed at uncovering the lived meanings that family carers assign to these interactions.

Gilbar and Gilbar (2009) explored the relationship between the spouses of breast cancer patients and the doctor providing care within the context of medical decision-making. These scholars contend that the lack of research in family-physician interaction may stem from a fundamental principle of patient autonomy where the only sanctioned relationship is that of the patient with the physician. The physicians’ duty is to convey information exclusively to the patient while ignoring and discouraging family participation in the medical interaction. Yet, argue Gilbar and Gilbar, illness does not unfold in a vacuum but rather it emerges against the background of a family milieu. Autonomy, posit Gilbar and Gilbar, can also be conceptualized as relational autonomy that takes into account the “context of social relationships with others” (p. 185). Within this family relational system, “people depend on each other” (p. 185) and thus the family also plays an essential role in medicine.

Participants in Gilbar and Gilbar’s (2009) study were women (aged 30-69) who were undergoing breast cancer treatment at an oncology clinic, and their accompanying husbands (aged 37-75). Participants answered a series of five-point Likert type questionnaires assessing autonomy-based models, doctor-family decision making, doctor-spouse relationship, family carers’ participation in decision making as well as patient perceptions of the importance of their relatives being involved in treatment decision-making. These researchers found that for breast cancer patients the involvement of their husbands in medical treatment decision-making
was highly important. A large majority of patients (84.2%) thought that “their husband should participate in the medical decision-making process” (p. 191) and that “making a medical decision is not an individual project” (p. 191). Likewise, both patients and their spouses thought it was very important that, in addition to the spouse, other family members should also be included in the decision process, thus underscoring the significance of relations in illness. Gilbar and Gilbar’s findings lend support to the importance of the collective nature of decision making. An overwhelming majority of patients and their husbands (88.68%) indicated that they actively discussed amongst themselves any meetings that took place with doctors throughout the course of illness. Furthermore, close to 90% of breast cancer patients indicated it was very important to them to be in synchrony with their husbands’ decisions.

It is worth noting that Gilbar and Gilbar’s (2009) study is quantitative in nature. While quantitative studies allow the generalizations of findings, it is also the case that they are not designed to study relatively overlooked phenomena such as family-physician interactions. Quantitative research as well may only tap into the very surface of a complex and understudied phenomenon such as family-physician interactions in the context of oncology. Quantitative research is not designed to uncover the rich contextual details that may influence how an experience is lived (Guba & Lincoln, 1994). Quantitative research cannot uncover the meaning of a human experience as it is lived, thus Gilbar and Gilbar’s survey study may not tap into the uniqueness of the experience of these family carers and reveal the rich details of how the experience unfolds. It is also worth noting that in the Gilbar and Gilbar study participants were exclusively breast cancer patients and family members were exclusively spouses. The present study is not restricted to any specific type of cancer. Likewise, family members can be any blood relative involved in the patient’s care.

Despite the inherent limitations of quantitative methodology, this study nonetheless highlights the significance of family involvement in the cancer trajectory. Patients overwhelmingly expressed that their family companions should be involved in their care and that medical decision-making was a shared process among spouses. Thus, Gilbar and Gilbar’s (2009) study challenges the current western bioethical conception of the patient as an
autonomous agent devoid of a family. It supports a patient-family-physician triad in cancer care.

Gilbar and Gilbar’s (2009) findings are in line with recent research by Pardon et al. (2010) who found that the large majority of patients with advanced lung cancer chose to have a family member involved in their medical decision-making. Pardon et al. report that as the disease advanced and the patient’s physical competence deteriorated, almost all patients (94%) wished their family were involved in medical decisions. Almost 80% of patients said that their family carers should be the primary medical decision-makers (Pardon et al.). Thus, while respect for patient autonomy is at the core of western bioethics in institutionalized medicine, it may not be core to patients’ wishes.

Zeliadt et al. (2011) also examined spouse-physician interactions. For these authors, a diagnosis of cancer unfolds within the landscape of a family context of relations where families are likely to be involved from diagnosis to treatment. Their findings lend further support to the critical importance of welcoming the family carers into the family-physician interaction. Specifically, the study showed that when physicians actively interacted with the patients’ spouse by encouraging caregivers to ask questions, this led to more conversations by the couple with regards to cancer treatment options. Zeliadt et al. explain that upon receiving a cancer diagnosis it is likely that patients are shocked, terrified, paralyzed, and frightened by what is to come. Under these emotional conditions it is likely that patients experience a high degree of confusion at the same time as they are trying to understand crucial information regarding treatment. Zeliadt et al. suggest that the spouse-physician interaction should be viewed as part of the cancer protocol and thus physicians should make every effort to include and interact with spouses of cancer patients.

In Zeliadt et al.’s (2011) study participants were newly diagnosed patients with prostate cancer and their partners. Participants responded to a Likert-type survey. Specifically, the survey asked whether the physician included patients’ partners in the decision-making process, whether the doctor encouraged family members to ask questions, the degree of treatment discussion among spouses, as well as the timing of when the significant other found out about
the loved ones’ cancer. The survey also asked spouses to rate satisfaction with the patients’ physicians. It is worth noting that this study, in contrast to the present study, took place after the diagnosis but before initiating treatment.

Zeliadt et al. (2011) reported that 97% of patients were accompanied by their spouse when they were told they had cancer. Likewise, over 80% of spouses reported they accompanied their loved one into the follow-up appointments. Zeliadt et al. also found that during diagnosis spouses were actively involved in asking questions. Moreover, all decisions with regards to treatment were seen by the couple as a joint undertaking (Zeliadt et al., 2011). Importantly, the inclusion of the family during the physician-patient-interaction had a positive impact on treatment outcomes. When doctors created a climate of openness that encouraged the spouse to actively participate in the dialogue, patients were more inclined to discuss the upcoming treatment. The study also revealed that the more the doctor encouraged the spouses to ask questions, the more the spouses felt included in the process, and the higher they rated their satisfaction with the physician.

It is important to add that Zeliadt et al.’s (2011) study used a quantitative methodology and thus it does not explore how the experience is lived by the participants. Quantitative research is concerned with applying strict methodological rules aimed at the generalizations of the findings (van Manen, 1990). According to Polkinghorne (2005), quantitative research is designed to collect numerical data, typically by using standardized inventory, surveys, or likert type questionnaires such as in Zeliadt et al.’s case. Such quantitative instruments are designed to “gather surface information” (2011 p. 138) and do not delve into the rich contextual details nor seek to capture the complex meanings that people assign to their experience (Polkinghorne, 2005; van Manen, 1990). Thus the fullness of the experience as it is lived, felt, and sensed, remains unknown. It is also important to add that to be included in the study, participants needed to be exclusively spouses of prostate cancer patients.

More recently, Waldrop et al. (2012) investigated family carers and health care providers’ communication during the final stages of cancer and just prior to hospice enrollment from the perspective of the family carers. Participants in this study were family
caregivers of older cancer patients (65 years old or older) who had been enrolled in hospice for one or two weeks prior to death. The study criteria required that the participants loved ones be already deceased at time of the interview. Results show two emerging themes: satisfactory and unsatisfactory family-physician communication. Satisfactory communication was characterized by having regular family-provider contact as well as receiving adequate information. Families reported that when communication was perceived as responsive and compassionate it facilitated the grieving process and helped to manage the distress associated with the impending death. Responsive communication was highlighted as that in which the provider made himself or herself available for contact whether by phone or face-to-face or through family meetings. Above all, family carers reported that physicians were responsive “to the family intensified distress” (pp. 186-187). Family members also noted that unsatisfactory communication was when physicians communicated infrequently, when calls were not “returned” (p. 187), or when family members “struggle in getting any information” (p. 187).

It is worth noting that in Waldrop et al.’s (2012) study, a significant number of participants responded that they had no contact with the attending physician throughout the entire treatment. Many family carers said that as cancer advanced and death became imminent “physicians left the case” (p. 187). This in turn led to family carers feeling abandoned. Sparse communication also led to conflict, frustration and disagreement with the physician. Participants described communication as ‘blunt, short, and abrupt” (p. 188). For some families, health providers only communicated with them when the patient was at “the brink of death or dying was imminent” (p. 189). Waldrop et al.’s (2012) study took place within the realm of hospice care when treatment had ceased. In contrast, I explore family carers-physician interactions while patients were undergoing treatment. In Waldrop et al.’s study cancer patients had to be older than 65 and in the latest stages of terminal cancer. The current dissertation involves any stage of the disease and is not restricted age-wise.

There exists little empirical data in this area of physician-family member interaction, which is surprising given that how the three health care partners relate—the family carers-patients-physicians—has significant implications for all concerned (Kahana & Kahana, 2003). Speice et al. (2000) indicate that past research has shown that when the patient-provider-family
member interaction was perceived as ‘in sync’, care was enhanced. In contrast, anxiety, conflict, and tension arose when there were difficulties in the physician-family-patient dialogue. Communication strain in turn had a negative impact on the patients’ outcomes (Kahana & Kahana, 2003; Speice et al., 2000). Speice et al. note that poor communication “causes significant distress for cancer patients” that was only secondary to “unrelieved pain (Kristjanson & Ashcroft, 1994 as cited in Speice et al., 2000, p. 102). Open, collaborative patient-doctor-family communication leads to better patient health outcomes (Iconomou et al., 2001; Shin et al., 2013). For instance, collaborative communication facilitates the gathering of symptom information that may be essential to render a correct diagnosis. Open communication within the triad also encourages patient treatment adherence (Kahana & Kahana, 2003).

In Speice et al.’s (2000) study, participants were patients as well as health care providers. Both groups participated in a focus group. Health care providers were oncologists, nurses, surgical oncologists, and nurse practitioners. Their findings revealed that patients saw their family members as an essential partner within the health care team. In fact, patients categorically reported that family members should be by their side when the cancer diagnosis is disclosed. Likewise, most patients reported that welcoming and involving their family members as partners was very important to them. Patients suggested that part of welcoming their family members was as simple as inviting family carers into the examination room during diagnosis and treatment. Patients also indicated that health providers should convey information to the family and that information provided to their significant other was highly important to them. A large majority of patients indicated that health providers should make themselves available to be contacted by the family, whether the contact was in person, by phone, or by email.

It is worth noting that Speice et al.’s (2000) findings have important implications in terms of a patient’s cancer trajectory. Patients indicated that when the physicians involved their family companions in the cancer trajectory, this was perceived as a welcoming gesture that had a positive effect in terms of the patients’ engagement with the treatment. Patients noted that when their family members were included as health care partners it encouraged
them “to get treatment” (p. 106). Likewise, patients also became more active in the medical decision-making process.

Speice et al. (2000) indicate that health providers tended to support the idea of welcoming the patients’ family members. Providers acknowledged that the family plays a crucial role in engaging the patient in treatment. Yet it is also the case that these same health care providers made significantly more negative comments about including the family in the patient-provider interaction on a day-to-day basis. Many health care providers felt uneasy about the potential for dysfunctional family dynamics that might be disruptive to the cancer treatment. They felt fearful and uncomfortable with being in the middle of these dynamics. Some providers also said that involving family members might put further pressure on their very limited time and tight schedules. Some providers indicated that they had not really been well prepared to disclose bad news to families. Health providers also indicated that including the family could bring to the fore personal and professional ethical concerns and dilemmas.

Speice et al. (2000) suggested that such results might be explained by health care providers being seldom engaged in self-reflection with regards to their own discomfort, personal biases and beliefs in terms of working with family members. For example, providers may not be comfortable in terms of witnessing stressful family dynamics during diagnosis or treatment and in knowing how to address such distress. Speice et al. theorize that despite providers’ unpreparedness or discomfort in working with families, family members will continue to accompany cancer patients during diagnosis and treatment. It is worth noting that Speice et al. did not interview family members but, instead, patients and health care providers. These providers were not only physicians but also nurses, doctors’ assistants, social workers and nurse practitioners among others. The present study explores family member-physician interactions during oncological treatment from the perspective of family members.

Shin et al. (2013) examined preferences for family involvement in cancer treatment decision-making from the perspective of the cancer patient and the family carer. According to these authors the current body of knowledge shows that family members are rarely included in the medical decision-making as they are often not seen as stakeholders within cancer care.
Shin et al. posit that as of 2013 the body of research within cancer continues to focus on the patient-physician dyad despite the overwhelming evidence that families take on major responsibilities in all aspects of cancer treatment. This study was a national survey where both patients and family members were asked separately about their preferences for family involvement in deciding cancer treatment options. Results of the study showed that 93% of patients and 89.6% of family members reported that the family should be involved in treatment decisions. Shin et al. cautioned that, given the above findings, current models of cancer care that solely highlight patient autonomy may in fact not respect patients’ interests and preferences. Thus these results add to the small but increasing body of evidence that medical decisions in cancer treatment lie within the realm of the entire family unit and not just the patient-physician dyad.

Summary

The above studies lend support to the crucial presence and participation of family members of cancer patients in oncological care. Of the reviewed studies, however, none explored family-physician interactions. To my knowledge, except for three studies, the literature continues to remain silent in terms of the family members’ experience of interacting with physicians during oncological treatments. Hence, little is known of how family member-physician interaction may figure significantly in oncological treatments.

I carried out a literature review of two electronic databases PsychInfo and Medline. These were searched in terms of “family member”, “companion”, “partner”, “loved-one” and were combined with terms such as “physician” “doctor” and “interaction” (i.e., family-doctor interaction, family member-physician interaction, partner-physician interaction, spouse-physician interaction). A total of five studies were identified. Of those studies, only Zeliadt et al. (2011) explored this area of inquiry. A second study by Waldrop et al. (2012) investigated the timing and nature of family-provider communication. But this study was confined to the latest stages of cancer at the time the patient was dying or approaching death just before hospice enrolment. The current thesis seeks to uncover the family member-physician interaction throughout the cancer treatment trajectory, from diagnosis onwards.
Whereas Zeliadt et al. (2011) explored spouse-physician interactions, it is also the case that there are significant methodological differences and differing purposes between Zeliadt et al.’s study and the current dissertation. First, I am interested in uncovering the lived experiences of family carers when interacting with physicians during oncological treatment. Second, Zeliadt et al. surveyed spouses exclusively. Moreover, it was solely within the realm of prostate cancer. In contrast, I explore the family member-physician interactions in any type of cancer and with participants who are not restricted to spouses. Study eligibility rested on family members having been actively involved in caregiving throughout cancer treatments. Third, Zeliadt et al. investigated the spouse-physician interaction at the time of the diagnosis. In my thesis I explore the family-physician interaction dyad during cancer treatment. Lastly, and more importantly, Zeliadt and the present study are based on different methodological paradigms. I am not using quantitative methodology or instruments such as the survey as is the case in Zeliadt et al.’s research.

The present thesis gathers qualitative information in the form of rich personal and unique narratives as they are shared in in-depth interviews. I generate phenomenological data and thereby gain access to the structures of meaning of the lived experience of family-physicians interactions from the perspective of the family member caregivers. I ask: *What is it like for a family member caregiver to interact with the attending physician while accompanying a loved one through cancer treatments? What is the nature of this interaction from the perspective of the cancer patients’ family caregivers? What do these interactional experiences mean to them?*

This study is grounded in the paradigm of hermeneutic phenomenology as defined by scholars such as van Manen (1990). I am not offering a hypothesis or measuring constructs, nor do I seek to generalize my research findings as empirical findings (van Manen, 1990). This thesis does not attempt to capture a detached-objective reality nor “assume that there is an objective real world independent of an isolated individual subject” (ten Have & Gordijn, 2014, p. 169). I am part of the story. The current study is grounded in subjective, personal narratives of the cancer experience as related by those who are living it. Knowledge is co-constructed through the stories that people tell and the interaction of the teller and the listener and through the interpretations of what is said (Gadamer, 1989). Through attending to participants’ reports
one is able to further uncover the richly contextualized meanings that these participants assign to their interactions with physicians in cancer treatments.

I engage in this research in the hope of making known to others what it is like for family members who daily accompany their loved-ones through cancer treatment, often under conditions of extreme distress, and who interact verbally and non-verbally with the attending physicians. I aim to show the significance of extended, familial relationality and connectedness in cancer medical care.
Chapter 3.

Methodology

The central aim of my study is to ascertain the meaning that cancer caregivers ascribe to their experiences of relating to the physician. I chose a methodology wherein I could be free to explore the experience as it is lived rather than conceptualized in advance. Phenomenology has informed all aspects of this study, including the research method, rationale for the study, and the research question. Given that methodology includes “the basic belief system or worldview that guides the investigator” (Guba & Lincoln, 1994, p. 105), this inquiry is rooted also in hermeneutics. In the section below I offer the reader the philosophical tenets of hermeneutics and phenomenology which informed this study.

I begin with a brief discussion of the philosophical, clinical, and methodological framework that informed this study as proposed by Marcel, Stern and van Manen respectively. I also introduce Foucault’s conception of the birth of the clinic and its underlying influence on current medical curricula that inform medical practices.

Situating my inquiry

Philosophical framework

This inquiry makes telling references to the philosophical thoughts of Gabriel Marcel (1889-1973). His themes of incarnate presence, intersubjectivity, participation, and availability are particularly relevant in providing a conceptual framework for physician-family relationalities of care. In conducting a literature review I realized that Marcel’s philosophical thought is seldom mentioned in the literature on medical or counselling practices. This is surprising given that the above notions are highly relevant to our day-to-day practices where practitioners are situated, involved, and in dialogue with others.

Marcel’s (1963, 1964) philosophy speaks of a human being who is situated in a certain context and in a certain experience with others. Marcel asks, under what conditions is it
possible that in my act of responding I meet the other in his or her appeal? How does the relationship between “[me] and a stranger” come to be? (1963, pp. 38-40). For Marcel, responsiveness demands the primacy of an authentic intersubjective relation wherein one places oneself in others’ situation and makes oneself available. At the core of humanness is to be present, involved, available, and in communion with others (Marcel, 1964). Marcel’s notions of presence, intersubjectivity, and availability are intertwined and now I will touch briefly on them.

At the heart of Marcel’s philosophical inquiry is his notion of the non-reducibility of human existence. Philosophy is “not rational or logical but existential” (Marcel, 1964, p. 15) and the central task of philosophy is “restoring to human experience its ontological weight” (Marcel, 1963, p. 74). Marcel speaks of a philosophy that is incarnated, dialogical, reflective, and rooted in concrete experience (1964, pp. 12-17). He turns his attention to the need to restore the primacy of concrete experience. Lived experience is about “the everyday life. The everyday life pure and simple” (Marcel, 1967, p. 194). Thus, for Marcel, a concrete philosophy must turn to the subject and to his or her subjectivity. Although Marcel acknowledges the great advances of sciences made possible through Cartesian reductionism he rejects abstractionism and the reduction of the person to an impersonal thing, “to an image, to a representation” (1967, p. 78). Marcel embraces the subjective quality of the human condition. He sees human beings as incarnated beings with values, aspirations, expectations, goals, evident in lived experience.

The death of his mother at the age of four, and his later experience during the first world war had deep and lasting effect on Marcel’s thought. He speaks of how he first encountered the notion of commitment, availability, and presence when due to his poor health he was not called to serve on the war front (Marcel, 1963). Yet he could not envision being detached from what he calls a background of grief, death, and profound distress. Instead, putting himself in the position of others, he volunteered with the Red Cross where his participation entailed providing information to family members about their missing or injured loved ones. He described his job as one surrounded by death. It is against this background of war that Marcel would later turn his reflection into the question of being and existence. In relating his experience joining the Red Cross, Marcel writes:
I cannot bear the idea of being an outsider... The principal object of my work was to give information to those families who came to ask for news of soldiers reported missing.... Whenever I could, I made the point of seeing personally those who came to make inquiries and, far from treating them as mere cases from the files, did my best to show them the greatest possible sympathy. This gave me the opportunity of coming into contact with many people from all walks of life and of making a constant effort to put myself in their place, in order to imagine the anguish, they all shared. (Marcel, 1963, pp. 36-37)

To exist is to participate. “To say ‘I exist’ is to say I am in the world, I am involved in a consensus” (Marcel, 1967, p. 194). Participation demands to be present for the other. The other exists only in so far as the other and I are in a genuine contact, and this encounter is always incarnated. Presence is always to be present for the other. It is thus something that we sense and experience and is intrinsically tied to participation, availability, community, and intersubjectivity (Marcel, 1963). Marcel contends that presence is at the root of what it means to be human and is at the heart of ethics. Presence is tied to offering one’s resources to be at the disposal of others (Marcel, 1964). Presence is always incarnated. It unfolds in gestures, whether a gentle and welcoming smile, a comforting eye contact, bodily positions of attentiveness, a hand shake of understanding and support, or a simple touch conveying receptivity to the other’s emotional expressions.

Being is not a being detached from others, but a being “with” others in intersubjective relations. “Presence is intersubjective” (Marcel, 1967, p. 153) and interrelatedness is embodied in the preposition “with” bringing into presence a certain quality of being and “an increasing intimacy” (Marcel, 1963, p. 41) creating a certain bond among subjects who recognize each other as such. Recognition of each other as human beings ultimately leads to co-presence (p. 67). Only the recognition of two presences can lead to understanding and charity (Marcel, 1951).

Presence is also tied to the notion of disponibilité, that is, making oneself available to the other person. Presence requires what Marcel calls a willingness to make the self disposable to the other. Marcel suggests that his notion of disponibilité/availability is an invitation “to be” and to be “at home” or, in Marcel words, “chez soi” (1963, p. 127). Marcel highlights the reciprocal and interrelated quality of human presence and disponibilité. To be present, he notes, is to make myself available to the other’s reality. Being with the other is to respond. It is
an experiential attunement, a receptivity, an openness to being with the other, with oneself, and with what the other may offer.

Thus Marcel proposes that as human beings we are essentially connected to others, whether in our personal spheres or in our working fields. Our knowledge arises by participating, by being in dialogue with others whom we encounter, and by being present and available to the community in which we are situated. Presence evokes the resonance of what Marcel calls the “between you and me” or being with the other person(s). “Intersubjectivity is essentially an openness” (Marcel, 1967, p. 239) and this openness lies in the very quality of recognizing the other’s personhood. It is an openness without forethought, reservation, judgement, or prejudice.

Clinical Framework

This thesis is also situated within Daniel Stern’s clinical framework. As previously stated, I am a psychotherapist and my clinical work is informed by Stern’s clinical sensitivities (1985, 2004). Of crucial importance to this study are Stern’s propositions of “moments of meeting,” “affect attunement” “intersubjectivity,” and implicit/nonverbal knowing. These notions are referenced throughout this dissertation. Daniel Stern (1985, 2004), a renowned researcher in interpersonal interactions and human relationships within the context of children’s development and psychotherapy, observed that within the infant-mother dyad, prior to the emergence of language, the infant and mother have the capacity to communicate their feeling states to each other. Stern described a synchrony of intermodal perception, a kind of ‘dance,’ that brings a sense of intimacy and vitality to the infant-mother interaction (Ammaniti & Ferrari, 2014). In this infant-mother dance affect is communicated: the mother lets the baby know that she has grasped the baby’s subjective world (Stern, 1985, 2004). Stern calls this “the path to sharing inner feeling states” (2004, p. 84) or “affect attunement” (p. 84). It occurs at the level of implicit knowing and gives rise to intersubjectivity.

Stern’s (2004) notion of intersubjectivity is central to this study. He defines intersubjectivity as the “sharing of subjective experience” (p. 368) and argues that human beings are primed to share the other’s mental landscape, even if only briefly. The sharing of
each other’s mental landscape gives rise to co-created moments of mutual confirmation of experiences or intersubjectivity (Stern, 2004). In Stern’s words, it is the sense of, “I know that you know that I know’ or ‘I feel that you feel that I feel’” (p. 75) that matters. We live with others, we wish to be known, and understood by others (Stern, 2004) and we develop “through dialogue with other persons” (p. 181). We are born with the capacity for intersubjectivity and this intersubjectivity is a survival need and “a condition of humaneness” (p. 97). Through my work as a therapist I have observed that at the core of “sympathy, identification, empathy, sensitivity, caring, and loving” is intersubjectivity (Stern, 2008, p. 181). One may then ask, what are the evidentiary revelations of an intersubjective contact between the family and the physician?

What bodily and verbal expressions regulate the family-physician intersubjective field? As a practicing therapist, Stern’s implicit relational knowing, “nonverbal” knowing (2004, p. 113), is of crucial significance in interactions. Nonverbal knowing is a felt sense of knowing comprised of “affects, expectations, shifts in activation and motivation” (p. 114). As a therapist I need to pay close attention to gestures, movements, stances, positions, tone of voice that are revelatory of feelings and of the internal world of the patients I face. Bodily knowing allows me to bring into conscious awareness what is implicitly happening in the therapist-patient dyad as the “moving along” of therapy unfolds (Stern, 2004). In fact, both the therapist and the patient pay close attention to each others’ bodily expressions. As Stern writes, the “simultaneous reading of patient and therapist occurs largely unconsciously” (p. 120). What is the ‘reading’ of the physician by the family carers? It is worth noting that Stern, like Marcel, also places importance on presence since, as he noted, psychotherapy demands one to be fully present in the now moment, present moment (Stern, 2008).

**Historical Framework**

Lastly and briefly, throughout this thesis the reader will be exposed to the work of the French philosopher Michel Foucault (1973) and his seminal work, *The Birth of the Clinic*. Foucault’s thoughts influence this thesis in making visible the invisible framework of Cartesian biomedicine that is currently institutionalized within modern day medical practices. This
Cartesian framework upholds a belief system where detachment and desensitization are considered best practice. These beliefs are entrenched within the medical school curriculum where objectivity, reductionism and abstraction are central to current medical worldview, with lasting effect on new doctors who put this desensitization into their own daily practices.

In his book on the *Birth of the Clinic* Foucault (1973) provides an in-depth analysis of the conditions under which the birth of the modern hospital took place, highlighting three crucial notions: the *gaze*, the *case*, and the *clinic*. Foucault suggests that the *clinic* is a space of visualization where only the disease is *seen* and thus made visible. With the birth of the clinic, the teaching hospital became the place where the previous art of medicine was transformed into a ‘discipline’ and a ‘professional medical practice’ through a discourse of rationality and biological reductionism. In referring to the *gaze* of post-scientific revolution, Foucault (1973) writes of how discursive practices of the eighteenth century determined “the conditions of possibility of medical experience of modern times” (p. xix) from which “we have not yet escaped” (p. 198). Such practices brought new ways of *seeing* and a new *medical gaze* (Foucault, 1973).

The *gaze*, refers to “the ways in which the objects of medical knowledge—human beings—come to be viewed and understood” (Heaton, 1999, p. 769). For clinical medicine to emerge as a body of knowledge it required “a new definition of the status of the patient in society” (Foucault, 1973, p. 196). The medical *gaze* of the seventeenth century defined what constitutes *the case*, namely the human being “who became an object of study” (p. 114) seen and described in scientific discourse:

Caucasian female, 16 years; known non-Hodgkin lymphoma. Multiple admissions for chemo admin., fever and neutropenia. Physical exam positive for diffuse obesity, scalp alopecia, facial and truncal acne, grade II striae, loss of muscle bulk, particularly in central areas. (Lander & Graham-Pole, 2008, p. 155)

Foucault (1973), however, posits that this medical gaze, contrary to the ‘objective’ paradigm proposed by the eighteenth-century philosophers of science, is not neutral, unprejudiced, or value free.
In the next section I offer to the reader an account of the methodology that informs this study as well as the method of data generation and analysis.

**Phenomenology**

Phenomenology is the study of “lived experience,” writes van Manen (1990, p. 9) and thus “always begins in the lifeworld” (p. 7). Phenomenology is concerned with uncovering and “gaining a deeper understanding of the nature or meaning of our everyday experience” (p. 9). Phenomenology is not only a research method but it is also a philosophical movement (Finlay, 2009; Sloan & Bowe, 2014; van Manen, 1990, 2014). It is worth noting that as a research approach phenomenology encompasses several streams (Finlay, 2009). Phenomenological research does not seek to provide scientific explanations; it is concerned instead with methodically describing and understanding the essence of the phenomenon as it is lived by participants (Finlay, 2009; van Manen, 1990), and “giving voice to it” (Sloan & Bowe, 2014, p. 1293).

Husserl, the founder of phenomenology, spoke of “going back to the things themselves” (van Manen, 1990, p. 45) as they are lived before we reflect or impose judgement on them (Finlay, 2009; van Manen, 1990). Husserl wanted to uncover how the event or phenomenon “presents itself to consciousness” (van Manen, 1990, p. 9). To gain access and to reflect on the “life-world,” the phenomenological researcher must suspend previous assumptions, pre-conceived ideas, theories, beliefs, judgements, and values in a process described as the epoché or bracketing (van Manen, 1990, p. 48) in order to explore the experience as it is lived (Finlay, 2014; van Manen, 1990). “Phenomenology must describe what is given to us in immediate experience without being obstructed by pre-conceptions and theoretical notions” (van Manen, 1990, p. 184). It is only by bracketing our knowledge that the phenomenon under study, the “thing” itself as Husserl states, can emerge and be understood free of bias (van Manen, 1990). It is by “bracketing off” our assumptions, in the process known as the phenomenological reduction, that the very essence of the phenomenon can become known (Finlay, 2014). This is the *phenomenological attitude* that allows the researcher to see “with fresh, curious eyes” (p. 122).
Hermeneutic phenomenology

Martin Heidegger, a student of Husserl, brought about a major shift in phenomenology with the publication of *Being and Time* (1962, English translation). Heidegger turned his attention to the question of meaning and everydayness (Polkinghorne, 2000, p. 453). For Heidegger (1962) uncovering meaning in everyday events is inherently tied to the act of interpretation, taking hermeneutics, “the branch of knowledge that deals with interpretation, especially of the Bible or literary texts” (Online Etymology Dictionary), and applying it to human beings and our Being-in-the-world (Polkinghorne, 2000; Gadamer, 1989). “The meaning of phenomenological description as a method lies in interpretation” (Heidegger, 1962, p. 61). Thus descriptive phenomenology became an interpretive or hermeneutic phenomenology.

Heidegger (1962) notes that without Husserl’s phenomenology of turning “to the things themselves” (p. 58) the examination of Being would not have been possible. Yet, where Husserl proposed that objectivity could be found in the bracketing of one’s experiences, biases, beliefs and judgements, Heidegger instead stressed that humans are interpretive beings, and thus our ‘Being-in-the-world’ and Being-with others is “never a presuppositionless apprehending of something presented to us” (Heidegger, 1962, pp. 191-192). “Interpretation is grounded in something that we have in advance…in something we see in advance…in something we grasp in advance” (p. 191). We encounter the world through the prism of our perspective and through the knowledge we already have (Finlay, 2014; Vessey, 2009) and our understanding is always contextually situated. Central to my work as a practitioner-researcher is the awareness that all knowledge is filtered through my own lived experiences and that my assumptions, biases, and beliefs can influence the questions put forward in the study and the interpretation of the answers.

For Heidegger (1962) humans are inherently linked to their socio-culture world and to others, and this relatedness is always through discourse. It is through discourse and language that *Dasein* (being-there) is “made known” (p. 205). Being-in a certain mood is “made known in
discourse and indicated in language by intonation, modulation, the tempo of talk, “the way of speaking” (p. 205).

**Horizon of understanding**

For Gadamer (1989), in turn a student of Heidegger, understanding and language are at the core of the hermeneutic inquiry. He posits that understanding unfolds through a dialogue between two parties: the researcher and the streams of words to be interpreted. Gadamer (1989) underscores the significance of understanding and language and the dynamic dialogue between the text and its interpreter. Yet the researcher does not come to the linguistic encounter devoid of assumptions and beliefs. Interpretation does not involve “neutrality nor the extinction of one’s self” (1989, p. 238). Vessey (2009) notes that Gadamer, borrowing from Husserl and Heidegger, coined the term “fusion of horizons” (p. 531) where “the horizon is everything that we are aware of” (p. 534) such as our “beliefs” (p. 536). Thus, becoming aware through a process of reflection of one’s biases, prejudices, and suppositions is critical to the process of interpretation and dialogue (Vessey, 2009). Understanding unfolds through language and dialogue and in the fusion of perspectives by which we interpret our everydayness (Vessey, 2009). Gadamer thus reminds us of the importance of reflection as one reads the text. As a researcher I needed to fuse my understanding with that of participants through the interpretation of the texts of our verbal exchanges.

**Method**

Max van Manen (1990), a scholar from the Dutch Utrecht School, offers a method that draws from both the Husserlian and Heideggerian traditions. His method is descriptive as well as interpretive. Central to van Manen’s interpretive phenomenological approach is language where the description of the lived experience requires thoughtfulness, sensitivity, and “an evocative ‘tone’ of language” (p. 122) that allows us “to see” the experience as it appears. van Manen’ interpretive phenomenology aims at offering concrete and thoughtful descriptions through a process of writing and re-writing (van Manen, 1990).
Phenomenology seeks to uncover structures of meaning and thus requires an attitude of wonder and attentiveness (van Manen, 1990, 2014). For van Manen, “to do research is always to question the way we experience the world” (p. 5). As such it does not impose a set of rules that must be followed. It is worth noting that van Manen’s method has become particularly popular with health care professionals in the realm of counselling, social work, nursing, medicine and for researchers exploring the lived experiences of those afflicted by illness (Dowling, 2007; Heinonen, 2015; van Manen, 2014).

As a practitioner, this study is situated within van Manen’s (2007, 2014) *Phenomenology of practice*. As a health professional and researcher, I am “interested in the promise that phenomenology can make to practice” (p. 13) and more specifically to clinical practices. Central to this study is van Manen’s work in challenging the idea that reductionism and objectification are the only lenses through which to construct valid knowledge. He instead proposes a knowledge that is pathic: “corporeal, relational, temporal, situational, and actional” (van Manen, 2014, p. 270). I ask how as practitioners we can comport ourselves in the everydayness of our professional lives to be “completely present” (van Manen, 2007, p. 14). The concern of a "phenomenology of practice" is to offer insightful and sensible knowledge “in how to act in everyday situations and relations” (p. 13). In the everydayness of medical practice, we are situated in relations and thus our routines, our ways of acting, and our ways of *being* are informed beyond what scientific knowledge can offer. Our professional stance, sensitive responsiveness, and thoughtful acts need to be attentive to a knowledge that “remains oriented to the experiential or lived sensibility of the lifeworld” (p. 20). Pathic knowledge is committed to be attentive to:

- the sense and sensuality of the body, personal presence, relational perceptiveness, tact for knowing what to say and do in contingent situations, thoughtful routines and practices, and other aspects of knowledge that are in part pre-reflective, pre-theoretic, pre-linguistic…our gestures, the way we smile, the tone of our voice, the tilt of our head, and the way we look the other in the eye are expressive of the way we know our world and comport ourselves. (p. 22)
Participants

In this inquiry I explored the lived experience of family-physician interactions in advanced cancer treatment from the perspective of the cancer patients’ family. I wanted to hear, in their own words, about their interactions with the physician(s) involved in the care of their loved ones. In this dissertation, “family member(s)” will be defined as “those persons with significant interests and roles in the patient’s life, including spouses/partners, parents, siblings and children” (Speice et al., 2000, p. 102). For the purpose of this dissertation the word family member(s), family carer(s), family, and family caregiver(s) are used interchangeably referring to those family members of patients who were actively involved and present throughout their loved ones’ cancer treatment and who had interactions with the physicians providing care to their loved ones (see Appendix A and B).

I selected participants who had first-hand knowledge of the lived experience in question (Kleiman, 2004). To take part in the study participants needed to be 19 years of age or older, male or female, and have been actively involved in the care of a loved one through cancer treatment and have interacted with the physicians providing care. Participants also needed to be fluent in English. Participants were invited to take part in a face-to-face, in-depth interview. I placed posters in several community settings: two local universities, at a library poster board, as well as on posting boards at local recreational/community centres. Participants were also drawn from personal contact and word of mouth referrals. (See Appendix A for pamphlet).

Interview procedures

I selected the in-depth interview as a tool to gather the data, placing emphasis on what van Manen (2014) calls the “where, who, when, why and how” of phenomenological interviews (pp. 314-315). I conducted all the interviews personally. To ensure participants’ comfort, interview locations and times were chosen by them. In-depth interviews were audiotaped and then transcribed verbatim. Interviews lasted one and a half to three hours and the questions were open-ended. Participants were not required to provide their names and they chose a pseudonym to protect their identities. Participants were largely drawn through
word of mouth, with participants being aware that my thesis centred on being a cancer caregiver. My first informal meeting with the participants was face-to-face, with the exception of one participant who I contacted first by email. In this first informal meeting we explored potential participation and reviewed the inclusion criteria. We also spoke about the aim of the study, the logistics of participation, and the potential risks. All participants met the criteria for participation and all agreed to take part in the study. The final sample was comprised of five women.

Prior to the interview I emailed the participants the informed consent document detailing the goals of the study, what their participation would entail, any potential risks, and their rights as study participants. I assured the participants that they could contact me via email or phone should they have any additional questions, (see Appendix A for informed consent). On the day of the interview, I asked the participants to carefully read the informed consent document. Again I encouraged participants to clarify any additional questions they might have regarding the study and/or their participation. Participants then signed the consent form. Data collection began January 2013. The last interview took place in early 2015.

The Ethics Board of Simon Fraser University approved this study.

The Interview

van Manen (2014) notes that the phenomenological interview is a tool “for exploring and gathering experiential material” and that the “phenomenological interview aims for pre-reflective experiential accounts” (p. 314). I was interested in gaining access to the complexity of the family carers’ experiential world as they interacted with their loved one’s physicians. In-depth interviews permitted me to explore the everydayness of the participants’ experiences: their thoughts, feelings, meaningful moments, and vivid images of what they found significant, as related in their own words (van Manen, 2014). van Manen notes that the interview should unfold as “a conversation” (p. 315) rather than a formal interview. The conversational interviews make possible a dialogue, “to tell and share their “lived experiences,”” (p. 314) between the researcher, those “sharing” their experience, and ultimately the reader in reading
the text. It is this ‘telling’ and ‘sharing’ that gives rise to a deeper and more intimate understanding of how humans live out the events of daily life (van Manen, 1990, 2014).

I drew from my experience as a clinical counsellor with over sixteen years of experience to facilitate the unfolding of participants’ stories. Consistent with my counselling background and van Manen’s conversational approach, I opened our dialogues by encouraging the participants to recount a time in their loved one’s cancer treatment during which they interacted with the physician in as much detail as they felt comfortable, including their thoughts, feelings, moods, and the significant events that came to mind (van Manen, 1990, 2014). As a counsellor, active listening is the crux of building rapport, facilitation of empathy, and the unfolding of the story. I kept my verbal responses to a very minimum. Using my skills as a counsellor I actively listened to the story, using paraphrasing, reflective listening skills, and open-ended questions. I also used prompts, minimum encouragers such as nodding, and silences that facilitated the unfolding of the story.

Crucial to the conversational interview is trust, rapport, and empathic understanding (Kleiman, 2004). As van Manen (1990) suggests, and consistent with my counselling background, I avoided asking too many questions that could interfere with conveying an empathic understanding, or become a roadblock to empathic communication. This is even more pressing when the lived experience is one that involves personal reflection on illness or a “fragile matter” (p. 315). van Manen (2014) suggests “a personal sharing” (p. 315) to foster trust and rapport which in turn allows participants to feel comfortable in opening up and safely sharing their experiences.

My personal experience was an important factor in facilitating rapport and trust with the participants. All participants knew that I had also been a family member caring for a loved one diagnosed with and treated for cancer. Participants were also aware that my husband had died in the course of treatment. In a sense there was a feeling of having shared in a common experience. Participants also knew that I work in clinical counselling within a hospital setting. I made sure participants felt comfortable while addressing the questions. As a therapist I am comfortable with silences and how respecting silences may further facilitate rapport. I also
used gestured nuances such as nodding. I needed also to be attentive to relational boundaries and thus participants knew that my stance was that of a researcher rather than a counsellor or fellow caregiver.

Consistent with van Manen’s “where and when” (2014, p. 315) of hermeneutic phenomenological interviews, participants selected the time and location for the interview. All participants chose to carry out our conversation in coffee shops located within the Greater Vancouver area. Participants were aware that the length of the conversation was up to their discretion. I allowed myself sufficient time so that no participant would feel rushed and so that the conversation would unfold fully.

Questions

What is it like for family member caregivers to interact with the attending physicians throughout cancer treatment? What are the meanings that are embedded in this interaction? What meanings do family carers assign to their interaction with physicians? These are the questions that guided my study. While I encouraged the participants to relate their stories freely, I also prepared guiding questions, followed by prompts (i.e. can you tell me more about...? if you could give me an example?) to trigger further reflection. In line with van Manen’s suggestion, I actively listened to the narratives against the background of the interview question. Questions were left open and asked only if they were not covered spontaneously by the participants. An example of guiding questions was: What was it like for you to interact with the attending physician while accompanying your loved one through cancer treatment?

Data analysis and interpretation

I followed van Manen’s data analysis and thematic interpretation as proposed in his books on Researching Lived Experience (1990), and a Phenomenology of Practice (2014). The below framework is a synthesis of van Manen’s (1990) “methodological structure of human science research” (p. 30):

1. One must discover and turn fully to the phenomenon of study.
2. One must investigate the “experience as we live it”, in all its aspects, “rather than conceptualize it.”

3. It is necessary to reflect “on the essential themes which characterize the phenomenon,” that is, thoughtfully asking oneself: what makes this experience significant? What is essential to this person’s experience of having a family member undergo cancer treatment?

4. One describes the phenomenon through “writing and rewriting”: it is about a rich and deep interpretation of evocative descriptions. Lastly, it is to consider the parts as well as the whole. (pp. 30-31)

In facilitating the process of revealing themes, van Manen proposes three narrative reading approaches: the wholistic, the selective, and the detailed approach (2014, p. 320). I used the wholistic reading approach and the selective reading approach (for a review of van Manen’s thematic approaches, see van Manen 1990, pp. 31-32 and van Manen 2014, pp. 320-321). In using van Manen’s wholistic approach, I needed to fully immerse myself in the narratives to grasp the meaning of the text holistically. Thus, I needed to be open to the stories being told, at the same time examine my biases, preconceptions and prior personal knowledge. I paid attention to particular phrases or expressions that might capture the “hidden meaning” of the story or the significance of the narrative “as a whole.” In the selective meaning approach, I listened and re-listened to the recordings and read and re-read the text while asking myself “what statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described?” (p. 320). I attended particularly to phrases that were evocative of the meaning of the experience, highlighting those phrases or text expressions.

Based on van Manen’s framework of thematic analysis, I used the following protocol to conduct an in-depth exploration of the interview transcripts. First, I listened to the tape multiple times to obtain a global sense of the participants’ narratives. I then transcribed the entire audiotape verbatim. Later, while listening to the audiotape, I was attentive to the tone of voice and changes in the voice tonality as well as giving attention to pauses or long silences that might be revelatory of affectivity. I made notes of those nuances. I read the entire text several times against the background of my notes. Consistent with van Manen’s suggestion, I slowly read and listened to the recording, pausing and asking myself: What does this narrative tell me as a whole about the experience of this family member interacting with the physicians?
Throughout the entire data analysis process, I went back to my notes about my personal knowledge of the experience as well as prior literature in the area (Kleiman, 2004). I then wrote my impression of the global sense of the experience of family caregivers interacting with physicians during cancer treatment, as voiced by the participants (van Manen, 1990).

I then turned my attention to identifying the essential themes and sub-themes embedded in what was said. To accomplish this, I went back to the paper transcripts, and re-read the text, this time with the goal of capturing words, phrases, or passages that stood out and that seemed to describe compelling aspects of the experience. I asked myself: What is powerful here? What is the meaning embedded in the words that seem to stand out? Using Finlay’s (2009) words: From these passages, “what comes to life?” I then highlighted those passages and wrote tentative captions on the side of the page. I repeated this process several times, checking if the phrases or passages I selected connected to other passages in the text. I then clustered related themes and sub-themes, trying to give names to the themes and sub-themes by using evocative words from the participants’ narratives or expressions that best captured the meaning embedded in the theme.

As I listened to the audio recordings I paid careful attention to what Foley and Gentile (2010) call the interrelation of the verbal and non-verbal. Thus, while paying attention to each word spoken I was also attuned to the unspoken rhythms, volume, intonations of the voice, pitch of the speech and, long silences (Foley & Gentile). The listening and reading and re-reading of the text also unfolded against the background of my personal reflections and field notes that I had written immediately after the interview. These field notes included moments in which participants’ voices became soft or broken, or where the tempo of the speech was one of slowness, pause, tearfulness, or long silences. I entered some of the unspoken cues in the narrative excerpts in square brackets. My field notes also included observations of facial expressions, gestures, eye gazes, and the interpretations I made of those gestures as the interview concluded (Kleiman, 2004).

As preliminary themes and sub-themes began to emerge, I wrote down my initial interpretations and tentative understandings of what the caregivers’ interactions with the
physicians meant to them. Throughout the thematic analysis I kept a stance of “attentive openness” (Kleiman, 2004, p. 8) to the unique meaning of the stories. Central to van Manen’s interpretive phenomenology is the “art of writing and rewriting” (van Manen, 1990, p. 31) of the text and reflection on the essential themes. “Hermeneutic phenomenology is fundamentally a writing activity” (p. 7) and, accordingly, the text was written and re-written as I balanced the parts and whole. This was a messy, frustrating, and exhausting process.

Kleiman (2004) contends that the interpretive phenomenological analysis must also turn to the disciplinary perspective that informs the researcher. I asked myself: What implicit meaning could these narratives have for my practice? For medical practices? And what is the significance of this study for future medical practices? How can the physician-family carer interaction impact the overall wellness of the family? As I wrote the text I reflected on the uniqueness of “transposing” my “insights into a textual form” (p. 8). It is through this process of writing and rewriting that I “entered the world of the text” (van Manen, 2014, p. 359). While the process of writing and rewriting was fraught with many challenges, writer’s blocks and mental resistances, it also gave me the opportunity to uncover new insights, challenge pre-conceived notions, and gain a deeper understanding of the relational nuances of family-physician interactions during cancer treatment.

The text is typically worked by presenting excerpts from participants accompanied by my interpretations. This is followed by the work of phenomenological scholars, such as Marcel, Stern, and Foucault, to flesh out the significance of the themes as they are lived. I also include empirical medical literature, as well as literature written by physicians since this thesis is largely oriented to clinicians and health care professionals working in in-patient settings or in the community. The protocol discussed above informs the reader as to how I carried out the thematic analysis. “The preferred method for human science involves description, interpretation, and self-reflective or critical analysis,” writes van Manen (1990, p. 4).

**Hermeneutic self-reflective/critical analysis**

The uncovering of fundamental themes is not a “rule-bound process” (van Manen, 2014, p. 320). Themes, rather, are brought to light through “insightful invention, discovery,
and disclosure” (p. 320). It follows that reflexivity or “reflecting critically on oneself as a researcher” (p. 292) is crucial for the interpretation. Throughout the course of this inquiry I embraced a reflexive stance. Reflexivity is something that I practice in the day-to-day realities of my work as a psychotherapist. I paid close attention to my prior understanding of the experience, of how I see the world, knowing full well that while “the self retreats or steps back” it does so “without completely stepping out of his or her social, historical, biographic being” (van Manen, 2014, p. 359).

I continuously reflected on the essential themes throughout the data analysis. I kept notes of assumptions, expectations, presuppositions, biases, and prior knowledge that could potentially influence my understanding of what the participants told me. Full bracketing is not possible but it is also part of the hermeneutic tradition (Finlay, 2014; Kleiman, 2004; Tuohy, Cooney, Dowling, & Murphy, 2013). I also reflected, in terms of being attuned to non-verbal behaviour, on the potential impact of my questions. Reflection led me to further immerse myself in the data and again to reflect deeply on what participants had said. This is the self-reflected stance that strengthens the credibility of the present findings of this thesis.

As a researcher, health care practitioner, and family member of a cancer patient, I have come to the research process with prior experiential knowledge, professional knowledge, and past assumptions. Thus, embracing a reflexive stance has been a central focus of my responsibility as a researcher from the very conception of this thesis and throughout the entire research process. For instance, an assumption on my part was that participants would be mainly spouses acting as caregivers, however my assumption was not borne out. In fact, none of the participants were spouses. Another of my pre-conceptions was that physicians’ nuances of compassion in the interaction would be stronger when patients made the transition into palliative or end-of life care.

Kleiman (2004) suggests that as part of the research process the researcher turns to the critical analysis of one’s work. Below I offer a summary of criteria to evaluate hermeneutic phenomenology. I ground this section again in the work of Max van Manen (2014). I also offer
to the reader a brief synopsis of the specifics of how I met these criteria in the creation of this dissertation.

**Criteria to evaluate hermeneutic phenomenology**

Scholars caution us against evaluating qualitative research with standards (i.e. inter-rater reliability) designed to assess quantitative methodology (van Manen, 2014; de Witt & Ploeg, 2006). Such practices become even more troublesome when they are applied to hermeneutic phenomenological research (de Witt & Ploeg, 2006). Interpretive phenomenology is not a step-by-step method and it does not aim to produce measurable and replicable outcomes (van Manen, 2014). Rather, interpretive phenomenology is concerned with the meaning and “intuitive understanding” (p. 351) of the event through a process that is “ambiguous” and “never complete” (p. 351). So “how” is it that one “appraises a phenomenological study?” (p. 355). For van Manen, the evaluation of the research inquiry rests with the one reading the text. He suggests asking oneself: “Does the text induce a sense of contemplative wonder?” “Does the text offer rich and recognizable experiential material?” “Does the text ‘speak’ to and address our sense of embodied being?” (pp. 354-355).

The power of interpretive phenomenological texts, writes van Manen (2014), lies in a text that “speaks” to the reader in a manner such that he or she “recognizes the plausibility of an experience even if he or she has never personally experienced this particular moment or this kind of event” (p. 240). For the text to ‘speak’ it needs to be *vocative*. “The project of phenomenology not only rests on the critical role of the reduction, it also requires the expressive method of the vocative” (p. 240). A *vocative* text is one that describes the experience in as vivid detail as possible so that the text instils vivid images inviting the reader to “phenomenologically reflect on it” (p. 287) and bring the experience “into presence” (p. 285). The text *speaks* to the reader in a manner that is “sensed,” “felt,” and “lived” by the reader. It becomes recognizable and familiar.

At the very core of this study I have attempted to bring to the reader concrete, detailed, and evocative descriptions. My goal was to produce a text that “resonates” with the reader: one that admits into presence the meaning of the interactions that physicians have with the
families of cancer patients. This is the power of the text. The vocative words allow the reader to “suddenly see” (van Manen, 1997, p. 345) “feel,” and “sense” the nuanced dynamics of the physician’s interactions with family carers.

Interpretation is the essence and goal of hermeneutic phenomenology, with the researcher going beyond the realm of the participant’s words (Gadamer, 1989). “Interpretation” is not “simply reproduction” (p. 386). In this thesis, I attempt to engage the reader in a written text that is thoughtful, alive, and addresses the reader (van Manen, 2014). To do that, I provide experiential and detailed “thick” descriptions in the form of participants’ excerpts, keeping always in mind the tone of what is said in the hope that readers “sense,” “feel,” and bring into “presence” (van Manen, 1997, p. 353) the experience of these family carers. As I reread the text I went beyond the realm of what was said but remained attentive to the participants’ voices. Their emotional and vivid descriptions are intertwined with telling philosophical thoughts, my own reflections, phenomenological writings, and knowledge from medicine to offer thoughtful and new interpretations in the hope that the text will grasp the meaning of being-in-the world for family caregivers when interacting with the medical professionals.

I attempted to capture rich and insightful experiential descriptions even at the risk of being repetitive, wanting to convey the stories as they were lived by the family members. A slow text puts into words the passage of time from diagnosis to treatment and death. By slowing the text, there is an intense tone, a certain kind of moving slowly from the instant that the word cancer makes itself present. In this way I try to evoke a real sense of what the experience was like for the one living it. For van Manen, tone, vividness, texture, concreteness, and detail in the participants’ accounts are crucial. The experience as it is lived comes alive through writing and rewriting. Writing is, as van Manen posits, the embodiment of the phenomenon. Through a text that “speaks,” participants’ voices and my voice come alive. Thus my goal was to produce a text that “speaks” to the reader and to the affective dimensions of “our professional lives” (van Manen, 2007, p. 13). This is the “feelingly understanding” (van Manen, 1997, p. 360) that induces “contemplative wonder” (p. 355).
The researcher

“Phenomenological engagement is always personal engagement” (van Manen, 1990, p. 156). “I am not just a researcher who observes life” (p. 90). Youngson (2011) speaks of “a defining moment when personal commitment becomes absolute” (p. 38). For me, and as previously mentioned, this defining moment came when my husband attended 18 months of inpatient and outpatient cancer treatment. I cannot remain indifferent. A researcher’s background and experience are central to the hermeneutic phenomenological method. van Manen (1990) proposes that a phenomenological question must have been “lived by the researcher” (p. 44) and that “the problem of phenomenological inquiry is not always that we know too little about the phenomenon we wish to investigate, but that we know too much” (p. 46). My own personal experiences of interacting with physicians while caregiving for my husband plays a significant role in the research process, influencing the interview process and the lenses through which I, as a researcher, see, interpret, and find meaning in the spoken and silent exchanges. Yet, notes van Manen, what we “already know” cannot be suspended. Rather, our assumptions, biases, prior knowledge, and pre-suppositions must be acknowledged. The investigator must make clear the stance that influences an interest in the phenomenon being examined. My own background must be made explicit to the reader since it is this background that influences the topic and the research methodology that I have selected for this study.

Throughout this research process I oriented myself as a woman, a past cancer caregiver, a health care practitioner, and a researcher. Currently I am completing my doctoral dissertation at Simon Fraser University. For the last eight years, I have worked as a psychotherapist within a 21st century bio-medical hospital located within the Greater Vancouver Region. I am part of three multidisciplinary teams providing clinical services for specialized medical clinics. Health care providers include infectious disease physicians, cardiologists, endocrinologists, psychiatrists, clinical pharmacists, social workers, nurses, nurse practitioners, and physiotherapists among others. Within these specialized clinics, I provide clinical counselling to patients who, because of a major or traumatic health event, are affected by mental health issues such as depression, anxiety, panic disorders, PTSD, trauma, and the complications of bereavement. Our program, which is a joint venture of biomedicine and
mental health, aims at responding to the need to provide holistic and compassionate care to those whose lives have been suddenly interrupted by a major health event.

As a counsellor, I am aware of the importance of compassion in the space of care that I inhabit daily. Counselling requires compassionate counselors with professionalism being more than the acquisition of skills and technical knowledge. Professionalism also requires sensitivity, respect, an attitude of availability, free of biases and assumptions, in receiving the other. It requires being open to understanding the client’s worldview. My own development as a counsellor has solidified the importance of entering the world of the client with humility so that I can appreciate and respect the client’s life experiences, suffering, hopes, values, and spiritual beliefs. Humility provides a way of being compassionately present throughout the healing encounter.

I have also been teaching counselling courses at Simon Fraser University for twelve years. My interest in cancer during my doctoral studies has been driven by my own experience as a full-time caregiver of my spouse. In January 2006, without any prior symptoms or signs of malignancy, my husband was diagnosed with a type of blood cancer. The diagnosis was sudden and unexpected. His treatment required complex treatment protocols such as a bone marrow transplant and chemotherapy lasting 20 months. Treatments took place at a major hospital. Treatment in blood cancer is complex and requires lengthy periods of total hospitalization. It also requires that the patients must rely wholly on others to accompany them to treatment and attend daily outpatient care for periods of months or years. As a caregiver, attending daily outpatient treatment entailed 6 to 8 hours of providing care, and it continued while at home. Indeed, cancer caregiving is a full-time job with no days off and no statutory holidays.

Phenomenological research, observes van Manen (1990), begins with personal experience, then one wonders if that experience could be possible for others. As I sat each day in the hospital room I sought the presence of the physician who might guide me in how best to provide emotional, physical, and instrumental care for my husband. In the fragile environment of cancer treatment where death always hung close, I waited to see and to speak to the physician. I longed for those moments where crucial information could be made
available. As I sat there, I observed other caregivers who appeared to be accompanying a father, a mother, a spouse, or an adult child. I witnessed them also seeking the physician’s presence. I wondered what it was like for these carers to relate to the physician. I wondered about their feelings as they received dire information. How was the information conveyed to them? Was my experience similar to theirs? What was different, and if so, in what ways?

The decision and choice to use hermeneutic phenomenology for this thesis arose organically from the situation. Hermeneutic phenomenology is concerned with exploring, understanding, and interpreting the complexity of people’s subjective lifeworlds through the stories that they tell. It is in this way that we co-construct knowledge. I now introduce those who shared their lives with me: Ernie, Emma, Kate, Anne and Amy.

The participants: Ernie, Emma, Kate, Anne, and Amy

Ernie was the first person I interviewed. I met Ernie through a common acquaintance who related that I was beginning a doctoral study and was contemplating interviewing family caregivers about their experiences of interacting with physicians. Ernie was the principal caregiver for her father and the main liaison with the doctors as her mother did not speak English, and her brother was too young. “It was me who took dad for treatments and it was me who got the news of the cancer [diagnosis],” Ernie said. She explained that her father was celebrating having reached an important milestone in his work, a promotion that he had been working for many years. As Ernie stated, “life was good.” Two days later her father was diagnosed with cancer of the tongue which had metastasized to the esophagus. Later, his cancer metastasized to the lungs. He was 51 when diagnosed and 53 years old at time of death. Ernie is the eldest of two children. She identified herself as Caucasian of European background. Ernie was a stay-at-home mother of two young children at the time of her father’s diagnosis and treatment. Her father’s treatment consisted of numerous surgeries, radiation and chemotherapy. “My girls were little…I was there [hospital] all the time and I took my girls. I would bring my daughter and she would draw things for my dad. We would be in the room so he wouldn’t be alone. And I would leave her there and then I would drive my mom home, and I would drive my brother, and then I would drive back to the hospital.”
Emma was the second participant I interviewed. Emma is the eldest of three siblings. I met Emma through work and she was familiar with my MA thesis. After completion of my master studies we spoke informally about my next educational pursuit. We spoke briefly of potential areas of interest should I ever pursue a doctoral degree. Later, when I commenced my studies, we briefly discussed my interest in the area of relationalities of care and more specifically physician-family caregivers’ interactions dynamics. I did not know at the time that her mother had died recently. Later, we spoke formally as to whether she would be interested in participating in the present study. Her mother was twice diagnosed with cancer within a span of 10 years. She was the caregiver on both occasions. Emma explained that she had strong emotional ties to her mother. The first diagnosis was breast cancer and she underwent surgery and six months of chemotherapy. The second bout of cancer was unexpected. She noted that her mother “was in shock.” Emma said:

She figured that she was going to get a cast on her arm and that they were going to send her off. I was expecting the same thing. She said she had done something silly and had broken her arm, thinking they would wrap it up for her and give her pain killers and then we’d go home.

Instead the diagnosis was one of advanced bone cancer secondary to colon cancer. Emma’s ethnicity is Caucasian. Emma is divorced and has one daughter.

The third participant I interviewed was Kate. I met Kate through work which was where she found out I am a doctoral student. Prior to her enrolment in the study, we had an informal meeting where we spoke about my research interests. I explained in detail the aim of the study. Kate disclosed she had been her mother’s caregiver throughout her mother’s cancer treatment. She explained that she has no siblings and that her mother was a widow. She was also very close to her mother. Kate met the criteria for participation and expressed her desire to be interviewed. Kate noted that the cancer diagnosis was “out of the blue.” Her mom seemed in good health. She underwent a common procedure only to be diagnosed with liver cancer secondary to esophagus cancer. Treatment included radiation and then hospital palliative care. She survived five months following the diagnosis. Kate identified herself as being of Caucasian ethnicity, and is married with children.
Anne was the fourth participant I interviewed. Her father was diagnosed with blood cancer for which he underwent successful treatment. Unfortunately, the cancer re-occurred in a more aggressive way. She reported having been actively involved in her father’s treatment, assuming the role of caregiver. She explained how she was “very close to her father.” She was emphatic that her dad “would never ever feel alone or be by himself in that unit (Leukemia ward).” Her father’s treatment included long periods of hospitalization, over ten months of chemotherapy, as well as bone marrow transplantation. He was twice admitted to ICU during cancer treatment. “For one and a half of those two years of treatment I was living at the hospital” Anne said. Anne is the oldest of three siblings. She identified herself as being of a European background. At the time of her father’s cancer treatment she was in her twenties and single.

Amy was the last participant I interviewed in 2015. Amy is the eldest of her sisters. Amy was in her early twenties at the time of her father’s cancer diagnosis in December 2005. I first met Amy when she volunteered to participate in my master’s research. Amy noted that that she took on the role of the main caregiver, interacting daily with the physicians involved in her father’s care. She explained that her father and mother did not speak English and therefore the responsibility to converse with the doctor fell to her. “When you have to relate bad news, it is best that it comes from a loved one” Amy said. She also said that she was very close to her father. Amy noted that the diagnosis was shocking as her father seemed healthy. “I was shaking,” she said. “Everything happens so fast. It is scary. I remembered I was working in retail and I got a phone call from my mom who said “you need to come home right now. Dad is not well.” Then we drove to the hospital to see the doctor and he was admitted right away.” Her father’s diagnosis was Acute Myeloid Leukemia with treatment involving lengthy hospitalizations, months of in-hospital chemotherapy and years of outpatient chemotherapy, supportive therapy, clinical trials, salvage therapy, and multiple stays in ICU. “He was diagnosed in 2005. He passed away in 2010. He picked a good time. New Years day, January 1st 2010. It was kind of like he wanted to bring in the New Year [laughs]” Amy said. She identified her ethnicity as Chinese.
Themes:

In the next chapters I articulate the themes drawn from the participants’ narratives along with my interpretations. I present to the reader the themes and sub-themes in detail. Five essential themes emerged from the stories of Ernie, Amy, Emma, Anne and Kate. 1) Seeking presence—Finding absence, 2) Feeling bereft—Turning away, 3) Turning towards—Gestures of presence, 4) To give and lastly 5) Words from the family—A practice of embodied care. Each of these five main themes consists of associated sub-themes. These broader themes are grounded in lived time or temporality. The interaction with physicians unfolds through time from the moment that the patient and the family caregiver hear the word cancer, through treatment and, lastly, through death. Gestures, intonations, facial expressions and stances, were identified by the family as being crucial to making them feel welcomed by, or invisible to, the medical community.

I have named the first main theme, chapter four, Seeking presence—Finding absence. This theme encompasses two sub-themes: On becoming invisible and Gestures of absence. This theme and its sub-themes provide a compelling composite narrative of what it is like for these participants to interact with the physician while they accompanied their loved one through the cancer journey. Most participants described a landscape where they felt unseen, unheard and unacknowledged. They spoke of being made to feel as though they were intruders in their loved ones’ care rather than welcomed collaborators. Chapter five presents the second essential theme: Feeling bereft—Turning away. This chapter exposes the reader to the caregivers’ desperate plea for information, as well as for compassionate presence from the attending physician. Chapter six, Turning Towards—Gestures of presence involves participants’ experiences of physicians’ recognition and acknowledgment of their personhood and their experience of caring for a loved one. Chapter 7, To give encompasses two sub-themes: the gift of time, and the gift of oneself. Chapter 8, Words of the family—A practice of embodied care, is the last theme that emerged from the participants’ stories, where family members give voice to how to humanize the relationality of care between the physician and family. Lastly, in chapter nine, I turn to the conclusion and implications of this study.
Youngson, a physician and advocate for compassionate medical practices states that “There is no greater moral authority than a patient or family member who with dignity speaks of grievous loss” (Youngson, 2011, p. 10). In the chapters that follow I invite the reader to join me and together explore what it is like to be in the world for these five family carers. I invite you to listen, to feel, and to see the significance of their experiences (van Manen, 1990, p. 149). It is my hope that the reader can take to heart the poignancy of this study as a basis for “humanizing human institutions to help human beings to become increasingly thoughtful and thus better prepared to act tactfully in situations” (p. 21).
Chapter 4.

Seeking presence-Finding absence

*The other bears the words that I say; but he does not hear me.* (Marcel, 1967, p. 237)

The impact of a sudden cancer diagnosis cannot be understated. From the initial cancer diagnosis on, these participants begin to contemplate the incomprehensible possibility of the death of their loved one. Treatment is lived as one of drastic changes to one's daily routine. The normal rhythm of everyday life ends abruptly. “The experience takes your breath away. It feels like a dream,” Emma said.

The physician is the person to whom the family turns first as they begin the cancer journey. The physician represents the crucial point of contact for giving guidance through diagnosis, treatment, and bereavement. Yet Anne, Emma, Ernie, and Kate use words such as “non-existent,” “ignored” and “invisible” to describe how they were treated within the physician interaction. In the reality of the hospital dwelling, the gestures—eye contact, manners and demeanor—with which physicians engaged the family worked to render them invisible. In the voices of many of the participants, diagnosis and the treatment that followed became a “lonely journey.”

This chapter encompasses two sub-themes: *On becoming invisible* and *Gestures of absence*. The first theme is illustrated by how the family members often felt they were rendered invisible by the physicians. This invisibility seemed to them intentional through the physicians’ gestures, nuanced comportments and mannerisms, which are described in the second thematic section of the chapter.

**On becoming invisible**

*The other exists for me insofar as I am open to him (insofar as he is a thou), but I only open to him insofar I cease to form a circle with myself.* (Marcel, 1964, p. 72)

*If the others do not exist neither do I.* (Marcel, 1967, p. 26)
I am trying to understand how the experience of physician-family member interaction is lived by the family members during cancer treatments. One may ask, “What is the experience of the self in contact” (Marcel, 1967, p. 29) with the other which is “an experience which can affect…the most disconcerting modalities” (p. 29). “Interaction is the fundamental instrument” (Roter & Hall, 2011, p. 55) upon which relationalities of care are built. Medical care, write Roter and Hall, is about interactions. It involves the “talk—what is said, the words used, the facts exchanged, the advice given and the social amenities that tie the conversation together” (p. 55). Yet, add Roter and Hall, it is the nonverbal expressions—a head nod, a smile, a gesture, the tone of the voice—that “give context and enhanced meaning” (p. 55) to the words being spoken. Whereas there has been an explosion of medical technology to advance cure it is also the case that the power of such technology “is limited without the interactions” (Roter & Hall, 2011, p. 55) between the human being providing medical care and the recipients of such care.

Etymologically the word interaction originates from inter + action. Action, in turn, derives from the Latin actionem meaning “a putting in motion, a doing.” The word inter is “a living prefix in English” from the Latin inter meaning “between, in the midst of” (Online Etymology Dictionary). In the midst of the interpersonal meeting between the physicians and the family carer, what are the physicians’ doings, their motions and actions as perceived by the family? And what meanings do family caregivers ascribe to those doings? Do these doings involve actions of sensitive responsiveness, engagement, and connectedness? Or does their absence denote a serious lack? It is worth noting that the prefix inter is spelled entre in French” (Online Etymology Dictionary). This detail provides a segue to the work of Marcel who talks about the “entre nous, ’the between you and me’” (Marcel, 1964, p. 41). Marcel asks “how is this dialogue itself, this dialogue between human beings, at all possible?” (Marcel 1963, p. 38). For Marcel it is only by being with—the between you and me—that we can then have an authentic encounter between two human beings.

In his phenomenological analysis of the encounter, Smith (1963) suggests that “to be encountered means more than a meeting” (p. 205). The word encounter means, “to withstand…” (p. 205). For Smith, to encounter is also about “standing with” the other (p.
The “encounter is the moment of presence [Gegenwart], in which the one being presents itself as presence to the other…encounter means to be there with the other. We stand with the other and withstand him or her” (p. 205). Smith affirms that the encounter, wherein the interaction unfolds, is about presence and a way of being-in-the-world. It is important to note that for Smith “Being-for” invokes “the root meaning of caring” (p. 199).

Against the background of what he calls “simple encounters,” Abram (2011, p. 8), like Smith (1963), highlights the importance of presence in the interaction with others and the world. For Abram we are “fully human” through “the intensity of our contact with the other bodies that surround us” (pp. 3-4). It is through the flow of tonal modalities, bodily expressions, rhythm, language of movements, gestures and “the primordial power of utterance” (p. 11) that we call “ourselves into the vital presence” (p. 11), “and into deep and attentive presence with one another” (p. 11). This is an incarnated sensible, responsible, responsive embodied presence “that honors the immeasurable otherness of things” (p. 11). Abram suggests that presence invokes humility, from which compassion and empathy spring forth to respond to the appeal of the other (pp. 299-300). It is the contact of tangible presences conveying the essence of caring for one another and one’s world. It is worth noting that both Abram and Smith associate encounter with a felt presence.

Presence and connection permeate the thought of the French philosopher Gabriel Marcel. In answering the question of inter-subjectivity, Marcel (1964) also attends to the encounter between human beings that is always genuine, personal and inherently linked to presence and inter-subjectivity. Inter-subjectivity is always a co-presence, writes Marcel (1964). He contends that contrary to rationalist conceptualizations of the encounter as the occurrence of “a simple and accidental meeting” (Marcel, 1964, p. 12) an encounter is never accidental, nor does it occur at the level of things. An encounter summons one to be “near to or with” the other (p. 12). “To encounter someone is not merely to cross his path but to be, for the moment at least, near to or with him,...it means being a co-presence” (p. 12). That is, I act by exposing myself to the other’s appeal, writes Marcel. This is the “vital milieu” of the presence of the thou that makes possible a dialogical relation (p. 36).
Yet most participants spoke of that vital physician contact as a mere “fortuitous intersection…, mere bodies occupying a certain shared space” (Sweetman, 2011, p. 75). The in-between space, the “concrete we,” appears mostly absent within the hospital. For the participants in my study there would be no we. Despite being by their loved one’s side every day, the participants recalled feeling as though they were invisible to the medical community. “There is little human contact,” Emma noted. She and the other participants used words such as being of “no consequence” and “being ignored.” “I didn’t exist.” “I was invisible.” “You are just a figure.” “You are just a number” or “just nothing,” Emma added:

You, as a family member, just sit there. You are literally looked through. It is like you are invisible. Yeah, you are invisible. You really are. It is very isolating. [long silence].

Interviewer: So, do you think that a key word is invisible?

Yes. Absolutely. You are invisible. You really are. And it is time to make those people (family members) visible. YES! I guess he [doctor] figured you hear anyway because you are in the room, so why am I [the doctor] going to tell you anyway?

Invisible to the medical gaze, Emma feels like an object, a figure sitting by her mother’s side, or a “thing” a “number.” She is “of no consequence.” “If the other ceases to be grasped as other: he is no more than a bundle of abstractions [with] which we are unable to maintain any living communication” (Marcel, 1967, p. 28). A category does not invoke a call to make myself available to the possibility of responding to a personal plea (Marcel, 1964, p. 51). An object cannot summon responsiveness. This is Emma’s daily experience of absent interaction with the physician.

Anne described her experience as one of “non-existence.” “I didn’t exist,” says Anne. When I asked whether she felt seen by the doctors, she replied definitively: “NO! Of course not!” For Anne, this invisibility called her own existence into question:

I really didn’t exist. When the initial diagnosis came I really didn’t exist. They really ignored me. I was only the daughter so they wouldn’t speak to me. It took me to be very overt about the fact that I am my dad’s caregiver. No, I am not his spouse. I am his daughter, but I still exist. I am still here sitting by his
bedside every night. And this was through the whole course of the disease. You have to remember that we were there close to a year.

The impact of rendering the family member non-existent is readily apparent in Anne’s words. Like Emma, she is “just a daughter.” While she sees herself as her father’s companion, the physician’s gaze has relegated her to invisibility. No acknowledgment let alone contact is made, though her presence is one of constant vigilance by her father’s bedside, night after night, month after month. Despite her everyday presence, she “does not exist.” In Anne’s words, in the clinical encounter, in the hospital space of care, she struggles to have her humanity recognized. She needs to be, in her words, “overt” so as to exist for the physicians.

Anne asks, “What interaction can you have with a person who just ignores that you are there?” When I asked her whether she meant that doctors ignored her as a family member, Anne responded: “Yes, of course they did! But the doctors are not fighting the illness alone” continued Anne. When I asked if she meant the family, she emphatically responded:

YES! [emphasis]. The family carries the fight. The family member is the one who has to make four trips daily, back and forth to the hospital. It is not just the patient. For two years, I didn't think of anything other than cancer. And for one and a half of those two years, I was living out of the hospital [long silence-tears].

And I don't resent any of that time. I don't resent that …sometimes coming back to drop my mom off and then coming back to the hospital at 11 o'clock at night. I would just squeeze in as they were closing the hospital doors to spend the night with my dad. I would be there at night to get whatever he needed. I made sure if something happened I would be there for him or that someone would be there to answer questions if he couldn’t. And I never resented or regretted it. It wasn’t a burden for me to do this.

When I asked Anne if there was anything specific that she would have liked to see in terms of interaction with the physicians, she said:

An acknowledgement that you are there, and that you are a crucial link. But they (doctors) didn't. There is no acknowledgement.

To be acknowledged, as Anne describes above, requires an “admittance into existence” (Merriam-Webster Dictionary). To be “acknowledged” is “to regard someone as having or
deserving a particular status, to admit as being one entitled to be heard” (Merriam-Webster Dictionary, 2010, p. 9). Yet Anne is not heard. Her concerns and observations are brushed off. Her existence is denied.

Emma’s narrative echoes that of Anne. Emma described previously how the family member is “left to be invisible.” For Emma, the lack of acknowledgement is an intentional inaction through which she is made to feel invisible. She said:

In the hospital, I was right there with my mother. I was there [long silence-tears]. And I don’t know whether the doctors think that you are going to be too emotionally invested and that is why the doctors don’t want to talk to you. But just give us the benefit of the doubt. Just listen to us and if it sounds that we are getting a bit crazy then that is when you as a doctor need to say—we are going to answer all your questions but we are going to need a few minutes until we get the test back. Or something like that. At least acknowledge that you, as the family member, are there.

Interviewer: So were you acknowledged by the doctors?

No, I wasn’t. It is very sad, extremely sad when you think about it. Like I said when you think that through the entire journey of the disease, from the broken arm, until the end, the only doctor who gave me any answer was the palliative care doctor. And that was too late, way too late [long silence-tears].

In his book Presence and Immortality (1967) Marcel invites the reader to explore the nuances of recognition between beings. Marcel observes that to be recognized is to be situated in value, which is the very essence of the human being. To be recognized is about a relation of interiority wherein “the other has been truly with me” (p. 87).

It seems to me that the more a being has been recognized, greeted by me in his essence as being, the less he is in fact confused with the details and views that circumstances have permitted me to see of him; the more in fact I have been able to recognize his value. (p. 88)

Another participant, Kate, explained that she had assumed the physicians would acknowledge her presence. She told me that her family was well known in the medical community and had strong ties to the local hospital. Her mother had been actively involved in volunteer work at this same hospital for many years. Kate reminisced how her mother’s
attending doctor had also known her father. Yet, when I asked Kate whether this doctor acknowledged her, Kate responded, “No.” When I asked her if a greeting was offered, Kate again replied, “No. Not really.” Of the doctor, Kate said:

He saw me there but no, not really…he would say little to me. Again, as I said, he saw his responsibility as dealing with my mother but he did not necessarily see that his responsibility was also with the family.

Kate’s reality summons no investment from the physician. In cancer care, Kate’s being and concrete reality is foreign to the doctor. The doctor sees her but she is not being seen. He acknowledges no responsibility for her. She is just a family member. In Marcel’s words, there is no “being with” her.

Emma uses the word “invisible.” Anne, in turn, used “nonexistence” to signify that she “did not exist” in the eyes of the doctors. For Ernie, her existence was one of “nothingness.” “I was just nothing,” Ernie said. Yet, like Anne, she, too, was also there each day by her father’s side. In describing her interaction with the physicians, Ernie related:

I was just nothing. They never talked to me. NO! Nothing at all. I would bring him there but a doctor never approached me or said anything. Never, like, I need to talk to you or whatever.

I remember going there and taking my dad every day. They (doctors) were talking among themselves. And I was with my dad. And that was about all they said. Nothing else. Did they ever talk to me? NO. I was never approached. No, they never did. And No, I did not get mad or upset. Did they ever explain anything? No. Never. No recognition.

Interviewer: Meaning, no recognition of your presence?

No. No recognition. I think one doctor who was from North Vancouver, a general family doctor, was really nice but he was the same doctor that I had. He was a general doctor. But from the oncologists, no, nothing. They could not care less.

The other “exists in the measure that I have relations” (Marcel, 1963, p. 46). Ernie, however, stands alone.
Throughout his work, Marcel (1951, 1964, 1967) affirmed the intersubjective nature of existence. “Existence” is always “co-essence” and thus, it is grounded in inter-subjectivity as the “unity of a we” (1967, p. 84). It involves an openness and an approach of “[r]eaching out of myself toward the intersubjective nature of existence, a reaching out which is an essential part of the human condition” (Marcel as cited in Sweetman, 2008, p. 62). Yet, “I was never approached,” Ernie stated in the narrative above. There is no we in Ernie’s experience when interacting with the physician. There is no being with her, no reaching out, no words acknowledging her presence. Doctors stand out there talking among themselves. Ernie stands silent by her father’s side.

Ernie felt strongly that her invisibility was created by an intentional lack of interaction. The physicians stand amongst themselves but never with her. When I asked Ernie whether she thought that she mattered to the physicians, she replied “No.”

It is like people are just numbers, people are just nothing. That is exactly what it is.

I think most people would like to be treated as human beings and that they matter. But some doctors just don’t care to do that. No. I did not seem to matter to them.

For Marcel, notes Sweetman (2011), “the most basic level of human existence, is being-in-a-situation, or “situated involvement” (p. 5). It is the level at which the “subject is immersed in a context, [and] where the subject does not experience objects” (p. 5). The participants are just there every day by their loved one’s side. Yet they are “nonexistent, not anything.” They experience being reduced to nothingness, unseen, unheard, not spoken to, not approached. They are an it. Marcel writes:

When I consider an individual as him, I treat him as essentially absent; it is his absence which allows me to objectify him, to reason about him as though he were a nature or given essence. However, there is a presence which is yet a mode of absence. I can act towards somebody as though he were absent. (1964, pp. 32-33)

“Existence in its higher form is inseparable from intersubjectivity,” writes Marcel (1967, p. 202). “To exist” is to participate and to be with others (pp. 194-195). For these family members, there would be no co-participation, no being with them. A sense of being
marginalized and excluded emerged from the participants’ narratives. It is best captured in Marcel’s, *The Existential Background of Human Dignity* (1963) in the chapter titled “Existence.” Here Marcel suggests that to be is to be with the other. The proposition with invokes a relationship, suggests Marcel (p. 67). “With” also beseeches a quality of being—one that gives light to togetherness, to a bond, and to a certain intimacy (pp. 67-68). Marcel posits that as human beings we can establish relations even where the other is seen as an object. In this subject-object relationship, there is no “with” the other—the other is being treated as a he, she or it (Marcel, 1963). Yet we can also choose to respond to the other as a subjectivity and thus to engage in a human-to-human relationship. Marcel writes:

I am thinking above all of the irritation a person invariably feels when he notes that two others are talking about him in his presence and calling him “he.” (“He is like this,” or “He usually does this,” and so on). A person spoken of in this way feels that he is being treated as an object and so is being relegated to the level of things—or, at best, to the animal level. He is being deprived of his status as subject. One might also say that he feels that he is not with (“avec”) the others, that he is being excluded from a certain community to which he feels he rightly belongs. (Marcel, 1963, p. 40)

Such are the experiences of Ernie, Emma, Kate, and Anne of being made invisible to “a certain community to which [they] feel [they] rightly belong” (Marcel, 1963, p. 40). “The doctor just saw me as no different than a figure standing by,” Emma said. Several participants used the phrase “seen as numbers” or “just a daughter” in referring to the objectification that, as Marcel said, leads to the invisibility of the human being. Insofar as being is objectified, posits Marcel, it assumes the characteristics of “non-existence” (Marcel, 1964, p. 17) such that one becomes “no more than a bundle of abstractions with which we are unable to maintain any living communication” (Marcel, 1967, p. 28). In the cancer experience, the family member when reduced to a category requires no attention from the attending doctor. This may explain the sense that Ernie, Anne, Emma and Kate have of becoming invisible.

In talking about the denial of being, Marcel makes it clear that it is a choice how we approach the other (Marcel, 1951). “I claim to be a person in so far as I assume responsibility for what I do and what I say” (Marcel, 1951, p. 21), but “I can act towards somebody as though he were absent” (Marcel, 1964, p. 33). Marcel continues to affirm that existence is always
“apprehended by incarnate beings, like you and me, and by virtue of being incarnated” (1963, p. 47). Thus to be present is to see, to hear, to touch (Marcel, 1963). This visibility, sonority and affective resonance is what Ernie, Emma, Amy, Anne, and Kate are calling for and what will be explored further in the next section on *Gestures of absence.*
Gestures of absence

The sub-theme Gestures of absence can be described as the family member’s perceptions of the subtle but powerful nonverbal nuances in the physician-family member interaction. Stern (2004) posits that:

We are capable of “reading” other people’s intentions and feeling within our bodies of what they are feeling. Not in any mystical way, but from watching their face, movements, and posture, hearing the tone of their voice, and noticing the immediate context for their behaviour. (pp. 75-76)

One may wonder, therefore, in the family-physician interaction what the family members “read” from a physician’s bodily expressions? What intention may be “read” from the physician’s “face, movements, posture, tone of voice”? What facial expressions are observed? What postures are watched? What feelings does a tone of voice convey to these carers? What information is transmitted by a physician’s stance, gaze, and motions? What feelings are evoked? What is noticed? Using Stern’s (2004) words, “what are the shifting responses” (p. 76) of these family carers to the physicians’ “small movements of their facial features, their head and gaze direction, and the tone of the background sounds of their voices?” (p. 76).

As we will see from the descriptions to follow, physician eye contact, tone of voice, interpersonal distance, touch, and body positions, were the most frequently mentioned nonverbal cues. Taking little time to perform, these gestures of absence serve a powerful purpose. In this dissertation, Ernie, Anne, Amy, Kate and Emma spoke of how, contrary to their expectations of meaningful, caring communications, nuances of caring were instead lived as gestures, manners, motions, and bodily positions intended to keep the family invisible. Family members sensed through nonverbal signals that they were not being heard, nor being seen or understood. They were and remained silent “outsiders.”

Gestures of absence not only rendered the family members non-existent but such gestures also made the family members’ distress invisible. Throughout treatment, a comforting touch, a welcoming smile, a close interpersonal space, or just a simple glance, were not to be found. The importance of nonverbal communication has received considerable attention in
the empirical literature outside the realm of biomedicine. A large body of knowledge highlights the powerful impact of gestures, positions, movements, stances, and facial expressions on human interactions (Hillen et al., 2015; Marcinowicz, Konstantynowicz, & Godlewski, 2010). Despite the plethora of research attesting to the impact and power of nonverbal behaviour, for the most part nonverbal communication has received little attention in clinical contexts (Hillen et al., 2015; Marcinowicz et al., 2010; McHenry, Parker, Balle & Lenzi, 2012; Roter, Frankel, Hall, & Sluyter, 2006; Schmid Mast, 2007). This is despite the fact that nonverbal behaviour has been shown to have a potent effect on patient outcomes such as patient and family member satisfaction, trust, patient centred-communication, perceptions of empathy, and physicians' risk of litigation, among others (Ambady et al., 2002; Hillen et al., 2014; Hillen et al., 2015).

Recently a few but growing number of researchers have begun to examine physicians’ nonverbal behaviour (Hillen et al. 2014; McHenry et al., 2012; Nicholson & Cushing, 2013). This literature indicates that eye contact, along with body posture and smiles, are three nonverbal behaviours that have a significant impact on patient-family-health provider interactions (Hillen et al., 2015; Roter et al., 2006). The importance of such nonverbal behaviours is attested to by my study participants as will be seen in the narratives below.

**Gestures of absence: Eye contact**

Presence, vital for healing, begins with eye contact, affirms Trout (2011). A large body of knowledge has now highlighted the crucial impact of eye contact in the encounter among human beings. Farroni, Csibra, Simion, and Johnson (2002) propose that eye contact is essential and the “main mode of establishing a communicative context between humans” (p. 9602). “Eye contact involves two people gazing at each other’s eyes” (Niedenthal, Mermillod, Maringer, & Hess, 2010, p. 426). It is a vital first step toward affective resonance and is a precursor to the development of empathy and compassion (Stern, 1985). “Eye contact triggers embodied simulation of the perceived facial expression and its correspondent feeling” (Niedenthal et al., 2010, p. 426).
The first interactional contact in the mother-infant relation occurs through gaze behavior. Gazing, note Jaffe, Stern, and Peery (1973), is involved not only in the mother-infant relationship, but also in terms of infant movements, vocalization, verbal communication and infant social contact. Gazing is the first “prelinguistic kinesic inter-action” (p. 322). As mother and new-born interact in the babbling period of infancy the interaction invokes gazing behavior (1973).

Trout (2011), explores the implications of an attuned presence in the interaction between mother and infant. He writes that: “In the nuanced exchange between mother and baby—with its exquisite attunement, which we now know creates neurobiological changes in both parties—we see a metaphor for the therapeutic relation in health care” (p. 16).

It is where everything begins… The first time another living being looks into our eyes. We are seen. We encounter another. We are seconds out of the uterus, where there has been kinetic, biological, and emotional attunement between mother and unborn child. Now, out here in the too bright lights of this outside world, eyes meet… The mother’s or father’s eye communicate, I see you. I know who you are. I will keep you safe. (Trout, 2011, p. 16)

Yet in the medical landscape, many of the participants told me that physician eye contact was at best elusive. In the face-to-face interaction the medical gaze is trained to look through the person but not to see her or him. “You are literally looked through,” commented Emma. “No. he didn’t see me. I was sitting by my mom’s side, not even once did he look at me,” she recalls. Of the main physician, Anne stated that “He never looked at me. So there was no interaction there.”

From the participants’ narratives we learn that the lack of eye contact is a defining characteristic of gestures of absence. Emma has vivid recollections of her mother’s first cancer diagnosis. Her mother’s diagnosis had been sudden and it was Emma’s first entrance into the cancer trajectory as a caregiver. Emma remembered:

My mom told me she had this doctor appointment and then she insisted on me coming. That was the only reason why I was there. The first thing that he said, more or less after the introduction was made, was: “You have cancer.” My mom immediately shut down. And not at any time did the doctor even acknowledge the fact that I was sitting beside my mom in the room until I
started to ask questions. At no time did he look at me, not even when I am asking him questions, and even then, the doctor was still not looking at me.

Interviewer: So there was no eye contact?
Emma: No. Never.

The doctors’ gaze appears closed to the human beings present in the room. For Emma there is no glance, no moment of mutual eye contact, even as the physician relates terrifying news.

While Emma vividly recalls the absence of eye contact during diagnosis, Anne notes that for the most part there is little eye contact to be found during treatment. In the hospital setting there is no eye contact, not one meaningful look that touches her, despite her presence every day by her father’s side. Time and space are lived for the most part as lacking meaningful moments of reciprocal eye engagement and thus reciprocal recognition. The team of physicians enter the room with the family member there, but no one really looks at her. Anne recounts:

They bring their team in the morning. Maybe one doctor sort of looks at you and acknowledges that you exist but it may as well be as if you are not there.

She adds that her father, the patient, is also not seen. He is just a case for medical consultation. Of the attending doctors, she says:

They talk to each other. They talk about the patient but they don’t look at the patient.

“A being who answers me in a certain tone of voice, who looks at me in a certain way, or who perhaps does not even look at me at all; but in this case I would have the painful impression that he is not treating me as a human being” (Marcel, 1963, p. 39). This appears to be Anne’s experience of not existing for the medical community. Morning after morning, Anne sees the medical providers entering the room. Yet there is no eye engagement that would recognize her and make her feel present.

When I asked Anne about the presence of the doctor and whether there was something specific she could recall, Anne’s description links presence to eye contact. She said:
Well, there was not a lot of presence. Not a lot of eye contact with him. That was hard for the doctor. I think he just wanted to tell you the results for the most part. And that is what he would tell me.

Anne connects eye contact to being “human.” When I asked her whether eye contact was something she would have liked to have had, she replied:

Eye contact would have been great [long silence, soft voice and sense of sadness]. They should teach doctors to look people in the eyes [soft spoken conveying a sense of sadness, long silence]. Yes, they should. They should teach doctors to be human. I think they have lost that.

Ernie uses the word “nothing” or “non-existent” multiple times throughout her interview to signify the lack of presence of the physicians, the lack of contact, and the insignificance of the family-physician interaction. She describes physicians as “those doctors,” who were “non-existent,” and with whom she “hardly had any contact.” A typical interaction with the physician was described as “nothing.” She cannot remember the names of “those doctors” either or recall their faces. Yet Ernie categorically remembers that the physicians’ eyes do not meet hers at any time. There is not one fleeting, momentary look. Ernie said:

The oncologists? Well I don’t even remember the oncologist. But I do remember that there was no eye contact. No, none at all.

Significantly, Ernie has vivid remembrances of the one doctor who met her eyes. She described him as “a caring doctor,” a theme to be discussed later in chapter six, Turning towards—Gestures of presence.

Amy described her father’s main attending doctor as one who was compassionate, and “very present,” although in Amy’s words, this doctor was an exception. Like the other participants, Amy also related that with other attending physicians there was no eye-to-eye contact. It is the object-at-hand, the clipboard, which occupies the physician’s attention. The clinical gaze is perceived, in Amy’s words, as “looking past” her. She is but a shadowy presence in the room.

He did not look at me. Of course not. All he did was look at his clipboard. And sometimes you can tell when they are sort of looking at you but really they are looking past you. With him, it was like that. You feel like: “Hello, I
am right here! Who are you talking to? ‘The wall?’ [laughing]. Oh yeah [silence] Are you talking to someone behind me? Am I a shadow? Maybe I am stuck in my shadow. Yeah, Yeah… [silence]. So it is a big contrast with my main doctor (Dr. X) [long silence]. And I know that we were lucky.

It is worth adding that, in a recent publication, Khan, Hanif, Tabasumm, Qidwai, and Nanji (2014) explored patients’ perceptions of physicians’ eye contact or lack of it. Khan et al. found that 96% of patients thought that eye contact was necessary to establish the relation between patients and doctors from the very first moment of meeting, and this effect was independent of level of education and gender. Importantly, having eye contact was associated with respect and attentiveness.

For these participants, the significance of eye contact resonates in their words. Participants spoke of the need to be recognized. They used the word “acknowledgment.” Amy related how she once returned to the critical care unit to find her father agitated and highly distressed. The hematologist who was being paged entered the room. When I asked Amy whether the doctor introduced himself upon entering the room, Amy responded: No [sarcastic laugh]. (Interviewer: Did he acknowledge anyone?) “No. No. No eye contact.”

For Anne, a lack of eye contact meant that the family presence was neutralized, nullifying any physician-family interaction that might have followed. A lack of eye contact, and its unspoken meaning, resulted in distrust. Anne said:

Our interaction was no different than if I went to the mechanic and I asked what is wrong with my car. And the mechanic would probably show more care for the car [laughs]. The mechanic would probably speak to me more nicely. The mechanic would probably care more. I’ve had mechanics actually talk or care more about telling me what winter tires I should have, [laughs sarcastically], which is sad, but the mechanic still looks you in the eyes.

Interviewer: So it seems that eye contact is very important for you?

Anne: Of course. Of course it is. If people don't look you in the eyes they are either hiding something or they are not acknowledging you. So when you are dealing with someone who is very sick, do you really want to be dealing with someone who either doesn’t acknowledge you or is hiding something or that you think is hiding something? How does that establish a relationship if one person does not acknowledge the other?
Anne used the expression “hiding something,” implying that lack of eye contact may be associated with dishonesty or mistrust. Recently Hillen et al. (2015) explored whether eye contact, body posture/orientation, and smiling were associated with cancer patients having trust in the physician. Hillen et al. reported that eye contact had a significant effect in fostering patient feelings of trust in the treating oncologist. The impact of smiling and a forward leaning position was not significant in developing trust. Hillen et al. invite us to ponder the great significance of trust in biomedicine: at the heart of medical practices is patient trust in the medical providers (Hillen et al. 2015). Trust is even more critical within cancer care, according to these researchers, since there is already a high degree of mistrust given the uncertainty of the treatment outcomes, the unknown efficacy of the treatment, as well as the severity of the side effects.

For Amy the bio-medical gaze denies one’s sense of presence. The lack of eye contact, notes Amy, diminishes the possibility to be, to exist. “At least rude and mean people look at you,” Amy notes. Impolite and unkind as they may be, “at least I exist” in their eyes. She went on to say, “You know there are people who leave you wondering, because they are mean and may be rude, but at least they have that eye contact (laughs).” Hymer (1986), a physician, stressed the importance of the look from the first moments of birth. For Hymer, this look is always relational and is connected to “knowing and understanding” (p. 149). Mutual gazing is fundamentally about the affirming of the self, of being (Hymer, 1986). I am known through the gaze; in turn, this mutual gazing affirms the self. “I count” proposes Hymer (p. 154). In contrast, the absent gaze can reveal alienation and separateness. Of the mother and child interaction, Hymer writes that:

During feeding a sense of mutuality develops between the mother and the infant via the gaze. The attuned mother looks into the baby’s eyes and sees the baby as a whole person; the baby in turn sees himself or herself in the mother’s face. (1986, p. 150)

Do these participants see their wholeness reflected in the physicians’ eyes? For these participants, and as Marcel states, most times the gaze is not at their disposal. There is little or no eye contact. For Ernie, Amy and Anne, the absence of eye contact is something that is clearly felt. The medical gaze “looks past you” or “through you” but never into you.
It is important to note that, for Anne, the meaning of eye contact registers in her memory and thoughts as a responsiveness that says “I’m here.” Throughout her account, Anne remembers feeling that her presence was overlooked by many physicians. In the shared landscape of the human experience of cancer, the doctor looks at the floor, and in that moment Anne knows that, for her, there would be no voice responding—Here I am! When I asked whether having eye contact was something, she would like to have had, Anne reflected:

Yes. Eye contact is important. It says “I’m here for you.” If there is no eye contact it means “I am not here.” [silence]. And you see these doctors cannot take their eyes from the floor. You can have a presence that says: I’m here. You can have a presence that says I’m sorry. Sometimes it is just in the look. But doctors are incapable of looking you in the eyes in this age because they’ve trained that out of their medical practice for whatever reason. Maybe that sense of care, that sense of comfort, is not there anymore, even saying “I’m sorry” is not there anymore.

Anne’s use of the expression “I’m here for you” or “I’m not here for you” brings us back to the work of the French philosopher Gabriel Marcel and his ethics of embodied presence. In Presence and Immortality (1967) Marcel exposes us to the meaning of the exclamation Here I am! (p. 205). At the root of existence is the recognition of Here I am! (p. 205). The here I am involves intentionality and thus the exclamation mark. Such intentionality is that of co-participation in the lived experience. According to Marcel, ultimately the exclamation ‘Here I am!’ involves a presence which is “felt as fullness” (p. 205). The contrary of that involves nonexistence which is sensed as emptiness. The ‘Here I am’ signifies a “need to call to witness” (p. 206) the other’s appeal. It is this “call to witness” that touches the one contemplating the vulnerabilities and needs of the other. The subject who makes the other an object no longer contemplates the other; the other’s appeal goes unheard, unseen, unfelt.

Certainly the study participants capture the powerful importance of eye contact for those who are living the illness experience, including the family member accompanying the cancer patient. In illness, unspoken nuances of contact such as eye contact or lack of it during the diagnosis or through cancer treatment are lived and re-lived by the care giving family member(s). But for most of the family members I interviewed, there was to be no gaze that
said, ‘Here I am!’ and therefore no response to witness the family member’s living experience of cancer.

**Movement, postures, and stances**

Gestures of absence are also revealed through inter-personal distance, and postures. Postures, positions and stances are important cues in terms of perceptions of physician empathy (Brugel, Postma-Nilsenovka, & Tates, 2015). Perceptions of empathy in turn can affect patient outcomes. It is likely that if the one seeking care perceives the physician’s positions as evincing an empathic understanding, he or she will be likely to reveal more symptoms or give a detailed account of the illness (Silverman & Kinnersley, 2010). Marcinowicz et al. (2010) note that postures and distances can also convey separateness, distance, and lack of interest. This may increase a sense of being unseen. Norrby, Wide, Nistrom, and Nilsson (2015) note that postures can increase social distance for those involved in the clinical encounter. Physicians, Silverman and Kinnersley (2010), remind us that nonverbal positions and postures can have an impact on the success of the doctor-patient-family relationship or its failure. In the midst of her mother’s sudden diagnosis, Emma shared with me how she sought contact with the attending physician:

I am asking questions of that particular doctor. He never once responded to me but he turned his back to me. All this time I am talking to him and he talked to the nurse who asked him my questions and then he answered her, and she answered back to me. He was a jerk.

There was no contact. No, I just saw his back. I am trying to explain to him that she wasn’t making sense, and it was the nurse who would then ask questions, like how long has she had this, and does she need oxygen? He was just standing there and observing. It was awkward, with me talking to him (doctor), the nurse talking to him, and the doctor talking to the nurse. I found that rather odd. Finally he turned and left. I looked and I said to the nurse, “What is going on here?” The nurse said: “well, he is just observing because he wants to know what stage she is in.” It was like, excuse me? It was bizarre. The experiences that I had with my mom’s illness and the doctor were all like that.

As Emma describes it, there appears to be no willingness or intention to alleviate her concerns or to provide much needed reassurance, despite the heightened conditions of stress.
The refusal to respond to her questions came in the form of body orientation and stances of “turning away.” There was no contact, no coming together, no participation in the Other’s anguish. The bodily movements were of rejection and intentional exclusion, a refusal to respond enacted through body and stance.

In line with Emma’s narrative, Anne also reports bodily postures of separation. Anne speaks of physicians seating themselves “away from the family.” There are no animated expressions from the doctor that might have signified an openness to mediate such distance. No gestures of “receiving” the other. Anne’s narrative seems to describe a physical distance that creates disconnection which is further reinforced by an expressionless face and a posture that renders the family members non-existent. Doctors were “there” but seated at a distance and acting very distantly.

Well our first doctor was just a robot. He was not comfortable with us. He always sat far behind his desk as far away as humanly possible. He never looked at me. There was no interaction there. What interaction can you have with a person who just ignores that you are there?

Emma in turn says “doctors are there” and “the family is here” — pointing to the interpersonal distance in the physician–family interaction that is felt as disconnectedness. There are no physician gestures conveying a desire to reach out to the family. From their vantage point, Anne and Emma are not being heard, they are not being seen, nor can they participate. They are on the outside looking in. Emma notes:

You, as family member, are here. The doctors are there. They (doctors) are doing what THEY think is best but you as a family member are left out. It is like looking through a window: they are there but you are looking on and left out. You are supposed to be able to understand what is happening, yet you don’t. It is a closed shop!! [emphasis].

From Emma’s narrative, two people, the physician and the patient’s family member, do not encounter each other. There is no in-between space; there can be no togetherness. You “are left out,” emphasized Emma, echoing what Anne, Ernie, and Kate also experienced. One being— the doctor— is on the inside and has the privilege of speaking, of being heard and being seen; the other family member cannot speak, be seen, or be heard. Emma said:
Yes, cancer is a family illness but doctors don’t treat it as such. Not in MY EXPERIENCE [strong voice]. It was all one sided. And when you think about it, when you are in that situation, it is like they hit you with a brick. There was no time to let the cancer diagnosis sink in. It was all a matter of fact to the patient: This is what you have. Yes, this, simply, is what you have.

And the doctors are standing way back because they are blurring it all out, and for the patient it is like: “OH my God I have Cancer.” “What do I do now?” Because they hear “Oh my God I have Cancer,” they are done, whereas the other person, the family member, is the one who has all the questions that need to be asked. But they are not allowed to ask them. So what do you do?

Savett (2002), a physician, writes that the family members are “sometimes the forgotten partners in collaboration” (p. 106), Emma, in describing her experience, uses expressions such as “one sided,” “the doctors standing way back” and the family “not being allowed to enter the medical relational space.”

Nicholson and Cushing (2013) found that in the patient-physician interaction, nonverbal behaviour such as interpersonal distance and facial expressions are perceived as carrying powerful meanings of “engagement or disengagement which, in turn affects trust, satisfaction, and participation” (p. 858). Anne uses the expression of a “robot,” to describe one doctor. It is important to indicate that an expressionless face is correlated with inattentiveness which, in turn, is linked to disrespect (Ambady et al. 2002). Martin and DiMatteo (2013) suggest that whereas the body of knowledge in nonverbal signals continues to be limited within medical practices, nonverbal, interpersonal distances convey subtle and powerful messages. Spatial closeness engenders feelings of trust, sympathy, empathy, and compassion which in turn affect patients’ medical outcomes. For Martin and DiMatteo (2013), closeness of interpersonal distance is part of “affiliative physicians’ behaviours” (p. 40) defined as “warmth, rapport, communion, or caring behaviours” (p. 40). For most of the family members with whom I spoke, however, there was no such affiliative behaviour. Nuances of inter-personal distance via postures and stances denied any sense of communion. When the family member and the physician met each other, there was often no acknowledgement of the former. There was no greeting, not even a simple handshake. Emma illustrates:
Like I said, I was not sure if the person who came was an emergency doctor or a specialist because there were no name tags and he never introduced himself.

Interviewer: So there was no introduction like, I am the oncologist.
Emma: Nope. No. Nothing. Here they don’t do that. They don’t touch anybody.

As Emma observes, there is no introductory greeting, no approaching touch in the extension of a hand and a welcoming handshake. “Shake my hand, introduce yourself,” Emma lamented. For Straus (1966) and Vandenberg (1959), a handshake is our first point of entrance into solidifying a partnership and reminds us of the powerful message that a handshake may carry. “A formalized handshake” signifies “acceptance” (Straus, 1966, p. 181). “[T]he hands stretched out toward us tell us that we are welcome and received into the group” (p. 181). The handshake “is symptomatic of our human relations” (Vandenberg, 1959, p. 28). A handshake may be “firm” or “ambiguous” (p. 31), “warm and strong, or cold and hesitant” (Straus, 1966, p. 182) but a handshake is always imbued with meaning.

What meaning does the handshake hold? For Vandenberg (1959), this motion is revelatory of possibilities of contact, engagement, partnership, trust or the lack of it. The power of the handshake ultimately and significantly is revelatory of affectivity. The simultaneously reciprocal motion of a handshake is “the basic readiness to establish contact” (p. 33). Informed by his experience as a psychiatrist, Vandenberg speaks of those who do not attempt to extend their hand to grasp the other’s hand that meets them. There is no contact, no involvement, “no warmth” (p. 28), only a “certain coldness” (p. 29). There is no “affective rapport” (p. 31). It is a hand that “has no community of feeling with us, only a certain aloofness of contact” (p. 31). Emma encounters such aloofness. There is no welcome for Emma. There is no handshake that tells her she is accepted in the space of care. There is no physician’s hand stretching toward her telling her she is received by the medical community. She stands alone.

Amy echoes the importance of gestures in creating an interpersonal contact, which is as important as the information being provided.
It is the way that the doctors talk to you. You want the doctors to talk to you with knowledge but also with open arms. But some other doctors talk down to you. They have no patience. They have no patience in explaining anything to you. If you don’t understand then they (doctors) just don’t care.

For Amy caring is associated with “open arms” and “having patience.” In his phenomenology of body posture, Straus (1966) notes that the arm motions can invoke bodily boundaries; they can open up or enclose one’s bodily space. “My intervening space is a medium between me and the world… it mediates between the other and me” (p. 181). In this intervening space, the arm motion “separates or connects” (p. 182). An open arm motion signifies a welcome. Straus writes,

In this space, which is not completely my own, I can meet the other as the other, join him as my partner, arm in arm, hand in hand, and yet leave him in his integrity. Through this space, I hold the other at arm’s length or let him come toward me and receive him with open arms. It is the space of the linking of arms, of embracing, but also of crossing the arms, a motion in which we keep distance, “circumwalling” ourselves in an attitude of defense, of fortification. (Straus, 1966, p. 181)

Open arms “receive” (Straus, 1966, p. 181) the other, the one approaching me, as other. This is the space of “embracing” another that open arms afford. To speak with open arms creates a sense of invitation and welcome that diminishes the relational distance between physician and family. It may be that open arms create the space that is in-between you and me.

**Tone of voice**

Gestures of absence also resound in the tone of the physician’s voice. Marcinowicz et al. (2010) explored which of the physicians’ nonverbal behaviours were more salient for patients and their families during the medical interaction. Marcinowicz et al. examined physicians’ touch, tone of voice, eye contact, facial expressions, interpersonal distance, and gestures and postures. These authors found a physician’s tone of voice was the most significant nonverbal cue affecting the medical interaction as perceived by patients as well as family members. Participants spoke of physicians showing a lack of patience through the tone of voice that was perceived as condescending, hostile and generally giving a feeling of being
unwelcome. They spoke of how a physician’s tone of voice worked to belittle the family or to exclude the family’s presence and in turn their needs.

Marcel posits that the tone of the voice may transform a subject-object relationship into one where two people meet and acknowledge each other as human beings. In this case, it is an inter-subjective contact where presence becomes co-presence. The other is no longer a “thing” but a welcome presence. “I am treating him as if he were a signpost. No doubt, even in its limiting case, a touch of genuine intersubjectivity can break through, thanks to the magical powers of the tone of voice…” (Marcel as cited in Sweetman, 2011, p. 82).

Amy continued by saying how the tone of voice brought up feelings of irritation and resentment through an already emotionally devastating experience.

I did not feel listened to. I felt disappointed [silence] and irritated by her. And of course, you feel lonely and that you were not worth her time.

When I asked her if it was something that the doctor had said, Amy replied:

It was the tone of her voice. It was not what she said but the tone of her voice. It was her mannerisms. Maybe that is how she talks every day with people. I don’t know… [Laughs] it is funny when you think back. Because I thought: Oh, this lady is not very nice. She was rude.

She talked down to you… She talked slow to you but not to help you. She talked slow to you to make you feel as if you just don’t understand. [Interviewer: Meaning condescending?] YES! [Emphasis] Yes. Yes. Yeah [3 times] [laughs]. She was NOT very nice.

Amy’s recollection informs us of the affective power of the tone of voice. In the vital contact between the family and the doctor, Amy knows from the physicians’ tone of voice that she is not heard, nor does she feel accepted in the hospital space that each day she inhabits. From the doctors’ tone of voice, Amy becomes aware that there will be no opportunities and spaces for connectedness. She is alone. She is “not worth” the doctor’s time. Amy speaks of being intentionally “talked down upon” or “talked to slowly.” For Amy, there is a force and an intention behind the physician talking “slow” since the slow rhythm is perceived as belittling. The doctor’s tone of voice does not carry any comfort in helping her come to terms
with her father’s treatment. The slow rhythm, rather, is suggestive of what Martin and DiMatteo (2013) refer to as a physician’s dominance display. Who in the medical space is seen and who has the power to speak? Amy feels she is invisible and powerless to speak.

Voice tone, like postures, positions, and facial expressions, affect human-to-human interaction (Bonnin, 2014). Yet voice tone has received modest consideration within the medical literature (Ambady et al., 2002; Knowlton & Larkin, 2006; Roter et al., 2006). As a psychotherapist, throughout my training and through my years of clinical experience, I have witnessed the importance of a warm, calm, genuine, and comforting tone of voice in diminishing asymmetry as well as relational distance (Bonnin, 2014). One may venture that the tone of voice becomes even more critical within cancer since this is a disease that brings fear and uncertainty and thus, a tone of voice may soothe or comfort and especially establish affective connection and compassion when distressing news is communicated.

In his book, The Interpersonal World of the Infant Stern (1985) reminds us of the importance of nonverbal nuances such as voice tone. For Stern, the human tone of voice with its different pitches, intensities, rhythms, and volumes has a crucial influence on how newborns experience their new world. Newborns respond to, and have preference for, the human tone of voice, with nuances that can stimulate or be soothing (Stern, 1985). Qualities of the tone of voice (i.e. rhythm, pitch, intensity) are evocative of vitality affects. These are “dynamic, kinetic qualities of the feelings that distinguish animate from inanimate” beings (Stern, 1985, p. 156). They are the ebbs and flows in the emerging infant-mother interaction. Ultimately these qualities of feeling can lead to a felt sense of self-affirmation of the lack thereof. These dynamic forms or vitality affects are important in terms of the emergence of what Stern (1985) calls the mutual understanding of each other’s emotional experience, namely, affect attunement. This is truly the meaning of to “be with another” (p. 157). It is not what the physician said, Amy revealed. It was the tone of the voice that left Amy feeling that the emotionality of her experience does not register with the physician. Attunement is not to be found with the physician.
It is important to note that physician tone of voice has legal ramifications in terms of malpractice litigation. Ambady et al. (2002) examined the interpersonal aspects of care that could be potentially associated with family and patient decisions to initiate malpractice litigation against their physicians. Specifically, they analysed the role of the physicians’ tone of voice in past medical litigation. The authors removed the content of what the physician had said preserving only the pitch, intonation and rhythm. It is important to add that the level of competency of the surgeon, years of training or specialization, were also controlled for. Ambady et al. were able to predict which doctor had been sued from just the tone of voice. Those physicians whose tone of voice registered nuances of what Martin and DiMatteo (2013) call “dominance,” such as talking down to, were more likely to have been sued. Moreover, Ambady et al. (2002) found that those doctors whose voice tone was perceived as “robotic,” that is, as monotone and inexpressive, were also more likely to have been sued. Physicians whose tone of voice was perceived as comforting were in the non-suited group. Gladwell’s (2006) work indirectly supports these finding by proposing that tone of voice carries the meaning of respect. “In the end it comes down to a matter of respect, and the simplest way that respect is communicated is through tone of voice, and the most corrosive tone of voice that a doctor can assume is a dominant tone,” writes Gladwell (2006, p. 3) when explaining Ambady et al.’s (2002) findings.

**Demeanors**

Amy speaks to how doctor’s manners in the family-physician interaction are also suggestive of not listening attentively or not listening at all. She recalls how some physicians simply go through a list of questions automatically, from one question to the next. At the time, Amy’s father was undergoing treatment for a blood cancer treatment that entailed rounds of chemotherapy, well-known for the harshness of the side effects and the uncertainty of the outcomes. Yet, nonverbal signals that might have conveyed expressions of sensitive understanding of her concern for her father’s well-being were mostly absent. Amy longed for a smile that might have conveyed a sense of empathy or compassion. “They are very robotic,” said Amy referring to some of the physicians. The powerful impact of nonverbal demeanours and manners are best expressed in Amy’s narrative below. Amy recounts:
It is also the demeanours. They (doctors) go through a list of things and this and that. And that’s it. Do this and do that. They ask questions from the list and then they go yeah, yeah, ok. They (doctors) are very robotic. I don’t think that I ever got a smile from Dr. Y unless he was laughing and talking to another doctor. No. He was a miserable guy. You can see. You can tell. You can tell even with his manners and when he was talking to other people. It is so transparent how miserable the doctor is, how rude he is to patients and their families. It was very transparent. Because my dad did not speak English, there was no direct communication with Dr. Y, but he [dad] could tell.

According to the Canadian Medical Protection Association [CMPA] (2015), compassionate communication with patients and their families is at the crux of respect. Verbal as well as nonverbal communication plays a crucial role in medical professionalism (CMPA, 2015). Yet the CMPA highlights that poor physician communication continues to be a problem. For this medical organization, communication specifically involves the physician’s tone of voice as well as manners and demeanours. The CMPA notes that physician manners and demeanors may lead to patients and families interpreting nonverbal cues as disrespectful which in turn increases, as indicated earlier, the risk of medico-legal difficulties for the doctor.

Amy notes how some physicians went from one question to the next in a process that seemed automatic, showing a lack of attentiveness and, more disturbingly, a measure of disrespect. “He was rude,” Amy said of one of the oncologists attending her father. Amy continued by describing how such demeanors gave the appearance of a rushed medical consultation. The doctor was “very quick,” and “abrupt,” she said. There is nothing in those small moments to recognize the other as human. “With the other doctors it was an automatic Hi,” but “they really don’t mean it” Amy said in comparison to her father’s main physician, who she described as compassionate and caring. The manner in which questions were asked and by which she was being spoken to carried the implicit sense that physicians actually do not see the family members and the distress that cancer brings upon them. Such interactions were abrupt and dismissive.

That doctor is quick and abrupt. He is very quick. Like when doing the rounds. I know that there are a lot of patients. I understand that. But really you don’t need to be that abrupt.
With the others, it was an automatic “Hi, how are you?” But they really don’t mean it. Dr. Y would ask: How are you feeling today? Well he asked my dad, but you could tell it was always part of the general questions that the doctor asks a patient. You can tell he DOES NOT CARE (emphasis) how you are actually feeling. It is a report that he needs to write and it is a question that he needs to ask. He is only asking because he has to and not because he cares. I am telling you, it is part of a checklist.

The patient and the family member see themselves as being reduced to a checklist and to a report that needs be written in the medical space where human beings meet.

Emma, like Amy, also speaks of the family member-doctor interaction as brief, rushed, and silent. There is no understanding of the importance of the interaction. There is no willingness to share the pain, uncertainty, and distress. There is no relational involvement. It is not their job and “off they run,” Emma recalls. Left behind, invisible, Emma is left “sitting at a loss.”

The doctors are running past you because they are too busy, or they figure another doctor took care of that; or “I don’t do that”; or “that is not my job” and off they run. And you are still there, sitting, at a loss.

From his study of the infant-caregiver dyad, Stern (1985) contends that human interactions carry a certain rhythm of movements and turnings: towards, to, forward, or away (pp. 146-149). These are the turning motions that lead the infant and the caregiver to “‘to be with, “to share,” “to participate in,” “to join in’” (1985, p. 148) or to a lack of “empathic responsiveness” (p. 138). These motions may also refer to those moments where a choice to disengage and detach is made (Zaner, 2015). The door to a shared space of connectedness can be closed and the “encounter as a moment of presence” (Smith, 1963, p. 205) fails to unfold as the physician turns away.
Chapter 5.

Feeling bereft–Turning away

The last few days, I was like, “Where’s [the doctor]?”. I thought maybe he would come over...and see him [participant’s husband], but he did not. So that kind of shocked me a little bit. He left. I mean, he just disappeared...we never saw him.

(Family carer, Back et al., 2009)

Feeling bereft–Turning away is the second of four inter-related themes that emerged. The theme Feeling bereft–Turning away is composed of two sub-themes named searching for information and searching for a compassionate presence. These sub-themes encompass a family member’s search for information and compassionate understanding, that is, for a knowledgeable and sensitive responsiveness from the physician caring for their loved one. What is it like for family members to navigate the unfamiliar and often bewildering landscape of the hospital in the daily lifeworld of cancer treatment? What do they experience as they encounter numerous physicians? Will they experience a presence that is “compassionate and helpful” (Marcel as cited in Anderson, 2006, p. 93) or a presence that is “distant, impersonal, or absent” (Marcel, 1998, p. 169)?

As we delve into their narratives and as treatment unfolds, the participants’ cancer journey becomes one of searching for information, for a helping hand, and a compassionate presence, given the distress of the illness.

Searching for information

A large body of psycho-social and medical literature has pointed out that fear and uncertainty of the unknown pervade the cancer experience (Shea-Budgell, Kostaras, Myhill, & Hagen, 2014). “Patients and caregivers operate in a crisis mode,” writes Dresser (2011, p. 14), a medical ethicist and cancer survivor. Patients and caregivers often face critical and, at times, life and death decisions throughout the cancer journey (Dresser, 2011). Under heightened conditions of fear and uncertainty it is natural that the caregiver seeks information and
guidance from the physician (Dresser, 2011). *Searching for information* is thus the first sub-theme that unfolded in almost all participant narratives.

It is the family caregiver who takes the patient through “the disease and into survivorship,” writes Longacre (2013, p. 297). Treatment requires intense emotional, psychological, and instrumental demands. In a recent research article, Longacre, Galloway, Parvanta and Fang (2015) found that 76% of family caregivers reported “having a high informational need” (p. 786) and, importantly, wanted that information to be delivered by the attending physician. Caregivers saw provision of information as critical to their ability to care for the patient. In the day-by-day reality of cancer treatment, were physicians responsive to the family’s need for guidance and information? Was the giving of information provided in a manner that was easily understandable to the carer, or was it offered in complex language and medical jargon? In the concreteness of the shared life of cancer care, was the presence of the physician perceived as being receptive to the carer’s quest for information?

Participants told me that their loved one’s cancer treatment was experienced as a constant search for any information that might alleviate their loved one’s pain and discomfort. Most participants related how they felt their need for information was often unacknowledged right from the first instant that cancer made itself present. Family caregivers told me of their constant struggles to secure information.

**Searching for information: the cancer journey**

Chen et al. (2014) highlight that, with cancer, caregivers assume a critical role in providing health care to their loved ones and most often with little to no medical support in how to provide that care. Caregivers often have little knowledge of cancer progression, potential outcomes, side effects of drugs, dispensing medications, and changing dressings (Chen et al., 2014). Such knowledge is indispensable once the cancer patient comes home and receives outpatient treatment. Chen et al. posit further that, given the complexity of cancer care, the communication of information to the carers should be a priority for the attending physician because how the caregivers navigate the complexity of the cancer trajectory carries
a great burden and has a lasting impact on both the patient and on the family’s emotional and psychological outcomes.

Authors Shea-Budgell, Kostaras, Myhill, and Hagen (2014) state that it is the duty of physicians to provide “information on diagnosis, prognosis, and treatment options to support patients and their families” (p. 165). I wondered if this statement reflected the caregiving journey as this study’s participants experienced it? As Chen et al. (2014) ask, what was the living experience of obtaining information from the physician like for these participants? Were they informed of their loved ones’ illness progression and what the physical caring of their loved one would entail? Were side effects of treatments and drugs discussed in a way that would be meaningful to the family carers? Were the potential treatment outcomes discussed? Were they given information that would prepare them for the debilitating pain and suffering that they would witness as treatment advanced?

Emma notes how, following her mother’s sudden diagnosis of advanced cancer, she was left to sit in the hospital emergency room to wait for the test results. Eight hours passed before anyone who might have knowledge of what the diagnosis meant spoke to her again. Despite the powerful impact of the word cancer, information did not arrive. Emma sat with many questions surrounding the disease and potential treatment, waiting for hours.

So the doctors did a lot of testing. We were in there for about eight hours and I stayed because I wanted to make sure that she was in good care. I understood that when the doctors were to come around they would be talking about this, to know what it is she would be up against. Then we were left in the waiting room. This was eight hours being left there.

Emma continues by relating how one night she had just come home and received a phone call from the doctor to say her mother had suffered a stroke. Emma recounts franticly rushing back to the hospital. When I asked her whether more information was offered at that point she said:

No. The doctor said she had a stroke. “You need to come.” That’s it. Then they were saying “well, we are not sure whether it is a stroke.” When I got there they were saying it is a mild one. But one side of her face had slipped and her right hand was like a hook. What would you call that? Really? She is having a hard time feeding herself and she is not improving. Would you call that mild?
Interviewer: After they said it was mild, did they say what they were going to do?

Emma: No. No information came from the doctor.

Emma describes waiting and worrying by her mother’s side. Aware of the meaning of an advanced cancer diagnosis, she wonders about the unknowns. She relives the experience of searching for information about potential treatment, survival, or having to face the prospect of the finality of life. Time is suspended for Emma. She waits and wonders.

And I was there at the hospital. But any information I was getting was from the nurses. The doctor finally shows up while I’m there and says to the nurse that the cancer is not just in my mother’s arm, it is in her lower back, and it is in the bone marrow. And the cancer is quite extensive. But at that point he still had not said to me what kind of path they were going to take. Whether it is going to be chemo, or...[long silence] or, how long she has. No, the doctor gave me no indications of how long it would be.

Anne too highlights the lack of information offered throughout her father’s cancer treatment. When I asked whether she was able to acquire information from the treating physician, she disclosed how as her father’s treatment unfolded she was left to familiarize herself with information that was complex to understand and often disheartening.

Well initially, I was just the daughter so why would they tell me anything? After it got a bit better just because I was always in their face. But NO! The most you get is just simple answers to your questions. I had to read up on the cancer. I had to do a whole bunch of research. It is not like the doctors provided any kind of help or a back story of what was going on. For example, if they told you ‘there is a fungal infection’ they hardly provided much more. You have to go and figure out why or what was going on. The doctors just don’t say anything, or they are really vague, or they tell you but in ways that make no sense to you.

Emma echoes Anne’s narrative. Despite the grave situation, Emma struggles in search of information from the physician. She awakens to a new reality: that in the medical space of illness her presence as a daughter is insufficient for the transmission of information. There is no readiness to provide her information about her mother’s illness. In her words, it is “not possible.”
The doctors were very reluctant to give me much information about her illness and state. Even making an appointment to see her doctor, because I am not the patient, was not possible. But in the hospital I was right there with my mother. I am present there. So it is very sad, extremely sad, when you think about it.

It is worth noting that the literature on cancer and family carers has highlighted the need to humanize medical practices (Youngson, 2011). Chen et al. (2014) note that while biomedical treatment and technology are important, the presence and availability of the attending doctor is important for the families providing care. In fact, caregivers overwhelmingly said that in order to best care for the ill loved one they needed “to have a doctor who listened and created a supportive environment where caregivers’ informational needs could be addressed” (p. 575). Almost all family caregivers expressed a desire to discuss their concerns with the doctors in terms of illness progression. Yet 90% of the participants in Chen et. al.’s study noted how, as treatment advanced, they received little contact and little information about symptom progression, treatment, and disease progression.

The need for information

As cancer and treatment advances one may wonder whether participants were aware of what was to come in terms of side effects or illness trajectory? Ernie related she was not at any time informed of the excruciating pain her father would experience as treatment and disease progressed. When I asked her whether the doctors prepared her for what was to come, Ernie replied: “No, No, [silence] nobody does.” She continued,

I remember when he was in the hospital the last week, on the last day I went to the nurse and said: “he is in too much pain. It hurts a lot [tears, soft voice].” And she said “it is because the cancer is all through his body.” But nobody had said that before. Nobody had said: “Oh, as the cancer advances it is going to hurt a lot” [tears, silence]. No doctor says it.

Emma highlights the importance of keeping the family informed and warns of the devastating emotional cost to both the patient and the caregiver when information about disease progression is not made available. With scant forewarning or information, the cancer
progression for carers is hard to witness. Emma speaks to the pain and physical deterioration that invades her mother’s body which indicates that the terminal phase is near. Emma said:

   At least keep us in the loop and tell us what is going to happen without us having to chase them.

Interviewer: Having to chase the doctors?

Yes, absolutely. Things were changing in her, things that were happening without her being able to articulate them. You can tell she is feeling trapped in her body, trying to get out, and there is no help coming. You are running in the hallways trying to get nurses to come and give her a sedative to calm her. It is so difficult. And the doctor goes blah, blah. And she needs this sedative. These are her last few days. Who cares! Give her what she needs.

Ernie speaks to the unnecessary anguish of being left to cope alone and uninformed when death approaches. Ernie said:

   I would go to the doctor and say “Please give him an intravenous.” I would say to the intravenous doctor “Please give him the intravenous.” Because [tone of disbelief] no doctor prepares you. It was just left to me. The doctors never talked with me. I don’t know if they talked to my dad but I don’t think so. It was: “OK you have cancer. That’s good. [laughs sarcastically]. Thank you. Next.”

So no. Nobody prepares you for what is to come. There wasn’t much contact with any of the other doctors, except the naturopath doctor. And we had to go through many doctors.

Emma also spoke about her experience in observing her mother’s health deteriorating. When I asked if the doctor prepared her for the possibility of more complications or bad news, Emma said:

   No, no doctors, only nurses until the palliative care gentleman showed up. He was the only doctor who actually came and said how destructive that major stroke was for her, to the point where she was now non-communicative. It was horrible to see. Two days before we were joking and laughing. We had gone to look at the fall colours in the window, and she was joking with the nurses. She was all there [smiles, cheerful voice tone], even with the bit of slippage in the mouth area and with her hands. She was all there.
Emma’s mother is left “feeling trapped in her body.” “She was feisty before the cancer,” Emma said. “She wanted to get out” but “she can’t.”

Kate also noted that wading through the emotional demands of cancer care with little information was getting to be “too much.” Four months of the cancer journey had passed and little had been conveyed about her mother’s cancer trajectory. In the middle of her mother’s birthday, she hears utterances and murmurs amongst the attending staff that her mother’s cancer has progressed and cancer might now be in her brain. Kate said:

It was just too much. I was just so frustrated. My mom was discharged to palliative care in the middle of March. By the beginning of June there was some debate going on as to whether the cancer had moved to my mom’s brain, but the doctors didn’t run any tests.

Interviewer: Did the doctor tell you?

Nope. I wasn’t seeing the doctor very often. It was around my mom’s birthday and someone at the nurses’ station was mumbling that her cancer was in her brain. The doctor didn’t come and say “Well, we know now, and so on.” Or, “We have run some tests and a CT-Scan and this is what we know.” The doctor did not run any tests.

Kate describes how when she arrives at the hospital palliative care she sees her mother’s skin is bruised. Without warning, Kate is informed that her mother’s life may be coming to an end.

So I walked in and she was actually black and blue. She looked like someone had taken a baseball bat and beat her up. …She was bruised all over. I rushed to the nurses’ station and I went WHAT! [emphasis].

A nurse said: “Well, there is the doctor,” and she pointed at him. He was by the elevator. To be fair, I don’t think that he was more neglectful than anybody else. So I went to him and I said: “What? What happened?” And then again I said “WHAT?” [Strong voice]. And he said: “Her organs are shutting down. Yes, I think her organs are shutting down. I think this is it. It is faster than we thought.” This was said as we stood by the elevator with a bunch of people around. And I replied, “The nurses are thinking it is in her brain?” Then he turned and said “Oh yeah, probably” [mimicking a casual tone]. And he left.
Once again I didn’t demand a CT-Scan. It was my first time dealing with cancer. Now I will demand a lot more.

I asked Kate if the doctor called to prepare her for the disease progression. She said:

No. Nothing. I did not get any call like that. I would phone and ask “How is she doing?” It also depended on who I got on the phone, whether they had some information for me or not. But no, there wasn’t any hint. No. No preparation. I was just devastated.

The experiences of these participants underscore the paucity of communication coming from many of the physicians to the family carer. They were left to observe their loved one’s pain in a changing and deteriorating body and with organs that begin to fail. Kate, without warning, hears that the disease is in her mother’s brain, while Ernie is told that it is all through her father’s body. Yet, argue Benkel, Wijk, and Mollander (2014), within advanced cancer where bad news is frequent, it is essential to provide information to the family to prepare them for what is to come.

According to Benkel et al. (2014), physicians should be prepared to provide information about stages of the disease, disease progression, symptoms of disease progression and deterioration. But the reality does not reflect this, since many physicians feel ill-prepared to provide difficult information. Because of a lack of training and preparation, health professionals avoid offering information to both the patient and the family (Benkel et al., 2014). Moreover, Benkel et al. found that nurses thought it was the physicians’ duty and responsibility to provide information about diagnosis, prognosis and disease progression. Nurses in turn felt their job was to provide information to the family in terms of daily care but not about disease progression. Significantly, the medical literature points out that carers look to the physicians to provide them with information (Chen et al., 2014; Benkel et al., 2014, Shea-Budgell et al., 2014).

A large body of literature has pointed to the negative impact of cancer treatment on family caregivers’ emotional health in terms of distress, depression, anxiety, low quality of life, and sense of burden (Girgis et al., 2013) These negative outcomes may be further exacerbated by a lack of information made available to family carers (Lund et al., 2015). Iconomou, et al.
point out that there is now worldwide recognition that provision of information to family caregivers during treatment is imperative. For Iconomou et al. it is the responsibility of medical professionals to provide information to family carers that supports the caregiver in continuing to do work that has direct implications for patients’ health outcomes.

In Ernie’s journey as a carer, she had to inform herself. When I asked Ernie whether information was readily conveyed, she responded, “No, no information.”

There was not much said. There was no doctor that, for example, said: “Ok, this went to the trachea and it went down to the lungs, it went here.” There was nobody really who said anything, like “here it is in the tongue and then this has to be removed, and then the cancer has gone down, etc.” Nobody really says anything. I did not have any doctor who said: “It went to the lungs and from here it went down to this other part, etc.” No, there was no information.

Ernie recounts that in neither diagnosis nor treatment were explanations ever offered or given. “Your father has twenty-seven tumours and nineteen are bad,” she heard the doctor say in the diagnosis. Grief must be suspended. She needs to gather her strength and embark on her own learning in order to support her father

The doctors almost never spoke to me. A typical interaction with them (doctors) was nothing. Did they ever explain anything? No! the doctors never explained anything. The doctors never talked to me. I had to read books and then conclude for myself: Ok, this is what it is. I think doctors should give the family information when the family wants it. But at the hospital nobody talks to you.

A consistent finding in the emerging literature on caregivers’ needs concerns the difficulties that caregivers face in accessing information about their loved one’s care (Hannon et al., 2013). This is despite the uncertainty that a cancer diagnosis instantly brings (Hannon et al., 2013). Hannon et al. surveyed patients and family carers’ satisfaction with oncology treatment. They found that the lowest satisfaction with oncological care, as reported by both patients and family members, was tied to a physician’s reluctance to provide information specifically in the areas of managing pain as well as prognosis. Hannon et al. stressed that a lack of information from physicians was not only experienced by the family carers but also by the patients themselves.
The barriers: “It’s like a big secret.”

Almost all participants in this study spoke of their struggles in accessing information, whether it was about upcoming treatments, survival odds, prognosis, symptom progression, or medication side effects. A lack of information further impacted caregivers’ uncertainty and distress and contributed to a pervasive sense of loneliness. Some participants used words such as “a block” or “a wall” to describe the barriers they confronted in gaining information about their ill loved ones. “It is like a big secret,” Emma said of her fight to access information.

Emma noted that physicians seemed not to recognize the scale of suffering and uncertainty that encompass the cancer journey for the patient and the family carers. Cancer brings with it a multitude of questions. Yet doctors would not provide even the most basic information. “I was listed as the person to be called if she ever ended up in the hospital. Then you get this call to go to the hospital. But you are not getting any answers,” Emma told me. She went on to say:

It’s as if they were only willing to talk to the person to whom this is happening. The doctors don’t realize that while it is not happening to you directly, it IS happening to you. You are concerned. The questions that are popping up are like: Exactly where is the cancer? Can it be treated? If it can’t be treated, what is the prognosis? How long will it be? Can we do home care? Can we do something? And while you are thinking about all this you are not getting any answers.

It is like some kind of a big secret. That is how I felt.

When I asked Emma if information was an important need for the caregivers, she said:

Yes, absolutely. Just tell me what happened and, again, what is it you are going to do, and what can I do to help? The patients are just not listening. Think about it, if someone told you that you have two weeks to live, what shape would you be in? And what would you do with that information? How can you process that?

Anne uses the word “a wall” to describe her struggles in trying to get information from the attending physician. Such information is vital given the uncertainty that Anne experiences.
daily in the leukaemia ward. Yet in this medical space of treatment where the nearness of death is always apparent, securing information is like hitting a ‘wall.’

You are asking questions but you might as well be talking to a wall. In my specific situation I would ask the doctors questions and it is almost like they are doing you a favour by bothering to answer you.

Kate’s account also reveals the family caregivers’ struggles to obtain information from the first moment that cancer is diagnosed. Kate states that she encountered “a block from the medical community,” what she perceived to be an intentional and impenetrable barrier to access information. When I asked Kate what information the doctor related about the type of cancer, or the prognosis, Kate said, “Not even the most basic information.”

The ‘block’ from the medical community was shocking to her as her mother’s treatment continued. In describing her attempts to access the specialist treating her mother, Kate said,

Well I would go to the hospital but I don’t think I had more than three phone conversations with the doctor. That was it. You just couldn’t talk to him. You couldn’t phone him during office hours because the nurse and his office staff would not put you through. You really had to be physically there at the hospital all the time to get some information.

Kate continues by describing how her mother implemented a legal formality so that information could be wholly accessed by Kate. But she was still forced to engage in negotiations with the doctor. Despite her mother’s signed authorization allowing Kate full access to information, Kate still faced difficulties when seeking out information:

In those days, or it might have been the hospital interpretation, which I think it was, you had to sign papers to authorize people to have information. My mother signed so I was allowed to have information. It took a while to figure out that I could actually ask for information. So she signed.

Interviewer: Did it help?

No [insistently]. It was all about me guessing even what kind of medication she was on. Even with the signature it took a bit of negotiation about who I should be asking, and when and why I should be asking. Unless you were physically there you couldn’t get information from the doctors. To a certain
extent, it was a complete block with the medical community. You had to be literally physically standing there in front of them, and they still would not give it to you.

Kate asserted that the ‘block’ was so powerful that when her mother’s treatment came suddenly to an end no information was provided. This was information she later discovered she was entitled to have. “She was going through radiation but the doctors stopped the radiation,” Kate said. When I asked whether the doctors or the oncologist(s) spoke to her about stopping the treatment, Kate replied:

No, there was never a conversation after that. The doctors said there was no more treatment and she was sent to palliative care and not to the hospice. This was my first time through cancer and afterwards you learn! Yes, you learn!

Emma, Kate, and Anne speak of encountering a wall, a block, a secret, when trying to reach the physician for information. The expression “a block from the medical community” and “talking to a wall” seem particularly revealing. The word “block,” derives from the French bloquer meaning “obstruct” (Online Etymology Dictionary). The word “wall” is from the old English weall signifying a “fortress, a defensive fortification,” “to keep from view,” or as Emma puts it, a “secret.” A wall is also defined as “a physical object that blocks the way” (Merriam-Webster Dictionary). In the medical environment, though the block and the wall are invisible, its presence obstructs the process of communication, keeping information secret, held within the confines set by the physicians who act as the gatekeepers of the medical community.

The above participants’ narratives bring us back to the work of the French philosopher Michel Foucault as introduced in chapter three. Foucault (1973) theorized that with the emergence of the modern medical clinic, new rules of ‘seeing’, ‘saying’, ‘listening and ‘acting’ were instituted by the medical gaze. Such practices ultimately were designed to assert new power dynamics in the space of medical practice (Foucault, 1972) and thus also the ways in which doctors would relate to the in-patients and the accompanying families. As a discipline, medicine needed to impose rituals (p. 216). These new rituals defined who could speak, and who could not, demarcating who was and who was not authorized to enter the space of discourse.
Perhaps what the participants described as *the wall, the block, and the big secret* are these same “rituals” that Foucault (1973) contends were created to distinguish those who could speak, the doctors, from those who could not, the family members. In the positivistic space of the biomedical *clinic*, writes Foucault (1973), the patient and the family must be “neutralized” (p. 9). The families providing care are seen as no more than a necessary “disturbance” that physicians “need to tolerate” (p. 9) but never as subjects of communication. Kate describes having to seek answers from her friends and relatives who were part of the medical community but, crucially, not from her mother’s doctor. She shared:

I have a sister-in-law who works in the medical faculty at the University. She was useful. I also had a number of medical friends who were able to provide me with information.

Another participant spoke of how information was often wrapped in medical jargon. One may speculate that jargon presents another barrier to information, clothing it in a kind of medical secrecy understood only by physicians, as illustrated by Anne’s narrative below:

I think the assumption is that the lay person is stupid because the doctors wouldn’t talk to you. They would be talking to you in jargon because they assumed that you were too stupid to figure out a common-sense explanation. It is strange trying to explain it but the doctors speak at you with jargon because they figure that you are too stupid to get it anyway [laughs sarcastically]. They didn’t even bother to explain it in a common-sense way or in plain English.

It is important to add that current medical literature strongly cautions against the practice of using medical jargon instead of understandable language (Mazor et al., 2013). Jargon can lead to misunderstanding, confusion, the delay of treatment, and interference in patient-physician communication, thereby impacting the patient’s safety and health outcomes (Cooke, Wilson, Cox, & Roalfe, 2000; Leblanc et al. 2014). The use of jargon is, in fact, the most significant barrier to communication (Deuster, Christopher, Donovan, & Farrel, 2008) and therefore any interaction that follows.

Cancer care is riddled with uncertainties in terms of disease progression and treatment outcome. Anne told me how early on in the cancer experience the family struggled to understand test results. She seems to imply that medical jargon is not a casual occurrence.
Rather, it serves to keep the family member silent. The encounter is lived silently and briefly. Of her conversations with many of the attending doctors she said, “They make sure to fill it up with as much jargon as possible so you are too dumbfounded to talk or ask too many questions and therefore they can go away very quickly.” The interaction is stopped before it can ever begin.

“The voice of medicine’ frequently speaks in inaccessible biomedical language,” writes Farrington (2011, p. 232). “Starting in medical school, physicians are trained by the culture of medicine” to use “unclarified jargon,” posit Castro, Wilson, Wang and Schillinger (2007, p. 92). It is a way of asserting “professionalism” (p. 92). Biomedical jargon, as Anne implies, signifies the line between medicine and power. Jargon ensures that the family member will not “ask too many questions” thus silencing and excluding the family in one stroke. Jargon may also serve to avoid interacting with family caregivers. Doctors “can go away quickly” Anne says. In cancer care, “jargon words were common, explanations were rare,” write Deuster et al. (2008, p. 1951). Medical jargon serves the purpose of separating those who are seen as having the right to speak from those who do not, leaving the latter blocked from accessing the information about their loved ones (Foucault, 1973).

Foucault (1972) contends that language is never value free. In the modern hospital space where the doctor, the patient, and the family meet, the medical discourse is not a transparent articulation of what appears visible to the doctor’s eye. What the doctor says to those facing him is regulated by preceding “scientific norms” (p. 114) which are not accidental, but intentionally express what Foucault calls discursive “rules of exclusion” (p. 216) inherent in current medical institutions and its governing bodies. Medical discourse, by virtue of being in the hands of institutional experts and what Foucault calls “institutionalized medicine” (p. 227) and its strict indoctrination, represents systems of exclusions and prohibitions by which discourse is “at once controlled” (p. 216).

Doctors, should eschew a ‘paternalistic’ approach characterized by doctor dominance and biomedical language in favor of a shared approach to diagnosis and treatment, in which an open and empathic atmosphere facilitates information exchange, joint understanding of diagnosis and treatment options, and the development of a relationship of trust. (Farrington, 2011, p. 232)
Whereas Foucault has provided an historical perspective on the experience of being excluded from participation, Gabriel Marcel embarks on a philosophical exploration of co-presence and communion in the relationality of care. To be engaged, notes Marcel, is to participate with the other in their reality (Marcel, 1964) and thus in the other’s illness reality. Sweetman (2008) notes that Marcel explores the meaning of non-disponibilité/unavailability, tracing the meaning of the word disponibilité to ‘responsiveness’ (p. 50). Disponibilité is a response of openness and receptivity to the other’s appeals (Marcel, 1964). To be, notes Marcel, is to be at the disposal of the other.

Disponibilité is “the vital reaction which is lacking in the being who is internally inert” (Marcel, 1964, p. 50) and therefore unavailable. Disponibilité is a way of giving, accepting, receiving, and welcoming. “I welcome you as a participant in my work,” affirms Marcel (1964, p. 40) and through that “I participate in existence” (p. 213). Disponibilité is a receptivity to the possibility of a shared experience—a communion—where human beings participate with each other as beings (Marcel, 1964). It is also the case, however, that if the other’s appeal is refused, it does not touch me. “Somebody appeals to my sympathy in a given situation” (Marcel, 1964, p. 50) but sympathy does not summon a response to offer my resources. Non-disponibilité, suggests Marcel, is a way of refusing the other’s appeal. “The suffering of the other is alien to me” (p. 51). This is the refusal of an invitation to participate in being with and alongside the other (Sweetman, 2008).

There is a way of listening which is a way of giving, and another way of listening which is a way of refusing, or refusing oneself. (Sweetman, 2008, p. 62)

For Kate, Emma, Ernie, and Anne there is no response, no openness, no receptivity and no responsiveness to their appeal. There is no welcoming to a shared participation with the physician. In the reality of the medical encounter, the participants told me that physicians turned away rather than toward them. For Marcel, disponibilité necessarily entreats one to be attuned to the other’s reality as he or she lives it. For Emma, Kate and Anne there is no such attunement to their experience. Participant’s accounts resonate with recent research in cancer. In 21st century biomedicine the family caregiver has been conceptualized as an outsider to be avoided by the surrounding medical establishment (Ekstedt et al., 2014; Lund et al., 2015).
Searching for information—Searching for the physician

The family identified the physician’s physical presence as being vital to their perception of receiving compassionate care. Being with the physician standing physically in the room and speaking face-to-face wove critical elements in the family’s experience of the interaction. Yet most participants used the word “non-existent” to describe the physician, signifying that doctors are for the most part not there or are fleeting presences rarely seen at the hospital. “There are only sightings of the doctors,” related Kate. “Most of the doctors were just not there (hospital). I don’t even remember anything about them,” said Ernie. When doctors accepted having to speak to family members, the participants told me that their interactions were kept “extremely brief and the physicians would come hours late for a meeting or “they will not show up at all.” Participants’ spoke of having to chase or track down the doctors in order to talk to them, albeit briefly. In the participants’ words, family members had to “hang out there (hospital)” waiting for them. Kate recalls vividly:

Well, the charming specialist (it is funny I blanked on his name completely) left town shortly after mom’s surgery [laughs sarcastically]. He moved to another city, which was a GOOD thing [laughs]. I think at that time when we saw him [doctor] he said the cancer folks will be in touch. He wasn’t particularly useful. Again he disappeared. After the surgery we were dealing with her general practitioner. The specialist disappeared. We did not see him again.

So no, there was no [sarcastic tone] contact. He phoned and delivered the news and said that her follow-up appointment was going to be “whenever”. After he delivered the news he hung up and then nothing [long silence] more [long silence].

Kate said that the physical presence of the doctor continued to be rare after diagnosis and throughout the cancer treatment. There were only sightings of the doctor. The much-needed family-physician interaction, the caring contact, was not available to her. Kate needed to hang out waiting, scanning for the elusive physicians’ presence. She must stand by. In Kate’s words:

When I was there and when he [sarcastic voice] decided to drop by, I would want to talk to him. So, you hang out there waiting. And you know when he is in the building because you can hear that he is being paged. The doctor would
pop in but I wouldn’t know when or where to expect him. They’d page him for me and he would show up two hours later if at all. There were sightings of him and yet at that time physicians were supposed to spend a lot [of time] in the hospital.

Emma, likewise, recalled receiving a call from the hospital. “I was listed as the next of kin,” she said. She supposed that because she had been contacted by the medical staff she would also be receiving information about “what her mother will be up against.” Yet, in the hospital space where she waited, silence inhabited the room. “Yes, the doctors made a showing and then they disappeared,” she commented sadly. She continued to describe her daily life at the hospital. In the four days that had passed since her mother’s cancer diagnosis, she noted that there was not “even a physical presence” of the physician. No information had been shared in regards to her mother’s course of treatment. There had been no physician presence as she witnessed her mother’s physical and emotional changes from the diagnosis or the stroke. There was no one to ask her if she needed anything in those four days. Emma said:

There was hardly any communication or even a physical presence of the doctors. I was there at the hospital every single day to make sure she was alright. It was really tough [tears/silence]. Sorry. It is really tough when you have to help feed and clean your mother. And she is frustrated because [tears] she can’t do this for herself [tears]. Up to this point I had not seen the doctors. Now it was into the end of the week. She had this minor stroke yet I still have not seen one doctor!! [emphasis]. I had gone to the desk but I only spoke to the nurses. So now it is getting close to the end of that week and then the doctor finally shows up.

Ernie also attested to physicians not being physically present during both inpatient and outpatient cancer treatments. Her father’s cancer treatment took eighteen months including surgery, radiation and chemotherapy. Ernie told me the attending doctors were “almost non-existent.”

The doctors were not there for anything. I don’t know who was taking care of my dad in the hospital but we hardly had any contact with the doctors. The oncologists? I can’t even remember them. No, I don’t remember any doctors taking care of him. I think the nurses took care of him. Most of them [doctors] were just not there at the hospital. I don’t remember anything about them. I don’t even remember the guy’s [doctor] face. That is how much impact they had on me.
Ernie related how there were never any answers for her, just physical absence. “The doctors were just not there,” Ernie said.

Anne spoke of the impact of the physician’s absence when she needed information. She said:

What people don’t understand is that when you are going through these invasive cancers you live and die on every result. There is no result that is minor. One result can mean that he is going to live and the next result could mean that the prognosis has become bad.

Your day is a roller coaster of ups and downs. And that is what people don’t understand. You’re living literally in the moment. Every test result can bring death and every test result can bring life [silence]. All that you want is to know the meaning of the test. But the doctors are not around.

The “roller coaster” symbolizes the intense emotions Anne feels every day in the cancer ward. “You live and die” searching for that information. “There is no result that is minor.” The nearness of life and the potential for death reside in information. She, like Emma, Kate and Ernie, must endure the uncertainty of the cancer journey uninformed.

For the participants, there was little receptivity to their appeal for information about treatment, prognosis, continuity of care, side effects, and disease progression. Their accounts speak loudly of feeling unseen, unheard, and left out as they sought information about their loved one’s illness. They felt that many physicians largely failed to respond in providing information requested by family caregivers. Doctors were not seen to recognize just how vital the information being sought was to the family (Hannon et al., 2013; Harding et al., 2012). The participants spoke of having to go to battle to secure the most basic of information, even when permission had been granted to them by the patient. These participants’ accounts capture what current medical literature is reporting which is that information provision continues to be the most unmet need for both cancer patients and their caregivers (Mazor et al., 2013; Williams & Bakitas, 2012).

Almost all participants stated that physicians largely did not seem attuned to the emotional and psychological impact that cancer treatment has on the family. They did not
experience an “intersubjective relatedness” or affective attunement to the other’s emotions, thoughts, or share a day-to-day reality in the cancer ward. This perceived lack of attunement becomes even more salient as the cancer journey progresses. Carers begin to experience what Stern (2004) calls “psychological aloneness” (p. 100) as a failure of emotional availability. Where there is no readiness to affectively attune to the other’s feelings or inner experience (pp. 75-96) there is no psychological presence, but only “marginalization” (p. 102) from the community to which one feels they rightly belong (Marcel, 1963).

In bringing us to the next sub-theme, seeking a compassionate presence, Stern (2004) suggests that “psychological belonging is achieved through intersubjective contacts” (p. 102) and feelings of “intersubjective belonging versus psychological aloneness” (p. 100). As Lingis (1994) notes,

“The other turns to me and speaks; he or she asks something of me. Her words, which I understand because they are the words of my own tongue, ask for information and indications. They ask for a response...an appeal for responsiveness. (pp. 130-131)

Seeking a compassionate presence

The other seeks the contact and the accompaniment. (Lingis, 1994, p. 132)

Participants spoke of having expectations that the cancer diagnosis would bring both fear and grief, but also compassion from those working in the medical arena. Yet, although noting that they endured tremendous “distress” (Thorne et al., 2010, p. 747) they received little in the way of compassion or understanding from the physicians treating their loved ones. Their search for compassion from the physician was an ongoing theme throughout their cancer journey, from the initial diagnosis until their loved one’s death.

Cancer is the “dreaded disease” (Thorne et al., 2010, p. 747), that brings “a sense of terror” (p. 747). It is a threat that represents an “existential crisis” (Epner, Ravi, & Baile, 2010, p. 1715) for the patient and for the family (Dresser, 2011). The threat of cancer to a loved one is no less terrifying simply because it is not physically afflicting family members. In fact,
participants voiced concerns that they lived cancer as if it were indeed happening to them. The mere utterance of cancer “triggers a profound and life-altering experience for most patients and their families” (Thorne et al., 2010, p. 746).

*Seeking a compassionate presence* encapsulates family members’ accounts of living through times when little to no compassionate responsiveness was shown to them by many of the physicians. This theme is consistent with the empirical literature on cancer care that highlights how many physicians respond to witnessing frequent circumstances of heightened emotional distress with detachment, withdrawal, and distance (Epstein & Back, 2015; Kerasidou & Horn, 2016; Post, 2011). According to Epstein and Back (2015), physicians are at the forefront of responsiveness to suffering as they directly interact with the patient and the accompanying family. Yet, so many times, the response to seeing suffering is withdrawal, detachment, and turning away (Epstein & Back).

The discourse of compassion has now gained considerable attention in 21st century biomedicine. Yet, de Zulueta (2013) claims that an entrenched belief held by medical students and practicing physicians is that attending to emotions is “akin to opening a can of worms” (p. 87) and that emotions are “to be avoided at all costs” (p. 87). Medical school continues to emphasize that “to be professional is to maintain a safe emotional distance and be detached and disengaged” (p. 87). In fact, a large of body of research has lent support to the claim that compassion and empathy diminish as medical school education advances (Weir, Aicken, Cupples, & Steele, 2015). Compassion is further eroded through the residency years (Neumann et al., 2011) and on past graduation (Roberts, Warner, Mountier, Geppert, & Hammond, 2011).

It is worth noting that a comprehensive historical, philosophical, and psychological conceptualization of compassion, empathy, sympathy, and compassion within medicine, is beyond the scope of this dissertation. Still, the current ‘buzz word’ of contemporary medicine is ‘compassion’ which involves empathic attunement (de Zulueta, 2013, p. 88). de Zulueta notes that while sympathy is associated with pity, empathy is associated with understanding but not necessarily with an action in response to the distress. Empathy, note Sinclair et al.
(2016), involves emotional resonance but not necessarily an action aimed at relieving the others’ sorrow.

Compassion involves both a “consciousness of others’ distress” along “with the desire to alleviate” their anguish (Merriam-Webster Dictionary). Roberts et al. (2011) physicians and researchers, define compassion in medicine as “the capacity to appreciate deeply the perspective of another person, and a compassionate physician is one who is well attuned to the experience of” (p. 367) the other. Post (2011) and de Zulueta (2013) propose that within the realm of medicine, compassion is inherently grounded in “attunement—the delicate but precise art of ‘reading’ another person’s emotion and responding sensitively and appropriately” (de Zulueta, 2013, p. 88). Compassion does not require an intimate relationship but, rather, acting in such a manner that the other knows that I know of his or her affective state (Stern, 1985, see Stern, 1985 for a detailed review of attunement). To be compassionate means essentially to turn to the other and to act (Epstein & Back, 2015).

Anguish and sorrow are readily present in all the twists and turns of the cancer journey. For Emma, Kate, Ernie and Anne, and contrary to their initial expectations, the family-physician interaction was perceived as one of little compassion, understanding and empathic responsiveness. They made statements such as “there was no empathy,” “there was no compassion,” and “no humanity” in describing their interactions with many of the attending physicians. Little was mentioned of any gestures or verbal nuances that would recognize their immense distress. “Doctors, where is your empathy?” Emma asks. Anne commented that “doctors are losing the capacity to be human.” Medical interactions are lived as being devoid of compassion in daily hospital life. “It is not family friendly and it is not human friendly for the one being cared for,” lamented Kate, when referring to the hospital palliative experience. Participants were searching for the needed compassion from the attending physician within the barrenness of what Kate calls an “unfriendly institution.”

**Seeking a compassionate presence: cancer diagnosis**

Thorne et al. (2010) propose that it is paramount to consider how the initial cancer diagnosis unfolds in terms of the patient-physician-family interaction. The patient and the
family enter into what is described as the cancer trajectory. It is in this initial meeting that patients and their families hear the bad news for the first time. A cancer diagnosis, note Thorne et al, brings instant feelings of dread, fear, shock, terror, and uncertainty. In the medical encounter between the patient, the accompanying family and the physician, one may assume that a compassionate presence is indeed a compelling need.

The cancer diagnosis for their loved one was sudden and unexpected for all the study participants. The cancer diagnosis indicated an advanced, metastasized stage that carried a high possibility of death. Despite such grim diagnoses, participant narratives revealed how bluntly the bad news was delivered during diagnosis. This blunt manner continued as treatment followed. Ernie recalled the moment when she first learned her father had cancer. She explained that her father had not been feeling well for some time. He had been coughing, however his complaints had largely been dismissed by his general practitioner.

And my dad was always coughing and complaining, and the doctor said it was nothing. Meaning, oh well, it is nothing, you know. So the doctor let it go. But then the doctor finally said “Oh, you should see a specialist.”

But even when they saw the specialist they had no idea what awaited them.

The specialist said, “Oh, we need to operate. You have cancer. Ok [silence]. Yes. It is cancer, just like that, as if it were nothing [she mimics with the shoulder]. It was just like that.

The doctor mentions the word cancer as “if it were nothing” despite the almost instant “association of cancer with death, suffering, and hopelessness” (Gordon, 1990, p. 275). When I asked Ernie whether she experienced the communication with the doctor as somewhat compassionate, she responded, negatively and definitively:

NO! He was just matter of fact. This is it. This is what it is. I know that my mom was upset when the doctor said to my dad: “You have Cancer.” I know my mom was upset that he just came and said that [mimics casually stating the word cancer] “Oh yes, you have cancer.” I know that she was MAD [emphasis] because of the way he said it. The doctors could be a little bit more caring. I used to work for a dentist and the dentists used to have to take special classes to learn how to relate to people. Physicians are physicians but some of them don’t really know how to talk to people. That was the case with the doctors who were there.
Ernie noted how the doctor appeared not to be attuned to the emotional meaning that the word cancer brings and was unable to recognize the impact on those receiving the news. Dread enters Ernie’s life in the anticipation of the upcoming chemotherapy and radiation. The familiarity of her life stops.

I think it is pretty sad because when the doctor said “oh, you have cancer,” your world goes [points down] all the way to the floor. No matter what cancer it is, you go: “Oh my God. What? Cancer!” You think about the treatments, you think about the chemo, and you think that he is going to get sick and you think about radiation, and all those kinds of things. Every time that a family member is told “you have cancer” everything becomes dark, everything is in the shadows.

When I asked Ernie whether any comforting words were offered, she replied: “No. Nobody offered anything. It was like the doctor said: ‘OK you have cancer’ [laughs sarcastically]. ‘Thank you. Next.’ It is pretty sad.” Ernie repeated this more than once, emphasizing what she perceived to be her physician’s lack of sensitivity. Once cancer had been unfamiliar to her. Now cancer threatens her father’s life. Cancer interrupts what Holm (2016), a physician, calls “the rhythm of life” (p. 1). For Ernie, life has followed a rhythm, a “recurring, pulsing” flow (p. 1). Now she hears her father has cancer. “Instantly, everything is blocked.” It is a paralyzing distress that engulfs her. Ernie’s habitual rhythm of life is now fading. Minutes stretch out as she sits in the consultation room and distressing images of the upcoming cancer treatment play upon her mind. The cancer is now happening to her as she lives it through her father.

Thorne et al. (2010) indicated in their study that most participants described the cancer diagnosis as a long-lasting moment that brings considerable “emotional turmoil,” “emotional intensity,” “disorientation” and “uncontrollable fear” (p. 751). They also underscore the “heightened surreal nature of the moment” (p. 751). This is Ernie’s temporal experience of cancer as a family member. Time stops when she hears the diagnosis. What is to come “is all dark” she said. The future appears “gloomy, sad, and sinister” (Online Etymology Dictionary). Yet despite the threat that the word cancer instantly conveys, in the family-physician interaction there are no words of comfort from the physician. Ernie instead perceives a callous dismissal, a motion signified by Ernie’s words “thank you” and then “next.” Ernie said:
People who go through the treatment with the patient know the interactions with the doctors are bad.

This is the current depersonalization and dehumanization associated with biomedical practices (Post, 2011). Dehumanization reduces a human being, the patient, to the discourse of “the kidney in Room 5” or “the liver in room 10,” rather than the person or persons sitting there, the “unique individuals with a unique story of illness” (p. 808). Her father is a “biological puzzle to be figured out” (p. 809). This is Ernie’s experience of the cancer diagnosis: she is the accompanying family member of the “cancer throat patient” in the consultation room. There is no acknowledgment of her pain. She is just a number, one among many families.

Life was also suddenly disrupted for Kate. She explained how her mother had gone to see a specialist because she had been losing weight. It was just a consultation. Kate explained that her father had passed away the year prior and therefore her mother’s weight loss was something she attributed to grief. Kate noted that cancer was not a diagnosis that she ever entertained as a possibility. Her mother was simply undergoing a common out-patient surgery.

My mother was having some problems and went to the doctor. My dad had died in October and she was not doing too well after my dad died. She had lost quite a bit of weight four or five months before that. She was recovering from my dad’s death so if she had lost a bunch of weight it was ok and actually she was happy about it. Anyway we went in to talk with the doctors.

Kate remembers how following her mother’s surgery she arrived at the hospital to be with her mother. A nurse approached her as she entered the room. Kate recalled how she sensed that something in the nurse’s tone of voice and bodily gestures indicated things were not right.

After her surgery I went to the hospital to stay with her. The nurse was a bit, well, kind of weird. She said: “Have you talked to the doctor?” And I said: “No.” And she said: “OH?? OK.” And she left very quickly. So I went to see my mom and she was pretty groggy. She had had the surgery and it was a laryngoscopy surgery that day. So I picked up my daughter and went back to my mom’s place.

Then the doctor, the specialist, phoned and said to me [somewhat mimicking a sarcastic doctor’s voice]: “Well, well, a little bit of a surprise here. When we went by her liver, it was full of cancer. We don’t know where the primary site is but we assume the liver is the secondary one.”
“Well I am thinking four months, I guess, to live.” Then he hung up. And it turned out that was also how he told my mother.

Kate conveys her deep sense of shock at what she considers to be a devastating way of giving this news. There is not even the slightest hint of sympathetic concern in the physician’s voice. When I asked whether anything else was said, Kate replied:

No, nope [sarcastic tone]. He phoned and delivered the news and said that her follow-up appointment was going to be “whenever.” So, no, after he delivered the news, he hung up. [silence-tears].

Emma recounts how her mother had already experienced a cancer diagnosis in the late 1990's. Emma also accompanied her mother through that first cancer diagnosis and treatment. Emma emphasized that ten years later when her mother received the second cancer diagnosis, nothing had changed in terms of expecting, but not receiving compassion from the attending physician(s). In recalling the second bout of cancer, Emma described how she had been called to the hospital after her mother had fallen from a chair. She had been taken to the emergency department at the local hospital. “I was listed as the contact person” she said. She remembers how, upon arrival at the ER, her mother, who “had been wheeled away for x-rays,” had returned in that moment to a tiny hospital bed in a busy ER hall. Emma, fighting tears and in an upset tone of voice, narrates her lived experience. Left in a “tiny cubicle” exposed to other patients, families, and people, she faces the attending physician to receive news of her loved one,

And in the middle of the ER, in front of other patients, an internist, though I wasn’t sure because he never introduced himself to me, proceeded to announce to the whole room that my mom's bone on her left arm is so eaten away by cancer that she will never use her arm again.

Emma, tearful and visibly upset, continues to recall her shock and grief at the manner in which the physician conveys the cancer diagnosis.

Yes, IN FRONT OF EVERYONE in the emergency room [emphasis]. I was stunned. Yes I was shocked. The drapes were not even closed. This is in the ER. It is full, with people walking by, and other people's loved ones here, and their families also standing by. We are sitting there in our little cubicle and the drapes are wide open. They did not take us to a special room. The doctor was
standing there with the social worker but she said nothing. It was weird. The doctor said it in front of everyone with the drapes fully open.

The American Medical Association [AMA] (2001) lists compassion and respect in their code of Ethics, stating that “[a] physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights” (AMA, 2001, principle 1). The Canadian Medical Association [CMA] (2004) also lists respect and dignity in their code of ethics. The CMA code of ethics, principle 2 states: “practice the profession of medicine in a manner that treats the patient with dignity and as a person worthy of respect.” The guiding code of medical professionalism for the CMA highlights “compassion and respect” as guiding values of medical professionalism (CMA, 2005, principle 1). Sinclair et al. (2016) contend that “compassion is a professional obligation of clinicians” (p. 1) and this obligation should prevail throughout the entire cancer journey. de Zulueta (2013) proposes that being attuned to the other’s fears, distress and uncertainty may be vital in engendering ‘trust and confidence” (p. 88) in the treatment that will soon follow.

Yet Emma describes how, in the space between her and the physician, there was no show of compassion, dignity, or respect in the communication of the diagnosis of cancer. She said:

I thought that it was terrible! [strong voice/tone]. When he said it, I was looking around and I thought: “Don’t you see all the people around here? This is a very personal thing to say to someone and you are acting as if you just said “we are going to get you a cup of coffee.” Yes, I can see why people shut down, why they cannot take this information when it is presented in such a way. I got better attention when I gave birth to my daughter.

Sinclair et al. (2016) conducted a literature review on compassion within the realm of medical practices. These researchers observed that, in the clinical encounter, compassion is enacted by physicians’ “acknowledgement, engagement, and action” (p. 16). Action is a fundamental quality of compassion and can be simply “attending to the small things,” (p. 9). Emma’s narrative reveals however, that in the middle of a busy hospital emergency room hall, only the disease matters. There was no engagement with her or with her mother; no acknowledgement, not one action in response to the word cancer and how it would impact them.
There is no movement to close the curtains surrounding the hospital bed in order to offer the patient and the family the much-needed solace. The “drapes are wide open,” Emma said more than once, reiterating her disbelief in how the cancer diagnosis could be communicated in such a shockingly public way. The open space was devoid of intimacy and protection, and their vulnerability was exposed for all to see. In this medical space, there are no gestures or nuances that reveal the comforting presence of the other, despite the instant image of “death, decay, and misery” that the news of cancer brings (Gordon, 1990, p. 276). “The way that the doctor had told her, the doctor had said there was nothing left of her left arm. All the way from the shoulder down it was all perforated bone,” recounted Emma. Yet, as Sinclair et al. (2016) note, there is no “attending to small things” (2016, p. 9)—not a handshake, a leaning forward, or a simple extended open arm, to acknowledge their distress. In this inhospitable space, there is no movement by the physician to get a chair, or even to stand close by Emma and her mother, no posture that might have conveyed an understanding of the new reality they face.

The narratives above tell us that in diagnosis there are no movements, no gestures, motions, or words that might alleviate Ernie’s, Anne’s, Kate’s, or Emma’s anguish. Thorne et al. (2010) write how patients and their families “carefully attend to the demeanor of the physicians for signs of attentiveness and compassion” (p. 749). Most participants in Thorne et al.’s study reported that comfort and compassion came in words and actions that acknowledged the “bad news” (pp. 749-750). Nuanced gestures convey warmth, attentiveness, sensitivity, understanding of others’ distress even when emotions or questions “were irrational” (p. 749). Yet Thorne et al. conclude that a lack of compassion in communicating “bad news” in a cancer diagnosis “is prevalent” (p. 752). The family carers see the physician, for the most part, as turning away from the appeal for help that surrounds them.

There are few instances of words or actions that acknowledge the vulnerability of Ernie, Anne, Kate and Emma, as they manage the unexpected impacts of their loved ones’ cancer diagnosis. A phone call to Kate coldly and efficiently indicates that death is to come within four months. There is no empathic tone or comforting word when cancer enters Ernie’s life. A lack of dignity in receiving the diagnosis permeates Emma’s experience. There is no
sitting down by the patient’s side in a posture that conveys compassion, presence and respect. Dehumanization is complete for Anne and Ernie. Ernie is just a number, her father just a diseased body.

Seeking a compassionate presence in treatment

Bad news during treatment continues to be communicated in trivializing ways that show little respect or compassion for the family’s cancer experience. This manner seemed to obscure the family members’ suffering and compromise the quality of life of their loved ones., Treatment was long and caregiver duties physically and emotionally taxing for three of the participants.

Amy describes the lack of compassion and respect when bad news is conveyed during treatment. Amy explained that her father’s diagnosis was acute myeloid leukemia with treatment failure signifying death. It is worth noting that Amy describes her main physician as one who exemplified compassionate care. Nonetheless, throughout treatment she interacted with many different physicians. She sat by her father’s side, in one instance separated by a thin curtain from the next patient and their families. The lived space of acute leukemia treatment, noted Amy, is one of constant darkness and gloom, denoting the profound anguish that inhabits the room. Bad news, is often blurted out in a loud voice with no discretion. Amy recounts:

You probably experienced the same thing when you went to the out-patient care and someone was getting bad news. All of a sudden, the mood in the whole room is dark and gloomy. And it is so uncomfortable to be there to begin with. There were a few times when Dr. Y was seeing a patient in the outpatient centre with the curtains drawn. He was very LOUD.

And respect is a big thing. There were so many times that you are sitting there and hearing the bad news for other people!! [Tone of voice expresses shock]. And you think: “Holy cow, can’t you just take the family member to a separate room or something?” It is very hard news for the patient and the family member. And I am sitting there listening to it.

When doctors are not discreet with medical information, it shows a lack of respect for the patient, and not only the patient they are talking to but all those
patients in the vicinity. If you don’t have respect for the patients you definitely have no respect for the patients’ family. It is sad, very sad.

In treatment just as in diagnosis, bad news is conveyed with little respect shown to the person. Amy expects that respect might at least be readily offered in such a space of suffering. Cripe (2016), an oncologist in blood cancer, writes that the space of acute leukemia is lived as one where “conversations are difficult” (p. 265) and that leukemia is a “disease for which treatment is frequently ineffective” (p. 265) and where distress is all encompassing given the toxicity of the treatments. “Death always hung close,” said Anne, whose father also had blood cancer, which involves a treatment where each test result brings with it the possibility of “life or death.” Yet in this desolate place where bad news is common, there is little effort to invite the family into a private, respectful space. This is the “tuned out” doctor, writes de Zulueta (2013, p. 88), who “is likely to add to distress” (p. 88) or, as Amy put it: “He was loud! There is no discreetness. And you have to be discreet because that is respectful and it is something that the patient deserves and the family member too.”

Compassion is inherently linked to respect and human dignity (Reid, 2012). If there is no respect for the personhood of the patient and the accompanying family, there will be no movement reaching out to the other in a compassionate manner. Amy said:

Yes, it is part of respect. Because it is very obvious that there are a lot of people around. There is no way that the doctors do not realize that there are a lot of people around. Especially because they are going on their rounds, checking patient by patient. And you definitely know that the curtain is the only thing that separates patients. It is a respect thing. Respect is important because when everything else is going down at least you get some respect.

“It is very sad” Amy repeated a number of times after witnessing the lack of compassion in the cancer ward. She continues to say how glad she is that her father cannot understand what is being said on the other side of the curtain. Frightening thoughts intrude upon her mind as she hears the other patients’ test results. The “worst” scenario of death can no longer be ignored. What is happening to the other, a bad turn, could also happen to her father. Amy describes overhearing that another patient is taking a turn for the worse:

So part of me is thinking that I’m glad my dad doesn’t understand English because if my dad listened to this it would be hard on him and I would feel
horrible. As a family member, you don’t want that. I can’t imagine having to have my dad hear about someone who is going through the same thing as him taking a bad turn. It is not pleasant because I am sure that if you were to go through the same thing and you hear about someone else taking a bad turn you would automatically think that person could be your family member. And your mind would start wondering and fearing for the worst.

The uncertain future threatens Amy’s present. Can death arrive? If her father had spoken English would he also have made the instant connection that would have intensified his fear? Like Thorne et al. (2010) who suggest that hope is critical for both patients and families, Amy insists that here hope becomes even more salient. Patients and families, frequently and throughout the cancer treatment, anticipate what lies ahead (Thorne et al., 2010). Patients and their families screen for compassionate nuances that can potentially allow them to “hold out hope” (p. 752) in these uncertain times.

Anne also remembers the instances of heightened distress and grief as treatment progresses. She describes how a lack of sensitivity to the other’s suffering can crush hope. The doctor came to tell her to “just give up.” Yet, all that was needed was a simple “I’m sorry.”

It was like someone had said to the one doctor who was in charge of my dad: “Ok you have to go and do it. You have to tell them it is not looking good and then get the heck out of there.” And that was what he came to do. I’ve always said it is not what you say but how you say it. The doctor came to the room to tell us to give up hope rather than to say “I’m sorry.”

Sinclair et al. (2016) propose that in clinical practices “compassion is largely conveyed through relational communication and clinicians’ presence” (p. 12). It can also be embodied through gestures, movements, positions, and contact which communicate a “clinician’s willingness to engage” (p. 12). In Anne’s interaction with the main attending physician, there would be no compassionate engagement, no bodily contact, or gestures to indicate understanding of her anguish. Anne sits besides her father, while the physician enters and quickly exits the room. There is not one bodily gesture to acknowledge the impact of the grim news. “He was very cold,” Anne said of the physician’s bodily language. Yet all she needed was a simple act of kindness to say “It is not looking good,” or simply “I am sorry.” These are the vocalizations of caring (Thorne et al., 2010). “They should teach doctors [silence] to be human,” Anne somberly affirmed.
Thorne et al. (2010) write about the crucial importance of offering hope. Cancer by definition questions one’s mortality.

A particularly vital element for patients as they navigate the emotional terrain of the cancer journey is their capacity to be supported towards hope…the human need for ‘something to hang on to’ some basis upon which to place one’s hope – becomes a critical piece of the subjective cancer experience. (Thorne et al., 2010, p. 752)

Anne recounted how her family was celebrating that her father had just been transferred back from the ICU to the cancer ward. Yet, without any expression of compassion from the physician, the doctor gives his ‘news’ as if her father were not there.

He said this in front of my dad as if my dad didn’t exist anymore, even though my dad was right there. He was listening to the doctor telling us about my dad’s demise. The doctor couldn’t care less that my dad was listening. As a family member, that really pissed me off [silence]. I mean, pull me aside. Come and tell me outside. Don’t say it in front of the person who is fighting for his life. The doctor, with no warmth, with no care, no compassion, nothing, said that basically my father did not [silence] have a chance [long silence].

Anne continued: “I’m sorry to say this, but if you think that some of these doctors are doing such an amazing job, well, they are NOT [emphasis]. Maybe someone else has a different experience.”

It is worth mentioning that the AML journey is a long one in which emotional, psychological, and physical pain become the daily reality. Research has documented that AML treatment is harsh and aggressive, requiring one of the most severe chemo-therapy protocols and toxicity (Redaelli, Stephens, Brandt, Botteman, & Pashos, 2004). It demands lengthy and total hospitalization followed by months of harsh daily outpatient protocols. Recurrence is high with multiple re-entry, high risk of complications, and high potentiality of death (Cheng, Hourigan, & Smith, 2014). The physical and emotional demands on the family are also extremely high (Cheng et al., 2014). Amy invites us to ponder the importance of compassionate presence in such an environment. Amy proposes that oncologists should be aware of the need to bring humaneness and compassion to the space of care. There is no excuse for a lack of compassion:
That lady doctor was just bad. Maybe she has become jaded by all those experiences. I don’t remember what she looked like but I do remember that she was very harsh! She had the demeanour to which you feel like saying “Who are you? And why are you here? And you doctor, you’re rude.”

As a human being, you know this person has cancer. And you know first-hand how difficult the treatments are, how difficult it is to be in the hospital facility, and how difficult it is to go through it all. And you as a doctor know this first hand. You as a hematologist are not like a regular doctor who is unfamiliar with leukemia. You know first-hand so you should show a little more compassion for what the patient is going through, let alone what the family is going through. Doctors, of all people, should show compassion.

Amy quietly whispered about another doctor,

No, there was no compassion. I have bad memories of this guy (doctor). Nope, not in his bag. There was no empathy.”

While Amy speaks of the need for compassion given the severity of AML’s treatment, Emma states that no matter what type of cancer you experience, empathy, humanity, and being treated as a human being are essential.

When you think about it, it does not seem to matter what type of cancer you have. We as a society are terrified of that word. Yes, absolutely terrified of that word. You can tell someone anything else and they will cope with it but not with that word. As a family member you are taken aback.

Emma needs to be strong to support her mother even when the word cancer frightens her. She questions where empathy has gone in medical care. Could it be possible that “doctors have stepped away from their humanity” she laments.

Is it because things are crowded in the hospital? Is it because the health system is overwhelmed? It is as if the doctors have stepped away from their humanity. These people are entering the profession because they want to help people? But you have caused my mother to shut down because of the way you told her that she has cancer.

Cancer and terror are fused. “One can cope with anything but not cancer,” Emma said. No matter what type of cancer it is, the journey brings instant feelings of dread.
Everything was very clinical. It was very sterile. No, nobody ever asked how are you holding up or do you have questions or please read this here, this is the type of cancer or this what we are going to do. There was none of that.

It is like a world is falling down all around you but nobody at the hospital asks: How are you? Is there something that we can do to alleviate things? The doctors need to show empathy.

This is Emma’s anguish as she sees her mother deteriorating. She feels thrown into a precarious state. What if death comes?

As a family member you are out on a limb. Your loved one goes from happy and healthy to deteriorate so quickly. Where is your empathy? You as a family are dealing with this long term, very long term, and it does not stop just because you lose that member.

There would be no understanding words, no recognition of her sorrow or despair. Emma lamented that the cancer journey was indeed “a solitary journey.”

Ernie related that her father’s treatment of a year and half involved surgery, radiation and chemotherapy. Consultation with different specialists was common throughout the cancer treatment. “So we have another appointment with the doctors, and you go and see the doctors, and it is blah, blah, blah,” notes Ernie in describing the perceived lack of interest when news of treatment was communicated. “And another specialist said to us: “you may need another operation if you want to live a little bit longer.” Ernie continued relating how she sat with her father as the upcoming surgery was explained. She hears about the medical treatment yet no one acknowledges the terrifying nature of the news being communicated:

So we went to see another specialist in another hospital. Then he [doctor] said to me: we will have to remove half of the face, the jaws, and the ear [long silence, tears] For me it was: wow.

Interviewer: Did you feel him (the doctor) trying to be empathic?

Ernie: NO! He gave me the facts in a matter of fact voice and that was it. And my dad decided not to do anything because it was: what’s the point!

Interviewer: So, throughout treatment the doctors did not approach you or ask how are you keeping?
No. No. Only the nurses in the hospital when my dad was there for the last week. That was it! That was the only time. I remember because my dad passed away on a Saturday. On Thursday he was almost gone [tears]. I remember because the nurses came running and we had to leave the room, and one of the nurses said: “what can we do for you?” It wasn’t what can we do for my father but what can we do for you.

Emma also speaks of how, prior to the cancer journey, she had assumed that a compassionate presence would be the hallmark of cancer care. Yet she found cancer to be treated in a trivial manner that dismisses the gravity of the diagnosis. “But it is cancer” said Emma.

The doctors go from one bed to another. We sat there for a very long time waiting for people to come to take blood and for her to go for more x-rays. It is like when I broke my toe [laughs]. They treated this as the same thing. But it is CANCER! [emphasis].

The trivial manner with which Emma’s mother’s cancer was treated suggests a lack of compassionate care.

A lack of compassion also impacted the last days for Kate’s mother. She remembers:

At one point fairly early on, my mom was in the hospital, and the doctors were trying to get the pain under control, and sorting out about her going home. The doctor wrote up all the prescriptions. My mom begged me [tears and in a broken voice] to go home to my kids. So I came back a couple of days later and she had been in horrible pain [silence]… I was sitting beside the chaplain and I said, this is just too much. And she said, “well you know the doctor could have written a morphine prescription to last more than 4 hours, so it works!”

Kate continues:

Oh my God. The doctor could have written it to last for 8 or 12 hours? He (doctor) could have given long lasting morphine! And that was a real turning point for me. Because, they (doctors) couldn’t come up with this? [Silence]. And they had seen me, how we were going back and forth, back and forth so many times. And I just looked at her (chaplain) [long silence, tears, broken voice]. She was the only support for me. She knew the system.

The inability to grasp the importance of a patient’s quality of life to the well-being of the family is perhaps reflective of an unwillingness to look out from that medical gaze.
Empirical studies have documented that most oncologists seem to have little awareness of patient and family needs (Adler & Page, 2008; Epner et al., 2010). Family caregivers and patients are indeed likely to report that more often than not their emotional needs go unrecognized and unmet (Adler & Page, 2008; Deshields & Applebaum, 2015). Doctors are more likely to pay attention to the biomedical aspects of the disease, even at the very latest stages of cancer when cure is no longer possible. For cancer patients and their families, write Adler and Page (2008), quality of life at the end of the cancer journey is likely to go unnoticed (Institute of Medicine, 2015). Whether for lack of compassion, insight, or a focus on the biomedical aspects of the disease, a diminished quality of life can bring further distress to cancer patients and their accompanying family members (Adler & Page, 2008; Deshields & Applebaum, 2015).

Dr. Paul Rousseau (2004), a physician and a palliative care director, highlights the lack of empathy and compassion in current medical practices and, in particular, within the cancer care setting. Such a lack of compassion he asserts increases the distress in an already stressed population, leaving the patient and the accompanying family feeling more vulnerable, more isolated, hopeless, and at a higher risk of anxiety and depression at the end of the cancer journey. Kate learns that there was no reason for her mother to endure being woken up to take the morphine every four hours. The attending physician had only to prescribe a longer lasting morphine. This was a defining moment when Kate realized the lack of compassion in her mother’s care.

“Compassion means being a good doctor. Nothing less, nothing more. For the most part I am not sure that doctors want that term applied to them because you want to be seen as competent and compassion can be the trade-off,” writes Foley, (2016, p. 97), a neuro-oncologist and internationally known expert in pain and palliative care. Foley notes that compassion summons actions. “There is a strong pragmatic element to compassion. You need to answer the patients’ phone calls; you need to respond to their questions quickly; you need to facilitate their care; you need to advocate for them” (p. 97). Yet despite Foley’s (2016) assertion that being a “good doctor” (p. 97) beckons a compassionate action to alleviate distress, it appears to be in short supply when transferring Kate’s mother from the hospital to
her home. There seems to be no understanding of the significance of providing adequate pain relief that could alleviate her physical pain at home.

Kate also relates other instances of a lack of compassionate care during her mother’s treatment. She commented how after two weeks of being home her mother, now exhausted, must return to the hospital. Then, after a few days at the hospital, Kate receives a call from the physician to tell her that the end is fast approaching:

She had been there a few days and the doctor phoned me and he said: you need to get here (hospital). So I phoned my cousin who is more like a kid sister. Then we found my mom in a chair strapped down. She is seated by the nurse’s station, strapped into this chair, awake [tears].

Happily she recognized us. I kind of looked at the nurses [tears]. And I went: WHAT! [long silence]. My mom was fighting the restraints, and I said to one of the nurses: “What is going on? What about this restraint?” And this is the only time in the whole mess, other than the meeting thing, that I got really REALLY angry. The nurse said: “Well, she is agitated. She needs to be protected.” She added casually, “Well, you know the cancer has probably gotten into her brain.”

Then I said, “Don’t you think that she may be agitated because she is dying?” There was no comprehension that maybe we need to support her. There was no kind of hospice mentality.

The participants in my study sought out a compassionate presence from the attending physician in diagnosis, throughout treatment, and with death approaching. Yet they mostly used words like “no compassion,” “no humanity,” and not “being seen or treated as a person.” “People are just numbers. Number one, number two, and so on, next. The patients’ families are also numbers” said Ernie. There would be no offer to help, no comforting words, and there would be no approaching touch for the patients’ families. Gestures of compassion come instead from a nurse, a chaplain, a local pharmacist, and the hospital volunteers.

Competence is the hallmark of western bio-technical medicine (Foley, 2016). The focus is on, if not cure, then on competent care, even in the twilight of-life. Hope and compassion are subjective feelings that are less valued in the medical space of disease treatment. Nevertheless, “compassion is as powerful as medicine” (Youngson, as cited in
Longmore, 2015, p. 43). “When our daughter broke her neck and endured three months of spinal traction in an acute ward, I finally understood how a system focused on clinical care can profoundly neglect the basic human needs” (Youngson, 2011, p. 6), writes this parent who is also a physician. “The neglect she experienced of her basic human needs can only be described as callous” (p. 7). For medical ethicists, patient advocates, and cancer activists, compassion should be viewed as being at the core of medical practices (Fotaki, 2015; Kerasidou & Horn, 2016; Youngson, 2011).

Many argue that physicians’ compassionate care is an impossibility given the lack of resources and tremendous pressure on medical time, and the pervasive discourse of costs and benefits that engulfs health care (Fogarty, Curbow, Wingard, McDonnell, & Somefield, 1999; de Zulueta, 2013). Yet Fogarty et al. (1999) found that “physicians’ expression of enhanced compassion took approximately 40 seconds” (p. 376). Physicians need to be scientifically competent doctors who provide excellence in evidence-based medicine and also be compassionate medical providers (Foley, 2016). We are “trying to be compassionate and competent physicians” (p. 98). One does not exclude the other.

**Seeking a compassionate presence in death**

Kate told me she had been vigilantly by her mother’s side until one night she decided to take the night off. The next morning she received a phone message to call her mother’s doctor.

He left a voice mail that simply said: “call me.” So I called his office and that is when he told me she had died, maybe in the morning? 1 o’clock. I don’t know [crying]. And was it in her sleep? I don’t know [tears]. The doctor just said: “I didn’t see the need to call you. I thought I would let you sleep.”

Kate lamented that though she had accompanied her mother throughout the cancer journey, her mother faced her death alone.

And that was the last time that I talked to the doctor [crying, long silence] with him saying: “I did not see the need to call you in the middle of the night.”
Emma explained that she had just come home from the hospital when she received the call. It was late at night and she was told to return to the hospital. “There was an urgency. You need to come now,” Emma remembers. “It seems like a dream.” “The experience takes your breath away, it is that fast,” Emma lamented. She described the urgency of trying to get there to say her last good bye.

My daughter and I had just gotten home from the hospital when we got the call. It was 10 o’clock at night. And now we are racing all the way back to the hospital, trying to beat the time, but it doesn’t work because she had already passed.

Now you are kind of lost. You are just standing there and they have moved her into another room. She was in another room. We were trying to say the last goodbyes. Then I’m called to the front desk and they hand me a bag with her personal effects and they said: “here is a letter that you will need for the funeral home” and that type of thing.

Interviewer: Did the doctor approach you?

No. No. NO! That was it!

Her loved one is gone. All that is left is a bag with her mother’s belongings. There is no expression of empathy or compassion.

Ernie informed me previously that throughout treatment the physicians’ presence was mostly “non-existent.” Sadly in death there would be no contact either.

And my daddy looked at me and he didn’t say anything, he didn’t say anything [twice], but I could see because of his eyes [tears] and I went and I said to the nurse that “he is in too much pain.” He just couldn’t stand it so I said: “Just give him another shot of morphine but he is too weak.” Then he never came out of it.

When I asked Ernie whether a doctor had come after her father’s passing, she replied:

No. Not really. We wanted to talk to a doctor to see how fast his body could come out of there (hospital). It is very sad, but you are not a doctor, so what can you do? [soft voice, tearfulness]. And that was it. We left almost right away.
Empathy and compassion should be viewed as a “physician’s standard tools” (Huffman & Stern, 2003, p. 133) given the immense distress that illness and disease cause. Huffman and Stern, physicians and medical professors from Harvard University go on to state: “Too much is taught about the need to protect oneself against becoming ‘too wrapped up,’” with the one entrusted to our care (p. 133). It is a protection that ultimately leads to self-engrossment and detachment. Detachment cannot possibly foster empathy and compassion, these authors insist. “The diagnosis of suffering is therefore often missed, even in severe illness and even when it stares physicians in the face” (Cassell, 1999, p. 531).

Kerasidou and Horn (2016), bioethicists with the Ethox Centre at the University of Oxford, observe that within the realm of contemporary bioethics it is now an ethical duty to “promote” and “support” empathy and compassion in physician practices in addition to biomedical competence. Yet, the culture of medicine continues to implicitly or explicitly sanction the “image of the technically skilful, rational, and emotionally detached doctor that dominates the profession” (p. 8). To be a professional practitioner is to be detached, just as Foucault described in the Birth of the clinic (1973). The detached, unavailable person is self-absorbed, and who “forms a hard shell” (Marcel as cited in Bollnow, 1984, p. 188) from which he seeks not to escape. He is ultimately “imprisoned” (p. 188) by functioning within the “the inhumanity of technocratic thinking” (p. 189). There is no sensitive receptiveness to the other’s appeal.

The misery of another person should move me to sympathy. Indeed, I am certain that “If I had that misery…before my eyes, the matter surely would be different; the immediate experience of it would release the well-springs of compassion in me and would burst open the walled-up gates. As it is however, I feel nothing, I remain indifferent. I remain “unavailable. (p. 186)

This is the attitude of the “detached spectator” (Marcel, 1949, pp. 19-20) who is unable to imagine what the experience might be for the other, that is, “by somehow mentally substituting myself for the other” (Marcel, 1984, p. 201). He is preoccupied by the functions that he or she performs. It is a self-absorption that does not summon an opening or a receptivity to respond (Marcel, 1964). This is the detached physician who is “unable to open the walled-up gates” (Bollnow, 1984, p. 186) which he or she had built around himself. He or
she becomes alienated from the community of those entrusted to his or her care. The detached observer, “self-absorbed” as Marcel suggests, is no longer in communion with fellow beings, namely, the patient and the family.

Somebody appeals to my sympathy in a given situation. …I do not succeed in summoning forth the sympathy which is entreated. I would have wished it to be otherwise and it is painful to deceive my questioner, but what can I do? I can only utter certain formulas I have in mind which are part of my repertory and seem to suit the present circumstances; perhaps I even find possible to give them a sympathetic intonation, but in any case I am only reading something out of a catalogue…it has nothing in common with that positive human sympathy to which the other person appeals and which I really do not feel. The suffering of the other person is alien to me and I do not succeed in making it my own. Why is this? It of course may be that I have certain personal preoccupations which are too absorbing to leave any room for this feeling. (Marcel, 1964, pp. 50-51)

Participants’ narratives largely alluded to physicians having an alienating preoccupation with the disease, rather than being humanly concerned with the disease, as Marcel (1964) suggests. The participants sensed that physicians for the most part turned away from them and their distress which effectively meant turning away from the “whole person” (Epstein & Back, 2015, p. 2623). There seems to be no offer of emotional support, no compassionate presence, no response to the need for information in the family-physician interaction. The environment seems uncaringly bare. Voices of comfort are mostly silent. There is no refuge there.

As I write this thesis I contemplate the last moments of my own cancer journey as a family member and carer. Memories intrude of sitting in silence by a hospital bed, quietly asking myself: Could there be another way, a better way in which my grief and my appeal for help is fully recognized? Can sensitive nuances of compassionate presence be revealed in the face of tremendous anguish? Simple, ordinary, and yet profound gestures that recognize my suffering? Rousseau (2010), a hospice physician, writes about compassionate presence as death approaches:

As she briefly rests, I wonder why we need an x-ray, or a blood test, or a drug, or words to feel as though we’re doing something clinical—or why we feel we must fix a problem to offer something of value? Why must sitting and being
with a patient feel so empty and so undervalued—why can’t we feel as though presence is doing something? And why must technological bunkers of computers and cell phones, and God knows what else, be the valued norm of care, rather than sitting beside and sharing the suffering of the patient and the essence of her being? Presence can create order out of chaos, particularly when patients and families reach the limits of treatment…

When I return to her room, the medical team is entering—an attending physician, a resident, an intern, and two medical students. As they all stand in the room, some with arms crossed, others looking out the window, the attending speaking about how if she was younger they might have more treatment options, Mrs. Alexander is silent, listening, speaking only when asked…

As they all march out of the room, I sit down again. No words, just the two of us alone in the room. My cell phone buzzes—the hospice center has a bed. I tell Mrs. Alexander, and she nods. I grab her hand and sit with her for a while longer. She quickly drifts off to sleep, so I stand and leave.

As I walk down the hall, I think of the doctors of the past. They all did it—the old doctors, the ones without antibiotics, morphine, and all the other modern medicaments—they sat by the bedside, held hands, and waited. They were present. (p. 3689)

Presence is about “engagement” (Marcel, 1964, p. 18) a compassionate engagement notes Marcel, a mode of existence that invokes “involvement and committal” (p. 18). Presence is fundamentally an act of being with the other. As Dr. Rousseau (2010) informs us in the narrative above, there is another way—that of compassionate presence in the clinical encounter. The clinical encounter is a particularly powerful kind of meeting (S. Smith, personal communication, February 13, 2016). S. Smith notes that for Bollnow (1984), the encounter is that which literally turns us around. For S. Smith, being-with the other, comes from the power of turning around, turning back on one’s steps. Yet, contends S. Smith, that which turns us around must first bring our easy course of action to a halt (personal communication, 2016). This halt is a pause, a moment of decision making to turn towards the family and see the appeal in their eyes (Zaner, 2015). It is a moment where actions of engagement, sensitive responsiveness, and connection are still possible and where the entre-noys can be co-created. Some participants spoke of the “halt” as an act of turning towards them. This brings us to the next chapter on Turning towards—Gestures of Presence.
Chapter 6.

Turning towards—Gestures of presence

*Presence is something which reveals itself immediately and unmistakeably in a look, a smile, an intonation, or a handshake.* (Marcel, 1967, p. 26)

This chapter captures interactions through which physicians turn towards the family in gestures and corporeal motions of presence that recognize the distress that cancer brings as it enters and irrevocably alters these family members’ lives. Presence is enacted through small gestures such as touch, eye contact, nodding, smiling, and manner of speaking. These are intentional actions that evoke attentive recognition of the accompanying family’s presence and appreciation of their lived experience. The power of small gestures also speaks to the family member feeling acknowledged as a human being and in the voices of the participants, “as a person” standing alongside the physician. Some participants spoke of how certain gestures were revelatory of the physicians’ ways of being-in-the world and one who, in their words, was a “caring” doctor. These were the transformative nuances of the time, space, and relationality of care, evidenced in intimate, shared moments of connectedness, togetherness and intersubjective relational engagement. Although some participants said that they felt moved by their physicians’ caring dispositions, it is worth noting that not all participants reported caring gestures. *Turning towards—gestures of presence* describes a few physicians’ caring responses to the family member’s plea to be seen and to be with them.

Cancer is fraught with uncertainties and a deep sense of dread and anguish. In the everyday living of cancer treatment, vulnerability inhabits Amy’s way of being in the world. “It is a very distressing time” where “everything is bad news,” “everything is negative,” and fear is inescapable. Amy said:

It is a VERY DISTRESSFUL TIME. It is. Because everything is bad news. But when you get that human touch of being acknowledged as a PERSON and also being talked to as a person, all these little things make the experience a little bit more pleasant and a little less upsetting. I believe that everyone likes to be acknowledged.
Amy continues:

Acknowledgment is the big word. And it could be a number of small gestures. It could be a smile, a nod, eye contact, a gentle touch. Just any little gesture of acknowledgement. And when you are in a hospital, when you are dealing with medication and bad news and all that stuff, it is nice to get those nice little gestures. It makes the experience just that much more tolerable.

Gestures that embodied presence served to acknowledge the human being who is deeply in anguish. We will see below gestures of a caring movement, a simple touch, a softened voice, or a comforting smile allowed the participants to endure their cancer caregiving journeys.

**Touch**

Amy describes moments of caring presence when a gentle touch would be felt. She would see her father’s physician walking the hospital hallway and, despite appearing “busy and immersed in his thought,” he still turned to face her and greet her. She remembers in these moments instances of a “gentle” comforting touch on her shoulder. Amy said:

I think that sometimes there was that extra acknowledgement where he would reach over with a gentle touch. Most of the time he would stop and then there was that gentle touch to the shoulder that inquired, “how are you?” It is a nice gesture. I find that when someone stops and just gently touches you and asks “How are you?” This is more than just saying simply “How are you.” It is a bit more. It says a bit more. With the gentle touch there is a sense of care.

A gentle touch gives rise to Amy’s felt sense of connectedness. “It is more than a simple “Hi,” Amy said. A touch acknowledges her experience in the cancer ward. This is the “extra acknowledgement” that she needs. The doctor stops, inquiring with just a few words about how is she today, and touches her shoulder. In this comforting touch, Amy feels herself as existing and no longer reduced to the realm of things standing in a hospital hallway. These gestures of caring show a thoughtful responsiveness to her lived experience. A caring touch recognizes her presence, her day-to-day fears, apprehensions, and vulnerability.

Touch creates a more intimate space of togetherness. As van Manen (2007) states, “touch is the primordial medium to overcome separation and relational distance” (p. 13). It is
in the physician’s touch that Amy senses the doctor’s responsiveness, perhaps sensing that he grasps the immensity of her day-to-day experience of living through cancer. Amy said:

Yes, the human touch is nice in any environment but when you are in a sterile environment, when you are in a negative environment, the human touch is more uplifting. It brings a little bit more warmth. It feels less like a clinic. And they are long, long hours that you are there at the bone marrow clinic. Even when you are not in the hospital, when you are in the day care, it is a long time. And to be in that room... [long silence].

That human touch is very important. Especially there, it is very important that you feel a little bit more warmth than just being in a room to get a few bags of blood or medicine and then go home.

Touch is a seemingly simple antidote to the inhospitable nature of the hospital. It is, as Lingis (1994) writes, a response to “…an appeal to the others to help us be at home in the alien elements into which we stray” (p. 122). Touch brings the warmth for which Amy longs. “The space feels less cold” she said.

The word *touch* traces its roots to the Old French *tochier* meaning “a sense of communication, to make deliberate physical contact, to bring into contact, *to be with.*” Touch is also connected to “affect or move mentally or emotionally,” or to “touch the heart or the mind” (Online Etymology Dictionary). Touch removes the physical distance between beings. Amy senses the physician reaching out to her, making contact, and *being with* her. As the physician’s hand makes contact, spatial and emotional distances in the sterile clinical space disappear. An intersubjective, intercorporeal space has been created. In this newly created space of touch and presence, Amy is no longer relegated to a background of blood transfusions and medications.

The touch reaches out to her and draws her out of her moment-to-moment isolation. These are the touching moments when time elongates as Amy feels the responsive other—the caring doctor.

When I look back occasionally, he did gently touch me and gently touched my dad too. The human touch is important. You need positive energy and gestures of touch make a BIG difference. They make the hospital a nicer place to be, rather than sitting there staring at a TV.
Amy is deeply moved by the physician’s touch. Though no words are spoken in the interaction, Amy senses the significance of the doctor’s touch. The physician reaches out because he sees her, and hears her call. The physician’s touch signifies to her that she and her father are “seen.” It is worth noting that in his article, “The Doctor’s Touch,” Bruhn (1978), a physician and phenomenology scholar, writes that touch can convey “recognition, empathy, and security” in medical practice (p. 1469).

Amy also reiterated the word gentle to describe the quality of the physician’s touch. S. Smith (2016) asks: “What distinguishes the gentle touch from the soft touch”? “What might be the power of the word gentle”? (S. Smith, personal communication, 2016). As S. Smith says, “there is something in the power of the gentle touch that might be suggestive of entering a vulnerability in a certain way which we call caring (personal communication, 2016). S. Smith reminds me that “the word gentle stems from the Latin gentilis” meaning “of the same family or clan” (Online Etymology Dictionary). The significance of Amy’s iteration of a touch that is gentle is that the “physician moves with this touch alongside the family member in a deep, familiar, and familial manner” (S. Smith, personal communication, 2016). A “gentle touch” manifests a mode of being to another (S. Smith, personal communication, 2016). Touch gives rise to a mutual revelation of co-presence (Marcel, 1964).

Anne notes that “a hand on the shoulder goes a long way.” In his analysis of touch, the French philosopher Jean-Luc Nancy (2015) notes that a “light touch” (p. 80), that is, a “touching without pressing down,” is a “turned toward” (p. 80) the outside and thus it is a “turned toward” the other. A light touch is an “exposure” (p. 80) that invokes an “offering” (p. 80). It is a promise of physical closeness, contact, and of “a presence” (p. 24). Touch, reveals a response (p. 80) or “at least the reassurance of kindness” (p. 80). “It brings a little bit of warmth,” as Amy commented.

To touch and be touched by the other, writes Nancy (2015), naturally involves a transformative movement that is “physically or emotionally” (p. 81) revelatory. Touch sets something in motion through a contact by which I am open to the “outside” (p. 82). The doctor’s hands gently touch Amy’s and Anne’s shoulders, and it is this gesture that signifies
“an approach to receptiveness” (p. 89). “It was definitely nice” Amy shared. The gentle touch on the shoulder sustains them and reduces the physical and emotional pain they feel. This is the gestural responsivenes which communicates, as Nancy contends, a desire to be contacted. The physician touches and is being touched by Amy.

“Neither the ear nor the eye gives us an experience of human contact in the same pathically direct manner as the touch. Indeed, we may be deeply moved by a human voice or a meaningful glance, but the touch stirs us in a particularly intimate manner” (van Manen, 1999, p. 30). For Anne, touch came in the form not only of a “touch on the shoulder” but a “handshake.” A “firm hand shake” was revelatory of the characteristics of the physician she was facing while accompanying her father. She said:

You don’t have to go around hugging someone, but a firm hand shake can tell you a lot about what a person is about, believe it or not.

Marcel points out that a gesture as simple as a handshake gives way to the affective sharing of the human experience. A handshake, a salutation, carries an immediate sense of recognition that, as a family member, one is welcome. Yet there is something more powerful that a handshake reveals; it is the “recognition of kinship…and the recognition of kinship is a recognition of obligation” (Lingis, 1994, pp. 155-156). The recognition of kinship in the handshake is the recognition that we are of the “same clan” and thus I know that I “will not turn away from the appeal for assistance” (pp. 156-157). “It is the effective recognition of common humanity” (p. 157). “The hand of the other extended to mine seeks not only the skills in my hand, which is an instrument among others available for his or her tasks; in the clasped handshake with which we greet one another and set out each to his or her own tasks, each one seeks the warmth of another” (p. 129). Stern (2004) beautifully exemplifies the power of the handshake:

As a regular practice, a therapist I knew shook hands with his patients when they entered the consulting room. It was a way of saying hello before they started to work… One day the patient recounted a very moving series of events that affected him (and the therapist deeply). The patient was sad and almost overwhelmed. At the end of the session, during the “goodbye” handshake, the therapist brought his left hand up and laid it on the patient’s right hand, which he was already holding, in a two-handed handshake. They looked at each other. Nothing was said. The whole
thing lasted several seconds... Yet, the relationship had shifted on its axis. Something vital was added to whatever had been said in the session—something so vital that the whole session was altered. The moment entered consciousness and was memorable. In fact, that handshake may stand out as the most memorable moment in the therapy. Often when someone is asked five or ten years after concluding successful therapy, “What were the most important or nodal moments in your therapy that change things?” they may well reply, “A certain handshake we shared one day as I left.” (Stern, 2004, p. 19)

Leder and Krucoff (2008), physicians and medical school professors, write about the significance of touch within medical practices. They distinguish between the objectifying and absent touch or technological touch and the healing touch. Leder and Krucoff, like Nancy (2015), contend that the healing touch is a gestural action that “reaches outward to sense the world” (p. 324) the self, and others. It is a reciprocal gesture of contact and intimacy. “There was that extra acknowledgement,” Amy says, when the physician “would reach over and there was a gentle touch.” Using Leder and Krucoff’s words, the physician turns to Amy in a relational intimacy where he “implicitly consents to be “touched” by the encounter” (p. 324). In touch and being touched there is a “surrender of boundaries and the adoption of relational intimacy” (p. 324).

Human beings make contact with each other through a variety of bodily expressions such as body positions, gestures, body orientations, facial expressions, and tones of voice. Heron (1970) posits that an interaction reveals itself corporeally through “mutual touching and mutual gazing” (p. 244). Touch and eye contact are always relational. They are “a reciprocal interaction” that comes into existence “when two people touch each other, make bodily contact; and in the case that when two people look into each other’s’ eyes; make eye contact,” writes Heron (p. 245). The felt meaning of the handshake, for Anne, came first and foremost through the eyes of the physician.

Eye contact

_We experience the presence of the other person most strikingly by way of the eye._

_(van Manen, 1991, p. 179)_
John Heron (1970) stresses the significance of both eye contact and touch in his analysis of the gaze. It is under these contact conditions that a meeting occurs between two persons who give and simultaneously receive. Whereas Heron observed that mutual eye contact and touch are important when human beings meet, it is also the case that it is the eyes that bear the weight in the interaction with the Other. Anne noted it was the mutual eye contact accompanying the handshake that immediately revealed the presence and character of the attending doctor. The eyes seemed to say I care or I don’t. She said:

When you get a firm handshake from a doctor and EYE contact [emphasis] it gives you a more a reassuring feeling that this is a person who will try, that he or she may fail and your dad may die anyway [silence], but he cares.

Anne senses the comforting presence of an “other” who is there and available when she looks into the doctor’s eyes and feels his hand firmly grasping hers. She feels an assurance that the doctor “will try.” Her father may yet perish but she feels that in the “trying” the physician will fulfill the promise of healing and care.

Anne spoke of how her father had instances where treatment was extremely emotionally challenging. Her father needed to be transferred to the intensive care unit on more than one occasion. The ICU is well known as a place where the emotional and psychological impacts on families are extremely high. Intense feelings of fear, anxiety, uncertainty, and trauma are common responses of family members whose loved ones are in ICU (Turner-Cobb, Smith, Ramchandani, Begen & Padkin, 2016). Death was always near in the intensive care unit for Anne. “We always knew that it could happen,” she said. Yet eye contact with the doctor brought a “reassuring feeling” that the doctor “will try.” “There is an interaction of trust. I trust this person. He will do everything.” Anne continues:

This doctor saw you. He looked at you. He included you. This doctor had a sense of duty to the patient and to us as a family, to the people that he cared about. For the first time I would walk around relaxed. When this doctor would come it was: Ok, relax. He gave you that space, even for just a minute, to be the person you were before the cancer came.

“We appeal to the others to help us be at home in the desert, in the rain forest …or in the shadow of death that advances” (Lingis, 1994, p. 118). Against a background of uncertainty
and fear, as the other’s eyes meet her eyes, the family member knows her anguish is visible to the doctor’s gaze. She reveals her fears, apprehensions, and suffering. “They looked at you,” Anne said, and as their eyes meet she knows she comes into existence as a person. Through the mutual eye contact the doctor reveals that he sees her and that he is “there trying.” This is the pact that is revealed in the mutual eye encounter: Physician and family member see each other, creating a bridge between them so that there is now a we standing together. This is the moment when trust enters the space and transforms it.

Anne uses the expression “the look” when speaking of the emotional significance of eye contact with the physician. According to Heron (1970), the look is fundamentally the possessor and carrier of meaning. “The meaning of the look is often primarily emotional” (p. 258). Although a look can create divisive emotional distance, the look can sensitively welcome us. For Heron, the look reveals the inner emotional state of the other. Presence, highlights Anne, is realised “just in the doctor’s look.” It says: “I’m here.” This is a presence that recognizes Anne’s affective experience. “I’m sorry” expresses the physician’s look as the eyes meet. Availability brings the promise of a response. As Marcel would say, “I am at your disposal.” This is the intimate space where a caring participation gives rise to intercorporeal relations such that the eyes touch each other. The other recognizes Anne’s affective experience and sensitively responds. As Marcel would suggest, to feel is to be feeling-with the other (as cited in Sweetman, 2008). A look is thus transformative of time, space and relations in this inhospitable landscape. The boundaries that separate the professional, the physician, and the family carers, lessen as the eyes look into each other. Anne said:

You can have a presence that says: “I’m here.” You can have a presence for those who are alongside you that says, “I’m sorry.” And sometimes it is just in their look. But doctors are incapable of looking at you in the eyes because they trained them out of doing that. That sense of care, that sense of comfort, is not there anymore. Saying “I'm sorry” is not there anymore.

Interviewer: You were saying before that the eye contact was really important for you.
Anne responded: Yes. It was. It says either, “I’m here for you,” or if the eye contact is not there it means “I’m not really here” [silence]. You are not really here and you don’t care.

Anne speaks of how the look can hear the plea of the other. The look in a mutual eye engagement opens the possibility of the response: ‘I am here.’ Through his look, the physician may offer the gift of himself or herself: the look can reveal the inner being of the physician. “Through the eyes we may sense the innermost being of the other person, his or her soul. They literally provide me a ‘glance’ of the other person’s essence. And through the eyes the other person also has access to my being” (van Manen, 1991, pp. 179-180). This is the unconditional offer of a caring presence that seeks to alleviate the hardship of the caring journey. The other is visible to the physician who responds ‘I’m here.’

Like Anne, Ernie also speaks of the look and its meaning. “I brought my dad to emergency. The doctor there actually felt bad for us,” she related. Her eyes meet those of the doctors, and she hears the doctor’s voice: “I can’t do anything but I’ll try.” Against the landscape of a busy and cold emergency room she senses the anguish of the physician as their eyes connect. And she knows he cares. Ernie related:

Communication was a matter of facts. But I do remember the doctor who was in emergency. He was a younger doctor. I remember him because he felt sorry. He cared.

When I asked her if there was something that the physician said by which she sensed him feeling sorry, Ernie replied:

No it wasn’t what he said. It was the posture, the tone of his voice [silence]. It was the way that he looked and the way he said it too.

Interviewer: The way that he looked? Meaning?

It was the eye contact. Yes, I remember that. He was a young guy, I remember. Yes, for sure the way he looked and the way he said it. But the others, the oncologists, no, there was no eye contact [Long silence]. No, not at all. I don’t think they really care. He was the exception.
The doctor’s eyes meet hers and in that moment Ernie senses the sadness of her father’s doctor. Two mutually sustaining gazes see and are being seen by the other. “You see my dad. He is dying. Can you do something about it?” Ernie appeals to the doctor. But he cannot. He cannot do anything; and Ernie acknowledges his helplessness. What is encountered in the eye contact? For Ernie, it was caring she found.

Amy also described the deep significance of the physician’s eye contact. She spoke of gratefulness for having been treated by her father’s doctor as a “person” and as a “human being.” Being seen as a person is reflected in the moment when the doctor meets Amy’s eyes directly. She said that “her doctor was a caring doctor who addressed her as a person.” When I asked her what that felt like, Amy said:

He made eye contact when he would ask how I was feeling. He always made eye contact when he asked my mom, my sister, and me how we were feeling. It was nice. It was nice to feel a bit more like a person than a patient or a patient’s family member.

The physician’s look reveals an availability to Amy (Marcel, 1964). It is a look where eye contact is imbued with palpable presence—I am here (Marcel, 1964). Through eye contact the physician recognizes her being, her existence as a human person. “Eye-to-eye contact is being-to-being contact” (van Manen, 1991, p. 180). The gaze is not a reductive one. To be treated as a person is to recognize “that the other is in no way here reducible to an image, to a representation” (Marcel, 1967, p. 79). Amy’s account illustrates that she does not perceive herself as being reduced to a “thing” or to a category. Her sense of self is reflected in the doctors’ eyes. She is seen to be a human being in all her alterity.

Amy also notes how the physician always addressed her father with eye contact even though he was aware her father did not speak English and could not understand the conversation between them. Rather than turning to the translator, Amy said her doctor turned to face her father. “Doctors will generally talk to the translator and not the patient” Amy said. But not her father’s doctor. She continued:

He would always address me with direct eye contact. He would always address my dad with direct eye contact and I know that this is not always the case because when the person doesn’t speak the language doctors will usually talk
to the translator and not to the patient. But our doctor always addressed my dad whether my dad understood or not.

The physician appears to sense Amy’s fears, sadness, and vulnerability as their eyes make contact (Stern, 2004). The inhospitable space that she dwells in becomes an hospitable place in which she can once again feel. The physician’s gaze summons her into existence. She remembers she is a person beyond the “family carer.” Her father is not just a category, a patient. Amy and her father are physical, spiritual and sensing beings who feel, see, move, and experience. “It feels nice,” Amy said. Heron (1970) posits that when I meet the other, it is the act of transcending the physical properties of the eyes that reveal the other as “I reveal myself to him” (p. 252). We meet each other in our essential beingness. Heron calls this physical transcendence the “luminosity of the gaze or the gaze light” (p. 252). The revelatory eye luminosity requires first a certain “emotional openness” such as “a strong mutual respect for each other’s intrinsic worth” and, secondly, a certain “mutual concern” (p. 252). It is under these conditions that the meaning of eye-to-eye contact is revealed (Heron, 1970).

For Foucault (1973), eye contact in medicine was directed at a motionless body, dissecting it with the gaze, and making only the disease visible. “The observing gaze refrains from intervening: it is silent and gestureless” (p. 108). The luminosity of the eye refers, however, to a humane medical gaze that is neither silent nor gestureless. On the contrary, the luminosity of the eye makes the family caregiver visible. The luminosity of the gaze contextualizes the lived experience of illness, which is to say, it illumines the intimate, personal and social aspects of illness. The luminosity of the eye makes visible the fact that we exist bodily, emotionally but also relationally, in health and illness.

The physicians’ eyes move toward the family members and see them as they attend the cancer ward. The eyes are the first entryway to interaction. They create the possibility of genuine dialogue. The eyes open a conversation since they appeal and summon a response. It is worth noting that in the narrative above Amy uses the expression “he would address me” multiple times in conjunction with eye contact. To “address” is to “come near or nearer to someone in space, time and quality” (Online Etymology Dictionary).
Eye contact is the gift of a presence that hears the family member’s plea. It is the primordial ethical responsibility—the “imperative” of responding to the appeal of the other (Lingis, 1994, p. 29). Amy, like Anne, also connected eye contact with presence, as we see in the narrative below. Throughout the interview Amy highlighted that her father’s doctor was always “very present” for her father and for the family as a whole. When I asked her about the particular way of noticing his presence, Amy replied:

Eye contact is a HUGE part of it [emphasis]. Eye contact is first. Yes, and listening. That lady doctor didn’t listen. She brushed us off. Doctors have to listen. That is a very big one. Because if they are not listening then they are not doing anything that you need.

“Eye contact is first” in announcing presence. “Eye contact is HUGE.” Eyes perceive the other. They move and are moved by the other. They touch and are being touched by the other. They affect and are affected by the other. This is the inter-affective corporeality of the eyes. Amy said:

He would stop then look at me and say: “Hi how are you.” And it was a genuine eye contact. And it was a genuine smile.

“Just a little smile”

One of the markers of compassionate caring is a warm smile. (Dr. R. Youngson, physician, 2012, p. 25)

Being fully present to another can also unfold in the simplicity of a smile. Amy speaks to the power of “little smiles” that are restorative of a much needed “warmth” in a place where “positive energy” is elusive at best. Amy tells us that through the cancer treatments she “lived in the hospital. When my father lived in the hospital I lived in the hospital with him.” She goes on to say that everyday became “depressing.”

You sit there and watch everybody with these needles hooked up and you sit there and it is very depressing. Most of them have no hair. And you can tell they are very sick. There is no quality of life. And they are there daily, getting transfusions, platelets, chemo, or whatever medication they need.

Amy continued:
So I think it is very important, especially there at the clinic, to feel that bit of warmth. It is very much a place where you need positive energy. Just a little smile makes a difference because it makes it better [tears]. Yes, just a little smile, a little acknowledgement. It makes it a happier environment. A smile goes a long way.

Amy is touched by the smile. The smile is the physician’s acknowledgement of her: that she is known, that her loss is visible. The physician’s smile offers protection in the face of loss. It modulates the fear and anguish that engulfs Amy. It only takes seconds to smile, yet such short duration of time can go a “long way,” she noted. A smile brings her back to a happier time, giving her much needed “positive energy” to sustain the journey. “The meaning of a smile is not something that can be transported into words” (Croken, Crowe, & Doran, 1996, p. 97), rather, it is felt in the moment. Amy said:

I was always there. And when you don’t see a smile you think: “Oh, this doctor is miserable.” Then you go: “Oh gosh, how is he caring for patients?” You don’t want a miserable guy to be treating you. As a family member, if you see the doctor laughing or smiling, it lifts your spirit. And you go: OK [smiling]. You are more at ease. When everyone is gloomy [silence], when everything is all gloomy, it is uncomfortable. But when the nurses come in and they are all cheerful and talk to you, it makes the hours a bit less long.

A smile, “does not describe the subject, it reveals him” (Croken et al., 1996, p. 98). Describing a doctor she met at the clinic, Amy said:

I don’t remember his name but he was a very nice man. We had him at the out-patient day care. He smiled. He was just a happy jolly man. I remember him now because he did my dad’s bone marrow puncture at the day care. I could not have asked for a better guy. He was very gentle, very nice. He joked with me a lot.

I don’t expect humour from all the doctors. I know that not everyone is a joking type. But that surely was refreshing. And especially when doing the puncture. It was very important to have that humour. Yes, because it is a very scary procedure which the doctor made less uncomfortable. And certainly that makes you think that he sees you and that he wants to take care of you. It was VERY NICE to be around that [emphasis].

The physician’s smile and laughter greets Amy in an “uncomfortable” place where misery inhabits her daily reality. It is an antidote to the often crushing distress of illness. “If
you see the doctor laughing or smiling it uplifts your spirit” Amy said, and she relaxes. Amy senses she is being touched by the other's smile, revealed by it, and her day to day living experience brightened by it. “Everyone is miserable,” Amy said, but the smile makes it possible to feel at ease even if for just a brief moment. A smile opens the possibility of “warm feelings” interrupting the misery. It brings “a bit of warmth” and makes for “a happier environment,” she said. She feels the gloom lessening in the smile of the physician. Fugitive moments of protection from the “darkness” of the cancer journey, from the bad news she is always awaiting, are held in the smile.

Anne also points to the power of the smile. She, too, was a daily companion for her father. She described how a smile allowed her as a daughter, and as a person, to be seen. She, too, felt the doctor’s smile to lessen the emotional and physical distances. There is a sense of giving in the smile and the laughter. Through a smile and just a few words, she feels invited into the space of caring.

If he saw me in the hallway he would say: “Hi” or smile. He would ask me things like: “How are you? How is your dad?” [Long silence].

Well at that point you have been dealing with doctors who only talked to you as if you were a machine or who just ignored you like you were a plant standing there. But he is a person who actually smiles, jokes, and laughs.

Interviewer: What did it mean for you to have that kind of contact?

Anne: That this is a person who I can trust.

In Anne’s words this doctor is a person who feels, who embodies motions and expressions of humanity. Smiling, laughing and joking are common, everyday expressions that bring us in contact with the other (Lingis, 2005). “Laughter and tears make us transparent to one another” (p. 453). The smile intimates this possibility for Anne.

A smile eases Amy’s and Anne’s cancer journeys. It acts to uplift their mood and supports the weight of caring that they bear. Although a fleeting moment, a smile brings lightness to a room too often filled with thoughts of death. These are the moments when “just a little smile” is transformative of the time and space. Amy tells me:
A simple smile is not going to take hours [silence]. No, just a few seconds. With a smile you know that they (the doctors) are genuinely happy to see you. And when they say hi, they mean it. They don’t expect your whole story but when they ask how you are, they mean it. And yes, you can tell. I don’t know how, but you can tell when it is genuine. Maybe it is the way that they say hi. Maybe it is the way that they smile. Maybe it is a combination of both—eye contact and the smile.

Interviewer: So you are saying it can be done?

Yes. DEFINITELY [Laughs]. Yes, it definitely can be done. Just look up from your clipboard. Just take a quick look at the person. Because all that some doctors do is look at their clipboards.

The potential for a personal and genuine encounter of the attending physician and the family caregiver is held in the smile. It offers ways of being in contact with the other. Ernie recalled:

In the waiting room there were about three people. All three had cancer. All of them were talking about how bad their cancer was or where it was and those kinds of things. But the doctor (naturopath) came in and he treated them, each one, smiling with an energetic voice: “Hi: how are you doing? How are things?” he asked. He was really NICE [emphasis]. He was joking around. He wasn’t saying: “Oh you have this cancer” …or things like that. No. He asked: “How are you? We are doing the best for you” [very friendly voice tone]. He was trying to be positive.

The doctor comes and greets them with smile. He jokes around and inquires about their days. A smile creates a personal connection that recognizes the person beyond the cancer.

**Other “little” gestures of presence**

Presence and caring are also seen in the other “little things,” notes Amy. Acknowledgment can come in the form of small but spontaneous moments of meeting. Amy describes occasions when her doctor, in the midst of his busy day, would pause for a moment to acknowledge her presence. She senses he realizes how immersed she is in her father’s daily treatments. In acknowledging her presence, her daily life at the cancer ward, her doctor ceases his habitual motion and stops.
Even when it is not a consult and he is just passing by at the hospital, he will always say ‘hi’ to me. He always says hi to you. Well, Ok, if he is not walking down the hallway with his head down and immersed in his thoughts [laughs].

Most doctors just walk by and when you say hi they say hi back, but then they just walk by. But when the doctor really stops and says: “Hi, how are you doing?” [emphasis], it is a nice gesture. Yes, it is a nice gesture. And those are the very small positive reinforcements that make a hard day feel a bit better.

“The other doctors walk by. They quickly go away,” Amy notes. But her father’s doctor stops. There is a transformation of space, time and relationship. “Hi, how are you doing?” he asks. It is a “nice gesture.” Amy reminisced:

Our doctor didn’t spent hours with us or anything like that. It is those few seconds of exchange that make you feel seen and acknowledged. It is that walking by in the hallway and then those few seconds when he stops and says “HI!” These are all the little moments that make the experience a little bit less upsetting. Even if he is in a rush, he looks at us and bows as a way of addressing us. It was definitely nice.

Such small motions of stopping and greeting are a “way of addressing us.” This arrest of busy motion creates an interplay between two living bodies where Amy perceives the doctor being fully present. These few seconds in duration open the possibility of meaningful human-to-human engagement. These small actions are neither time consuming nor difficult to enact. The physician touches her in the simplest of actions, whether it be a word, a glance, a whisper of a hi, a tender comforting touch, or a simple movement of bowing the head. Lingis (1994) reminds us that “to recognize the other is to respect the other” (p. 22) Despite the physician’s urgency to be elsewhere, a brief second to bow is all it takes, and using Lingis’ words, Amy feels that she is seen. Amy recalled:

It is just that little gesture to say: “I’m busy. I’m busy. I’m walking, walking, passing through, but I see you. How are you? It is those brief few seconds of time that he gives to acknowledge you.

“I am passing through, but I see you,” Amy reiterated.

Ernie commented on how the tone of voice was important to her. She noted how her father went to several appointments with a female doctor, a naturopath. ‘She was really nice,” Ernie repeated several times.
She tried to make us feel better. She was kind. My dad liked her so we kept on going and going, because she was nice and she cared. She was very sympathetic.

When I asked her if being nice and sympathetic was related to something that the doctor said, Ernie responded: “It was the tone of her voice.”

Lingis reminds us of the power of the tone of voice. “How do I make contact with you?” asks Lingis (2005, p. 449). “To make contact with someone whose physical body I see is not to grasp his or her identity conceptually and respect his or her boundaries and inner space. … It is first by the tone of voice that we make contact and communicate,” writes Lingis (2005, p. 449) with the other. Actions of caring presence are revealed not only by the words spoken but also by the manner in which words are uttered. What does the physician's way of speaking mean to these participants? What does it reveal? As Anne puts it, “It was how they spoke to you” that reveals the doctors’ presence:

There are manners of saying things without treating you like you are stupid, without dumbing it down or saying it in just plain English. These doctors would explain things in plain simple language.

These physicians offered simple explanations in everyday language, Anne recounted. Yet they were not “condescending” she added. “Don’t turn it into neutrophils and all these other terms.” Despite Anne having knowledge of medical terminology, she still appreciated being approached as a person, and as a carer, and in a manner that did not relegate her father to a mere object of medical science.

Like Anne and Ernie, Amy also perceives caring in how she is spoken to and listened to. She described how her doctor’s habitual mode of being with others is not “automatic” or mechanistic. In the daily world of cancer treatment, the doctor does not ask or listen in a repetitive and monotonous manner. He is, instead, attuned to the experience of the other. He cares about how to ask and how to listen. Just as Anne and Ernie had indicated, the significance of the physicians’ manner is fundamentally about caring.

When my father’s doctor asked questions, he would actually be listening. It wasn’t like the other doctors who in their minds have a set of questions to ask
and are very automatic. But our doctor cares to listen to the person. He cares how to ask. In these little interactions, it means you are just as important as the other person because there is no snobbery or hierarchy or anything like that. It makes your day a little bit nicer.

Manner thus opens the possibility of relations that are less hierarchal, closing the space between carer and physician rather than enlarging it. This is the gestural manner that animates the family carer-physician interactions and that makes Amy’s “day a little bit nicer.” The physician’s manner acknowledges her and reveals his caring commitment. There is a back and forth movement between deeply listening and asking.

Moments of gestured connection are described in Smith’s (2014) notion of vital contact where “my motility bears the inscriptions of others, the tracings of their needs and the potentiality of improvisational responsiveness” (p. 234). “Contact improvisation,” writes Smith, “carries a postural, positional, gestural, and expressional vocabulary” (p. 234). “The time of vital contact with others may be but a moment, yet moments can be stretched, becoming good moments” (p. 234). Moments of vital contact for Amy, Anne, and Ernie “make a hard day feel a bit better.” Ultimately, for these participants, physicians’ gestures of presence exemplify a compassionate and embodied model of cancer care.

Presence, writes Marcel, “is something which reveals itself immediately and unmistakably in a look, a smile, an intonation or a handshake” (Marcel as cited in Sweetman, 2011, p. 42). Lingis (1994) writes:

What recognizes the suffering of the other is a movement in one’s hand that turns one’s dexterity into tact and tenderness; a movement in one’s eyes that makes it lose sight of its objectives and turn down in a recoil of respect; and a movement in one’s voice that interrupts its coherence and its force, confuses its concepts and its reason, and troubles it with murmurs and silence. (pp. 31-32)

These are the gestures and bodily expressions that open the way to halting time. These are the subtle gestures that open the potentialities of a mutual contact, togetherness, and communion. These are the motions of a caring doctor, the gestures that offer a refuge from the turmoil of cancer, and the interactions of genuine personal connection. Presence manifests itself through
gestures (Marcel, 1963), small acts of opening oneself to the other, (Marcel, 1964). As Lingis writes,

What the face of the other asks for is not that I substitute my skills for his, take over her tasks for her. She seeks the support of my posture, the agile luminousness that shines in my eyes, the warmth in my hands, the ardor in my face, and the spirituality in my breath. The other seeks the contact and the accompaniment. (Lingis, 1994, p. 132)

Presence is a turning towards in an act of givenness and transcendence, and brings us to the offering of a gift, our next chapter, to give. It is in this gift that personhood is revealed. Marcel (1951) notes that modernity and its emphasis on technology and technocratic thinking has reduced human beings to the mere functions that they perform. “The individual tends to consider him or herself, and likewise tends to appear to others, as merely an agglomeration of functions” (Marcel 1998, p. 173) and robbed of freedom (Marcel, 1998). The richness of life’s meaning, the significance of the human being, has been lost (Marcel, 1951). In the act of giving, the physician transcends this imprisonment, seeing themselves and the other in their beingness. It is the gift of stepping out of one’s function that opens possibilities of reciprocity, of giving and receiving (Marcel, 1964). It ascribes identity.

This next chapter bring us to a deeper appreciation of intersubjectivity and relational moments in the family-physician interaction. The gift of time and the gift of oneself change the structure of family-physician interaction and how the grief that accompanies the carers is lived, from diagnosis, death and bereavement. This chapter speaks to the human being responding to the appeal in an exigency. “Exigences” can present itself to us and appeal to a more intimate understanding, to a more personal communication; it can invite us in some mysterious way to a renewal” (Marcel, 1967, p. 27).
Chapter 7.

To give

The gift is a call to which we have to make a response”…[an] urgency interiorly felt. (Marcel, 1951, pp. 63-64)

This chapter comprises two sub-themes: the gift of time and the gift of oneself. The first sub-theme, the gift of time, refers to physicians’ ways of making themselves present. Some participants spoke of how meaningful it was to have a physician who made time to listen, to explain, to facilitate and to guide the carer through the distressing days and decisions that come with illness. Whether it was taking the time to be patient, time to “just be there,” or taking time to stop and acknowledge the family’s presence, participants spoke of the relief this time gave them. This leads us to the second sub-theme, the gift of oneself. This sub-theme is about physicians’ gestures of openness that conveyed a sense of being exposed, and a willingness to reveal their own emotions and sensibilities. This sub-theme is also about physicians grasping the gravity of the situation and making themselves available to the enormity of the cancer experience.

The gift of time

Time is a gift from the other; it is the other who gives me time, and in giving time, gives life.
(Levinas as cited in Severson, 2013, p. 63)

The gift of time emerged as participants spoke of the physician offering time to listen, to explain, and to guide them through decisions. ‘Giving time’ was highlighted by the participants in gestures that made them feel seen and recognized as human beings. Through the gift of time participants felt that their distress and vulnerability were also seen and acknowledged. The cancer journey felt less scary even when they were given bad news. The gift of time, even in the face of death, facilitated the grieving process.
The impact of giving time is clear in the participants’ accounts. Amy spoke of how her father’s doctor took the time to acknowledge the power embedded in the word cancer. Dread and uncertainty have entered Amy’s life and, through a simple gesture, her doctor provides some solace. In the narrative below Amy repeats the expression “he gives time” in describing her interaction with her father’s oncologist.

He talks to you like a person. I have heard stories from people where the doctors come and say: “Yes, you have cancer and this and this” and they are very cold about it. But our doctor was very warm. He was very knowledgeable in what you should expect and what the plans were. And he took this time to go through with you what to do. It was very nice for me to have that acknowledgement and for him to be patient in explaining what it was. I did not feel rushed. He gave time to absorb the news. And he gave time to think about it and time to absorb all the information.

The oncologist gives time to absorb the news, taking time to explain and guide Amy through the treatment, and time for her to ponder the meaning of the word cancer. “I did not feel rushed,” she said. “He was patient.”

Anne also observes how some doctors take time to educate her in providing detailed and much needed explanations. Cancer has taken her hostage, too, as the disease invades her father’s body. Anne endures the daily wait for test results. She recalls:

I used to live and die based on how many neutrophils were in the blood counts in the results that would come back. You know what was really interesting is that sometimes the same doctors would explain the results to you. They would show them to you, not just to tell you the results, but why this is good and this is bad. These doctors were not condescending about it. They were educating me. It was like, “This is why we are concerned, because his liver is working too much.” And funnily enough those explanations tended to always come from the same doctors.

Doctors not only showed Anne the results but they also gave of their time to provide a deeper level of information. “They were educating me,” she noted. “These doctors were never condescending.” This quality of giving time is a nuance of sensitive responsiveness that readily recognizes her pain and vicarious suffering. It is a giving up of one’s own hurriedness for the sake of the other person’s need to linger in the present moment. Amy and Anne imply that there is a felt sense of shared presence, of two human beings partaking in one all consuming
cancer reality. For Levinas, time is always intersubjective (Severson, 2013). Time is constituted via our relations with the other (Levinas, 1998).

“He was very human about it,” Amy shared when relating how the oncologist delivered the news. “He was patient,” she again affirmed. The hospital ward began to feel a bit less scary. She appreciated the doctor supporting not only her father, the patient, but also her. The other doctors just “tell you what it is: Cancer,” Amy said, but this doctor “was very human about it.”

He would take time to tell us the bad news. He also gave us time to absorb it. And it was less scary when you are facing bad news. It is those little things whereby you can tell he is very human. The stories you always hear about doctors is that they don’t see you. They don’t give you time to think. They just tell you what it is: Cancer. Just like that. And then it’s: Next. I have to go to the next one [laughs]. Yes, I want to see the next patient.

I don’t know if it is the same for other people, but for me it is less scary to get the knowledge from a doctor who is patient and explains things.

The doctor knows that with the cancer diagnosis the family carer’s existence has become full of fear, sadness, worry and apprehension. He gives time for the family member to understand and “absorb” the news. He feels for the family members’ sorrow. The doctor worries about how Amy feels as she hears the bad news. This is the caring doctor who, as van Manen (2000) writes, treats caring as “a heedful attunement” (p. 318). For the doctor, there is a “lingering awareness” (p. 318) of Amy’s anguish to which he gives his time. This is the quality of presence in a caring doctor who worries for the patient and the family members to the extent that he readily gives of his time.

Ernie had previously disclosed how, for the most part, she felt invisible to the medical community. The cancer journey was one of isolation and exclusion for her. Previously Ernie noted that doctors seldom spoke to her. Yet, like Amy, Ernie also related how there were moments of a face-to-face interaction where one doctor’s presence resonated for her, a few moments when she felt she was seen as an important part of the process. Such inclusion was felt when the physicians gave her their time.
“He showed pictures of what they have to do,” Ernie said. As they face each other, the physician takes time to show her pictures of the upcoming treatment intervention and explains to her what he needs to do. She does not require information to be “sugar coated,” but just to be given a few precious seconds of time. The physician’s presence in those instances transcends the biomedical stance. He sees her in all her vulnerability. Ernie said that she “felt part of the conversation.” The gift of time not only brought her a sense of inclusion but also an assurance that she mattered. Ernie said:

I felt that I was an important part of the situation. I think that was it. I remember we were in the room and he showed pictures of what they have to do. He explained what he had to do. And he was really sincere, too. I didn’t expect anything. I didn’t want it sugar coated either.

To be seen is to have acknowledged the vulnerability and uncertainty that cancer brings. Fear immediately intrudes upon the family members’ existence and it projects inevitably into their future. Fear engulfs the carers’ experience since what is to come is unknown. This is the unknown that Ernie references in asking: “Where is the cancer? What is to be done? Where has it gone? What can be done? Who can we go to for help?” The physician takes the time to share information at a time that is so emotionally and existentially draining. Giving time is “caring,” Ernie said. It is saying that “you count.” When I asked Ernie what she needed most of all, she replied:

More time for things to be explained. Ok, let’s suppose someone learns she has breast cancer. “Ok, what are the treatments now? And the doctor could say: “This is what you should do and so on.” I think the doctor should explain exactly what it is to be done, what the prognosis is, and things like that. I think doctors should be ready if the patient and the family call them.

Interviewer: Is that for you a way of caring?

Yes, it is. It is a way of saying “You know what? You count!”

The giving of time thus bestows an authentic relationality in cancer care. It is worth noting that the Merriam-Webster Dictionary notes that “to count” signifies “to have value or importance” (2010, p. 271). One may speculate that giving time also conveys the message that one, as a family member, is important and worthy in the cancer journey. These are the
moments where relations of mutual caring are sensed and felt. Time thus makes possible \textit{being there} and being \textit{with} the other. This is the authentic response to the summons to care that “you count” and, thus, as a family member you are valued. Although Ernie mostly described the attending doctors as “non-existent,” she has vivid recollections of her interaction with a naturopath specializing in cancer treatments. “The naturopath was really nice. She was really nice,” Ernie said repeatedly. When I asked Ernie, what makes a doctor “nice,” she again emphasized the impact of giving time to explain what is going on. She recounted:

She (the naturopath) was spending time. She was caring for him and she cared about him. She cared for him, unlike the other doctors. I think she was nice because she tried and she cared. I saw her later on and she was very nice with me. When I talked to her she was very nice even when things were really very tough.

Interviewer: And what conveyed to you that she was being nice.

She would take time. She would explain things to me, but it was also how she would say things. At the hospital nobody took time. A typical interaction with them (doctors) was nothing. They would come in, and then just leave. That was it.

Amy’s account highlights how her physician also knew that she and her family might have difficulty grasping some of the necessary medical knowledge. Yet he wanted the family to have that knowledge. Despite the busy schedule of an oncologist, the physician would “take time to talk to us,” Amy repeated. “He wanted for us to understand” she said.

For example, when our doctor talked to us, he knew that we did not know. And he knew we would not understand. So he would take the time to talk to us. He explained things to you and educated you in what you needed to know. And he did it in a very respectful manner. I don’t know how to say it. But he understood what we needed to know and he took his time. He wanted for us to understand.

This is the unity of the \textit{he} and the \textit{us}. It is the unfolding of a shared landscape in illness, of two human beings in contact with each other and becoming a \textit{we} or, as Marcel (1963) would say, finding the \textit{in between you and me} space. But perhaps the giving of time in the narrative above is best captured by Levinas’ notion of responsibility for the other. This is the giving of time as a \textit{response ability}, “even if the responsibility amounts to nothing more than responding “here I
am” (Levinas, 1987, p. 110). These are the emotional dynamics of response and responsibility: time begins and elongates as the physician explains, educates, and talks to the other, doing so in a “respectful” manner. “He knew that we did not know.” “He took his time,” Amy articulated. These few words reveal the physicians’ awareness of what Amy and her family need to know. He takes time, Amy emphasised several more times. This is an intersubjective time that Amy and the doctor have found. As Levinas reminds us, “time is not the achievement of an isolated and lone subject, but that it is the very relationship of the subject with the Other” (1987, p. 39). This lived time, this “[p]resence—being in the moment with the patient and their families—can be a soothing balm when disease continues an unrelenting march” (Rousseau, 2011, p. 436).

The gift of time carries within its other-directedness a support lent to other families in the cancer ward. Taking time to relate with the family and patient creates a more giving space in cancer care. Amy noted that she did not mind waiting when the doctor was behind schedule. In fact, she said most of the time he was “a bit” late. Yet she senses deeply that any tardiness on his part is tied to him providing “extra time” to the other patients and their families.

It is funny now that we are talking about this. I think in most of our appointments with our doctor he was always a bit behind in his schedule because he was taking more time with some patients and their families than was scheduled. But that was OK. We never had a problem with it because we knew he was taking extra time with the patient. So, for us, he would not rush through either.

Amy is understanding of the pulls on the physician’s time. The gift of time connects Amy with the other family members accompanying their loved ones, creating in an otherwise inhospitable space a caring community. Amy knows that other families, like hers, need not be rushed as they meet with the physician. These singular moments add up, transforming space and relations, and creating communities in the cancer experience. There is now time to have shared and connected interactions. Amy sees the other who, just like her, is enduring the emotional, physical, and spiritual tolls of the cancer journey. She has been there and knows first-hand what it is to receive those precious moments of extra time.
The gift of time is also seen in the excerpt below. Amy recalls how the oncologist came to be her father’s doctor. Her family doctor, “a caring doctor,” knew the oncologist personally. She described how her family doctor immediately took the time to personally place a phone call to the oncologist.

My daddy got a blood test and that afternoon they found something wrong with his blood. My family doctor knew it was serious. He called his colleagues. And he knew Dr. X through their circle. So he called the oncologist personally and asked: “Can you take on this patient right away?” We knew normally it would take two weeks to see a specialist. But Dr. X took us right away, the following day. It happened very fast.

Two caring doctors readily offer their time. “If we did not have a family doctor who was that caring, my dad would have had to wait who knows how long to see a specialist. And he would not possibly have had the five years that he had. It is a scary idea,” Amy said. The diagnosis had been fast. Cancer arrives in a blood test and in that moment the family’s doctor instantly knows that it is serious. He worries for the patient. The family doctor does not ask the medical receptionist to place the phone call. He does not say to Amy that the office will contact the specialist and she will then be called back. Rather, in that moment, “he called Dr. X personally” and asks: “Can you take on this patient right away?”

Throughout the treatment the doctor was one who was present despite his busyness. “It is go, go, go at the leukaemia ward,” Amy explained. Yet a caring doctor acknowledged her experience. The few seconds that she has with her doctor reveals the nearness of his caring presence in motions that she senses as genuine. She had seen him many times immersed in his thoughts. “He is a busy doctor” Amy said. Yet, as they encounter each other, he ceases the hurriedness of his pace and stops. Only three words are said in asking, “How are you?” Yet they are sufficient in that moment to convey his care. The physician sees Amy in all her vulnerability.

Even when we were in the outpatient wing and we did not have an appointment with him, he walked by, saw us, and said “Hi.” Sometimes when he was less busy he would stop and ask me how I was and how things were. I think he was very different [long silence].
And I don’t think I have only one specific experience of him being there for me and understanding. It was almost all the time.

These are the seconds of time that afford a closer bond and a more intimate relationship of caring (Levinas, 1987). They are instances where despair may be eased and hope appears in no more than a simple word of acknowledgment. These are the moments of an ethical response and responsibility for the other (Levinas, 1987). Time is lived in saying quite simply: “Here I am” (p. 110). The gift of time is revealed when two human beings interact with each other, with the beseeching of the other to act. Amy said:

Again for me, it is the interpersonal experience. Like the time the doctors take to stop and ask “how are you,” you can tell when it is genuine or not. You know when it’s not just “the doctor thing” like having to say “OK [mimics harsh voice] HOW ARE YOU TODAY?” It was not like that. It was genuine.

Amy’s doctor moves fast in the hospital hallway. He is busy and yet he stops. Caring and acknowledgement of the other come in one evident bodily motion—a stop. He does not merely slow down, rather, he intentionally halts his walk. This purposeful motion signifies that the physician sees the vulnerable other. Time and movement pause. A simple “Hi, how are you?” is all that is said, however these words are punctuated in the motion of stopping. Amy is seen and held in the stop. She is no longer alone.

“It is the interpersonal experience” that transforms the space of the hospital. A relationship takes form when the doctor takes time to acknowledge Amy. The physician is busy, immersed in his thoughts. He stops, sees Amy, and is exposed to her need. Amy observes:

We would joke with the nurses about how busy our doctor is. He’s walking in the hall with his head down because you know he is thinking about a bunch of things. But even when it is not a consult and he is just passing by in the hospital, he will always stop and say ‘hi’ to me.

Anne relates a similar experience of the physician offering his time. She spoke of a doctor taking time out to approach and acknowledge her. Anne’s father has been transferred from the cancer ward to the hospital intensive care unit. She sees her father lying in the ICU bed with tubes, monitors, needles, and life supporting apparatus connected to his
unresponsive fragile body. Anne sits every day by her father’s side. She sees the attending physician from the leukaemia ward. He has come to ask her if she is OK. “How are you,” she hears him saying. She knows he did not need to come to the ICU, but he has come. He comes to be with her. Anne senses he is moved by the immediate vulnerability of another’s anguish—her own. The physician intentionally curtails his time in the leukaemia ward and moves down to the ICU. He moves as if he is being moved by the other. He takes the time to come and meet her at the ICU.

“He didn’t need to come to the ICU,” Anne said. But he did. “How is the day?” “How are you?” Anne hears the doctor addressing her. In the midst of a busy oncology ward, the doctor moves toward the ICU ward and does so “every day.” He came “to check on my dad and to talk to me,” Anne emphasized. These are the actions of caring and being present. They are movements of a physician who sees and is moved by the family member’s turmoil. Anne recalls:

I remember this one doctor who was an intern, a foreign intern, who was so NICE [laughs]. He always came down and checked on us. He would come to the ICU to ask simply “How is your day?

He didn't need to come to the ICU. He never needed to come but he did it every day to check on my dad and to talk to ME! He would say “How are you? How is your dad looking? Have you seen anything, like, have you seen if he is doing better?”

Anne relates another instance when a doctor gave of her time. “It was like three o’clock in the morning,” Anne said, and her father was “at his worst” yet “the doctor was still there.” “She was there to tell us that “yes, these test results don’t look good, but it doesn’t mean that he is failing.” This time “late, late at night” is when the physician is with Anne. These are the moments when Anne seems to feel assured that the doctor understands the immensity and depth of her grief. When her father is at his worst, in the middle of the night, the physician is there. Time, as Levinas proposes, gives life, gives strength to Anne to carry on with the harshness of the cancer journey.

Time is not a gift from an anonymous being, not a recovering of some internal possibility, nor a discovery made by the self in the world of matter. Time is a
Gift from the other; it is the other who gives me time, and in giving time, gives life. (Levinas as cited in Severson, 2013, p. 63)

The gift of time is held in bodily expressions, movements and motions of receptivity to vulnerability. This is the moving toward the other that recognizes intense turmoil. As these participants’ narratives reveal, the experience of witnessing cancer has the power to move one to be with the other.

The gift of time is also bestowed as guidance in the face of death. Amy relates how her doctor looks into clinical trials because conventional chemotherapy has stopped working. Amy noted that although death was imminent, her doctor rather than withdrawing or detaching himself from the cancer experience, instead gave his time to the family in suggesting different medical alternatives. “He gave us time to think about it. He never pushed us.”

I think we all knew that death would come. And he very much looked into alternative ways to treat the cancer. He was looking into alternative medications and also clinical trials. He was going through the list of what was available with us and what he personally thought could work or not. He guided us through all this. And, again, he gave us time to think about it. He never pushed us.

And it is funny because, even with any option he gave us he was very conscious of whether he was pushing us or not. He would say: “Please think about it.” It was not like “You should do this.” He was very calm and it was more like: “These are the pros and cons.” And no matter what way you go, he would tell you: “Don’t rush, don’t rush it. OK, just think about it.”

The physician chooses not to look away when death approaches. He has seen Amy’s face and he does not turn away from her. This is the ethical “moment when the self is challenged by the other” (Davis, 1996, p. 49). The doctor takes time to explain significant decisions as the end makes itself known.

Amy does not mention the word death explicitly, rather, she speaks about the “ending” when the doctor shared with her the final moments of her father’s life. Death is approaching fast for her father. “It was unknown, meaning we did not know when it would come” Amy said. “It is hard when things happen so fast because you don’t have time to absorb them.” But her father’s doctor takes time to guide her through what is happening. He takes time to explain
the test results. He prepares her for what is to come. Of her interaction with her doctor about her father's death, Amy said:

He prepared us. At that point he said: “choose if you want it to be at home or of if you want to be in palliative.” It was unknown, meaning we did not know when the day would come.

He explained that the leukaemia was not being attacked. He said: “nothing is working anymore in terms of treatment” and showed us the tests. He sent us home because Dr. X knew that my dad wanted to be at home, that for my dad it will be more comfortable. And my dad was fine for a week or two. But one night his heart just wasn’t… [silence, whispering] speeding very fast and his heart rate was not normal so Dr. X sent him to ER and from the ER he went to palliative care. From there the ending was very fast.

For Amy the last gift of time comes as her father's last breath is taken. Her doctor comes to the ER “as soon as he could be there.” He acknowledges the patient and the accompanying family in life and in death.

And when my dad died, our oncologist was there, he showed up.”… [Silence]. We were there early in the morning between 12 and 1 AM, or something like that. He was there in the morning. I don’t remember why but he showed up right away or as soon as he could. And he acknowledged the whole family.

Throughout the journey this physician has given the gift of his time, just as we have seen in the above narratives. ‘We had our doctor from the very beginning,” Amy said. And in death he also took the time to be there for her. Time is “the very relationship between human beings,” writes Severson (2013, p. 100). It is a gift that is given, as Anne observes, in life and in death.

Anne recalls:

The night my dad died the doctor was telling us of a specific procedure that had been done and that what my dad was experiencing was a normal reaction. That it might mean that the procedure [treatment] was working. On the other hand, there was something else going on and that was what the concern was about.

And I will tell you the difference. The difference is that she was still trying. Like when we were in the waiting room, the sleeping room [silence]. I was taking a few catnaps and she [doctor] was THERE [emphasises mimicking
amazement], telling us, yes, this does not look good. But she was there at three AM in the morning talking to us. That counts!

The doctor has come to Anne’s father’s hospital room to share the latest test results. The physician is aware of Anne’s profound vulnerability as she watches her father’s body begin to fail. Despite the oncologist’s gruelling schedule, Anne observed that the physician chose not to detach herself from suffering. Rather, in that hospital room, late at night, the physician moved into the space of suffering. Anne is deeply affected by the doctor’s presence. “Suffering and the death it portends, can make one aware of the world that is exterior to the self” (Severson, 2013, p. 97). Levinas (1987) describes how suffering is a temporal structure tied to the uncertainty of death. Death and suffering break the solitude of the self, affirms Levinas. “Suffering and death, like insomnia, are phenomena with the unique capacity to open a window past the walls of interiority that surround the self (Severson, 2013, p. 95).

The “movement” of time understood as transcendence toward the Infinity of the “wholly other” [tout Autre] does not temporalize in a linear fashion, does not resemble the straightforwardness of the intentional ray. Its way of signifying, marked by the mystery of death, makes a detour by entering into the ethical adventure of the relationship to the other person. (Levinas, 1987, p. 33)

Anne reveals how on the night of her father’s passing she saw the face of the other, the attending doctor. The physician was there, she says, despite the lateness of the night. Although exhausted, Anne is profoundly touched by the caring doctor. As death arrives, Anne shared the last and intimate existential moment with the doctor. “In the concreteness of need, the space that keeps us away from ourselves is always to be conquered,” posits Levinas (1987, p. 68). Anne is not alone. “That counts” Anne said, of the deep gratitude she feels. In death, time is given as hope even though “the results are not looking good.” But she [the doctor] is trying, she is there with them. Anne knows her father is dying, yet hope carries the deeper significance that human life is valued, that his human life is valued. This is the endless giving of the gift of time. Anne feels the gift of the other in the form of the physician standing in the room with her and her loved ones.

The presence of the other is felt as the gift of time that creates new existential spaces and relations. As Levinas reminds us, the gift of time transforms the space and its asymmetrical
relations into “an ethical adventure” where two human beings encounter each other and transform each other, the space between them, and the time leading forward from that moment. The gift of time is the gesture of “vigilance without end” (1987, p. 48). “There is no way of withdrawing” into the solitude of the self (Levinas, 1987). “This existing is not an in-itself [en-soi], which is already peace” (p. 49). In his work, *Time and the Other*, Levinas (1987) writes:

Suffering in all its degree entails the impossibility of detaching oneself from the instant of existence. It is the very irremissibility of being. The content of suffering merges with the impossibility of detaching oneself from suffering. …In suffering there is an absence of all refuge. It is the fact of being directly exposed to being. It is made up of the impossibility of flecing or retreating. The whole acuity of suffering lies in the impossibility of retreat. (Levinas, 1987, p. 69)

It is the gift of time in the vigilance of the physician who restores peace and hope for Anne. It is 3 o’clock in the morning and the vigilant doctor has come to Anne’s side. This is the gift of time that is offered and requires no return. The physician, when confronted by the profound suffering of the other, does not retreat, rather, she halts, stops, and remains with those who suffer. Doctors take the risk of giving their time, which is to say, giving of themselves in accompanying the family member in the death of a loved one.

**The gift of oneself**

*Presence belongs only to the being who is capable of giving himself.* (Marcel, 1967, p. 153)

*The gift of oneself* is a sub-theme of *To give*. The gift of oneself can be described as a physician’s awareness that illness is a human experience, and that the *other* may be more than a case of pathology. For our participants, a parent’s illness was lived side-by-side with sadness, despair, and a sense of loss. Within this landscape, some physicians made themselves available and ongoingly accessible to the family and the patient. They were present in offering themselves to the needs of the other. Such an offering of the physician’s emotional, spiritual, and psychological resources led to family members’ perceptions of closeness and togetherness with the physician as well as a sense of trust (Marcel, 1964).
“What is a gift? Can it be looked at as a simple transfer?” asks Marcel (1951, p. 132). “To transfer would be simply to move a certain object, a certain possession from one account to another,” contends Marcel (p. 132). For Marcel, rather, a gift is not something that is a handover or allocation to another. “Any gift is in some way a giving of oneself” (p. 132), a giving to the other with no conditions (Marcel, 1951, p. 132). “The soul of a gift is in its generosity” (Marcel, 1967, p. 133) and presence he states, “is the gift of oneself” (1967, p. 153). In his book Creative Fidelity (1964), Marcel writes that “the proper function of the subject is to emerge from itself and realize itself primarily in the gift of oneself” (p. 49). The gift of oneself is making one’s inner resources disposable to the appeal of the other. “Presence belongs only to the being who is capable of giving himself” (Marcel, 1967, p. 153).

Participants used the word *person* numerous times, invariably connecting it to the notion of caring. *Person* is intrinsically linked to presence and disponibilité (Marcel, 1967). At the core of being a *person* lies the admonition “to be involved” (Marcel, 1967, p. 143). Personhood is our mode of being-in-the-world as a self that reveals itself in disponibilité (Marcel, 1964). This disponibilité is a response to the appeal of the other: an openness to be exposed to, and to receive, the other as person. It is this gift-giving that allows one’s inner resources to be available to the other in a manner that is mindful of his or her appeal. The gift, as Marcel says, is “presence as a response to the act by which the subject opens himself to receive; in this sense it is the gift of oneself” (1967, p. 153).

As I began my conversation with Amy I asked her to think back on her interactions with the physicians treating her father and to tell me about those interactions, how they felt, and how she lived them day-to-day. In her answer Amy twice used the word “exceptional” when describing her experience with her father’s oncologist.

My most memorable memory was about doctor X. He was an exceptional doctor. We couldn’t have been luckier with his care as a doctor. But he was an exception. I know that for most families they were not so lucky.

In the everydayness of life within cancer care, what is it to be an exceptional doctor as Amy described? For Amy, such exceptionality in care came through the doctor’s attentiveness.
He was very attentive. He was attentive as a person and as a doctor. And as a doctor with so many patients, you can tell that he remembers each one of his patients. He makes a point to remember their names. And he makes a point to remember what their illnesses are. He made a point of remembering who the relatives were. I found that very rare in a doctor. Usually you get that with the nurses. He was exceptional.

To be ‘attentive’ is to “to be very concerned about the needs of others, thinking about or paying careful attention to someone or something; heedful of the concerns of others” (Merriam-Webster Dictionary). Significantly, it is worth noting that Amy makes a distinction between being attentive as a doctor and as a person.

“To be” and “to be a person” is about involvement and participation (Marcel, 1964, 1967). Personhood lies in the vitality of one’s involvement with the other. Her father’s doctor is attuned to the emotional and physical impact of cancer and he responds by remembering the personal details and names of their families. Where other doctors have offered quick glances, this doctor stops to name each member of the family, going beyond the confines of the bio-medical gaze to see the family beyond the disease. The doctor has turned to the human and to humanity, reconciling his biomedical way of knowing with the lives of the patient and the family. It is his way-of-being-with and towards the other that distinguishes him. He imbues the sterile biomedical space of cancer care with a certain familiarity and a more revelatory presence. Attentiveness is “being in attunement with another” (McCluskey, 2005, p. 42). He gives of himself through the responsiveness with which he attends to the human aspects of the illness. It transforms and re-humanizes the biomedical space of the hospital. Amy continued by explaining the meaning of “being exceptional.”

The fact that he was very present as a doctor and that he cared. It is hard to explain. It’s in the nuances of the mannerism and the delivery of how the doctor talks to you and, of course, when the doctors address you by your name.

Presence arrives in the form of being named, to “be called, to be known” (Online Etymology Dictionary). Naming instills in Amy an appreciation of her whole personhood when standing alongside her father’s physician. Naming opens new possibilities of a caring relationality where she feels a welcoming receptiveness. By using her name, she is not a ‘she’ (Treanor, 2006), she is Amy the person. “He has so many patients” Amy said, yet he addressed
her by name. The physician makes the point to remember her name, and who she is. In naming her, lies the intention to remember her, “to retain in memory, to be mindful of” (Online Etymology Dictionary) the face of a human being who faces him. He participates in being as he utters her name (Marcel, 1998). The affective registers of Amy’s experience as a human being are held in the act of naming her. The gift of oneself lies in the intention to free Amy from being reduced to a category, a thing sitting there. In that act he gives back her identity, dignity and freedom. In this gift of naming dwells attentive acknowledgment, “the act of showing that you know” (Merriam-Webster, 2010, p. 9). “To know is to have known tragedy, to understand, to recognize someone’s quality because of your experience with a situation, to know what it’s like” (pp. 657-658). It restores her dignity as he makes the point to receive her by name. The name calls her into presence. She is Amy.

For Marcel (1963), the gift of oneself is to participate with the other in a manner that brings humanness. Naming as a gift of oneself lies in the intentional attentiveness that transcends the objectifying gaze, and rejects anonymity or alienation. It embraces intimacy of participation in being. In the act of naming her, they both enter the realm of beings. Amy recalled:

It feels NICE because you feel remembered. You feel that the doctors remember you. As a family member, it definitely feels very nice that they remember you, remember your name, and remember who you are.

It is an acknowledgement that makes you feel like you are human to them. That you are very much a person in this whole ordeal, rather than just this thing that is always there. Yes, this is what being treated as a person means.

Amy’s narratives reveal that once she is named she no longer sees herself as an object taking up space in the hospital hallways. Being named embraces her whole being and she feels remembered as a human being. To be approached by name, an otherwise ordinary gesture of everyday life, creates a caring contact in the medical space. This closeness brings comfort to Amy. She feels the doctor near to her. She knows she is “human to them.” Presence unfolds through naming and gives rise to a felt sense of togetherness, nurturing a welcoming presence.
Natalie Goldberg (1986) invites us to consider the importance of being acknowledged by one’s name. To be addressed by name acknowledges our subjectivity and personal identity as beings. We are known to others through our names and to be singled out by name “gives dignity” (p. 299). For Goldberg, to address the other being by name brings us closer to the essence of the other. “It penetrates more deeply into the beingness” (p. 299) of the other. It is rude to say, “Hey, girl, get in line.” That “girl” has a name” (p. 299). To address the other by their name is to give them their “integrity” (p. 300). Addressing the other by name benefits both the one saying and the one receiving the call. “I am noticing what is around me and I can name it. It makes me more awake” (p. 300). In her writing workshops Goldberg ensures that all participants learn each other’s names as a way of connecting to the here and now and also because it “makes you more attentive to each other’s work” (p. 301).

A name is always given as a gift (Jagiela & Gebus, 2015). Such a gift “symbolizes the beginning of our existence” (p. 217) and our identity. “Giving a name to a child symbolizes legitimizing a new being” (p. 218). “To have a name means to be a Person” (p. 220), and to be addressed by name is to be welcomed as a person (Jagiela & Gebus, 2015). We are known to others and to ourselves through our names. As the doctor approaches Amy by her name he allows her to “come into being” (p. 218). When the physician utters Amy’s name, in that moment, he is awakened to her experience (Goldberg, 1986). He is attentive to the person in front of him: Amy, a person, a human being. “When we know the name of something, it brings us closer to the ground. It takes the blur out of our mind; it connects us… I feel more friendly” (p. 300). The physician has created a space of connectedness (Goldberg, 1986) where two selves are unified by the act of naming.

Addressing someone by name is also linked to dignity and humanity. In naming her, the physician restores her dignity: “I’m not a thing on a list,” Amy said. The gift of being named is an act of hospitality that restores Amy’s wholeness, vitality and dignity whereupon a more intimate mode of knowing, a communion with the other, is created (Marcel, 1967). In his analysis of availability/disponibilité Marcel (1964) calls to mind the notion of ‘the gift’ and ‘hospitality’ (p. 91). It is “a gift of self, of the person who is involved in the act of hospitality”
or of a “friendliness to the guests” (Online Etymology Dictionary). This doctor offers hospitality by honouring Amy’s being in a dwelling that has been alien to her.

To not acknowledge the human being by name may lead to objectification of the human being (Jagiela & Gebus, 2015), creating a danger of depersonalization and dehumanization. History has made the disturbing cost of nullifying a persons’ name abundantly clear (Jagiela & Gebus, 2015). In WWII people’s names were “taken away and replaced with a number” (p. 220) which made it possible to strip “people of their humanity” (p. 220). In the concentration camps the other was no longer seen as a human being and what is not human cannot be seen to feel or to suffer (Jagiela & Gebus, 2015). Emma also reaffirmed the importance of being addressed by name. She said:

The doctors should be using our name. It is not just someone sitting in a bed. The patient has a whole life, a family, and people who care about them.

Naming also reaffirms the subjectivity of the doctor. He becomes more than just a diagnostician, a mere functionary or the anonymous attending doctor (Marcel, 1964). The physician must juggle treating disease with his own emotional experience of witnessing cancer. In naming those in his care, the physician transcends the technicalities and mechanization of modern biomedicine (Agledahl, Gulbrandsen, Forde, & Gifstad, 2011). By naming the other the physician also invokes the humaneness innate to medicine.

The gift of oneself also comes in the form of the physical stances that the physician takes. Amy is received by what she calls the physicians’ stance as being “approachable and personable.” “This is a person-to person interaction,” Amy stated. She related:

There were only a few who I think were actually good doctors. From my experience it was Dr. X and this other young doctor.

Interviewer: meaning?

They were both very approachable. They were personable people. You did not feel intimidated. A lot of times you feel intimidated by doctors. The doctor talked to me like a person. And yes, you felt like a person. There is that sense that the doctors are better than you, or they want you to believe that [laughs]. But not with Doctor X. I never felt that way with him. You always felt it was
person to person. You never felt that this was a doctor to patient or doctor to family member interaction, so really it was never “I am the doctor!” You felt like a person.

Amy perceives the two physicians to be approachable or “welcoming, accessible, and friendly” (Merriam-Webster Dictionary). The physician offers to Amy a sensitive receptivity, an approachability that is transformative of a deeper relatedness. Despite the asymmetry of the relationship, Amy does not feel intimidated by the other, she feels welcomed. Amy connects the physician’s approachability with being seen and treated as a “person.”

Anne’s narrative also reveals the nuances of a physician’s approachable presence.

He didn’t come and talk just to me. He talked to all of us in the room. Well, you want the interaction with me as a family caregiver but there is also an interaction through my dad. So his interaction with me was also about how he treated my dad. So he asked my dad “what soccer teams do you like?” “I am from a very soccer loving nation [laughs], which one did you like? [very soft voice]. In England which team do you go for? [very soft voice].

The doctor encounters her father through sharing simple ordinary events of life—their mutual love of soccer affords a sharing that brings a sense of the personal to the interaction. He has come to talk to Anne and her father and in that moment he reveals himself. “I am from a soccer loving nation” Anne hears the doctor converse with her father. He offers his own self—his hobbies, his passion, his likes, his historicity. The doctor treating Anne’s father bridges the gap between the subjectivity of the human facing him and the objectivity of functioning as a doctor. This doctor brings a felt sense of vitality to the interaction, pushing away the fear that is prevalent in the space of cancer treatment.

The gift of oneself also encompasses sharing “mundane-common moments of caring” (van Manen, 2000, p. 317). Although the physician may not fully understand the totality and uniqueness of Anne’s day-to-day experience of caring for her father, he has come to share the simple and ordinary moments of life with her. The doctor closes the distance through his sharing. Anne knows their interaction will be of person-to-person contact. “No big fancy words.” In their interaction there would be no jargon. These are “subtle and deeply-felt
sensibilities” in caring (van Manen, 2000, p. 315) that illuminate what it is to be seen as a person.

Right there, that made me want him to be our doctor. Because I knew he would speak to me in plain English. And he did. When we asked questions he spoke straight, no jargon, no big fancy words about the different kind of neutrophils and the blood cells. No, none of that, just plain English.

“To understand another person I have to use a language common to both of us which will allow us to understand one another” (Marcel, 1964, p. 88). The physician need not merely be absorbed in his work as a doctor. He can see things through “the others’ ‘eyes’” (p. 51). He senses Anne’s fears and he makes the information available in a manner that transcends the technicality of biomedical jargon. Anne is not held at arm’s length or made to feel an outsider because she lacks the correct medical language. The relational distance that might have separated the carer from the doctor is diminished. Anne recalls other moments of contact with another doctor that allowed her to feel welcome as part of the journey. Anne recalled:

It was like having a conversation. He told me what it was like to be a doctor in his home country and what he had studied in his home country. We talked about the university I was attending, about my courses. He knew I was into writing and he was really interested in that topic of conversation.

Two human beings sharing simple moments of conversation. These are moments of time when the doctor enters into Anne’s world and makes it possible to encounter and recognize the other. He inquires about her daily routines—her school, her courses, her university, her writings—and creates living moments of connectivity that break through the cancer experience and remind Anne of her own life, her own self, before cancer came into being. These are powerful moments in which the physician can make an otherwise grim moment of time more humane.

Amy uses similar words to Anne’s in saying:

He would address me as a person. He spoke to me as if I was part of the conversation. Some doctors don’t do that with the family. Maybe because I am there translating he would address me more. But no, it was not like that. I was there for all of the consults and I always felt part of the experience. I was not just sitting there. I was not just the translator. He did not address me just because I was the translator.
He tried to be very careful with his words too. I could see he was very caring about my emotions. He knew that not only was I translating but I am also the daughter. So he gave me time to absorb the information before I translated it back to my dad. It was nice.

The doctor knows that she is the daughter but also the translator of grim news. He distinguishes her grief from that of the patient’s suffering. He worries for her. He is careful of the words he chooses, attuned to the power of the words he may offer. “He was very caring about my emotions.” This is “care-as-worry” (van Manen, 2000, p. 317) that Amy senses. She knows he is attuned to her sorrow and grief.

The gift of stepping outside oneself to welcome the other is to approach with an attitude of generosity (Marcel, 1950) and “receptivity” (Marcel, 1964, p. 89). For Marcel, receptivity is to receive the other who invokes me, by offering a sense to him or her of “being at home” (Marcel, 1964, p. 89). “To receive is to admit someone from the outside to one’s own home” (p. 91). To give summons receptivity to the other and makes them welcome, even in an often harsh and sterile medical space. Anne relates how shared moments of presence allowed her to feel at home. In this coming together, the space is now inhabited by human beings rather than just disease. There is no categorization of doctor, patient and family members. The exchanges are “person to person” Amy said. The virtual and psychological distances that separate the professional carer from the family fade as the physician offers the nearness of his presence. Personal and more intimate nuances of approachability allow for the unfolding of intersubjective encounters among beings that transform relations and foster a way of being-at-home in the hospital.

According to O’Malley (1984), Marcel moved from the person to the personal to draw attention to the intimacy of the personal existential involvement with the other. “I opened myself to this being in order to welcome him” (Marcel, 1967, p. 165). In the interactions between human beings, intimacy refers to the I and the other; it is the “unity of a we, a radical non-isolation of the subject” (pp. 200-201). Within this intimacy and unity of the we, some participants spoke of being given hope. “Hope is to lift the spirit, even if it is just a little bit,” Ernie said. The cancer may stop or it may not stop. Yet, in hope, a felt sense of animated energy entered the hospital room. She related:
The doctor approached the patients by trying to lift them up. Because if you have cancer you are not up there [pointing high], you really are down here. So really he talked to them to lift their spirits up a little bit. It was “hey you never know but…” It is like putting out some humour into the dark bleakness. It is hard because cancer is not a joke.

I think a doctor has to be positive and realistic in saying “we are doing our best and this is the treatment that he will be getting.” Things like that. And hope.

Ernie speaks of a balance between being realistic and keeping one's spirits up. With cancer, “lifting up is to offer inspiration or provid[e] hope” (Online Etymology Dictionary). It is an “act of helping, that of a cheering influence” (Online Etymology Dictionary). This doctor approaches with an attitude of hope, yet he is also sensitive to the significance of false hopes. Hope is a prevalent theme seen in numerous cancer awareness campaigns and slogans, as well as in fundraising, research and hospital emblems such as “light and hope in dark times” (Canadian Cancer Society), “wheels of hope” (Canadian Cancer Society) and “Team Hope” (National Alliance, USA).

For Anne, hope is revealed in “trying.” Anne describes one physician as amazing when her father was in intensive/critical care:

We had a different doctor at the beginning of ICU who really fought for my dad. I didn’t lose total faith in the doctors because of this doctor in the ICU, who was AMAZING!

When I asked Anne how he was amazing she replied:

Well he fought! He fought for him. He fought for my dad.

Interviewer: And what do you mean by he fought for him?

He never gave up hope. He always talked to my dad like there was hope. And he talked to US [emphasis] as if there was hope. Don’t worry, we are going to try…if this doesn’t work we are going to try this, he would say this.

Anne indicated that hope is not taken as an assurance that her father will not die. Rather, what she valued is that the physician addressed her father and showed that he was invested in his care. He would try, and keep trying. It is in these attempts to heal that he offers
hope. In the cold space of an ICU room, it is hope that lifts and holds Anne up. The doctor is fully present, talking to the patient and the family. There is a sense of trust in the physician. Anne knows outcomes are uncertain and potentially dire. The doctor offers a promise that he will not give up on her father. Death may come but the physician will try.

As a family you are not stupid. You know that you are in the ICU. You know that the chances of coming out are 50/50. It is not even 50/50 really. But you know that you are in the ICU because it is not going well. So what you want to hear is that they are going to do something, that they [doctors] haven’t given up on my dad. It’s what this doctor did. We knew these things might not work, but we knew he was always trying. “If this doesn’t work then we are going to try this. And if that doesn’t work then we are going to look at this,” he would say.

Hope is then fundamentally a response, a promise and a commitment (Marcel, 1964). “This is in an ICU unit where you have families who are living and dying,” Anne affirmed. The doctor does not know what the future will bring to Anne’s father. He feels and senses Anne’s despair and he offers a promise—a commitment that he will try. This is the transformative giving of the physician: he gives hope in trying. Anne describes another doctor who brought the gift of hope:

This other doctor never studied my dad. She never talked to me as if she were studying my dad. She was saying that there was still a chance. We can still do this. With the other ones it was, wow [takes long breath], “we can’t do this and we can’t do that.” All they [doctors] wanted to do was to tell us that there was no hope.

“Hope,” writes Marcel “is that which allows me not to despair, that which gives me the strength to continue to create myself in availability to the other” (Marcel as cited in Treanor 2006, p. 85). Hope reveals a “we” or “us” (Marcel as cited in Treanor 2006, p. 86). “Hope is only possible in the level of ‘us’” (Marcel, 1951, p. 10). Anne senses the “we”, the “us” as she encounters the presence of the doctor. “There is still a chance” Anne hears. As Marcel would say, in that moment the doctor is not resigned and Anne can hope. Placing one’s resources at the disposal of the other manifests in “hope” and “charity,” writes Marcel (1964, p. 47). Anne’s, Amy’s, and Ernie’s narratives show that these doctors addressed the unspoken fear of their loved one’s death. This is the spiritual availability or disponibilité that Ernie, Amy and Anne require. The physician is trying. He comes to the room to lift up the spirits of the cancer
patient. He greets each one with a smile in trying to be positive. This is the relational, temporal and spatial experiencing of the gift of hope. Hope reinstates an immediate intimacy with the patient and the family. Hope reveals the physician.

**Revealing the doctor**

Illness and disease bring people into a medical context as patients, family carers and treating physicians. Marcel notes that “to provide hospitality is truly to communicate something of oneself to the other” (1964, p. 91). What does the doctor communicate of himself or herself to the family member? What does the physician reveal of his or her own subjectivity to the family member? Participants describe how some physicians seem to take the risk of displaying their own emotions brought on by the toll of giving bad news. Amy knows from a simple glance at the physician that he has bad news. No words are needed.

Every time that we had our consult you could see when it was bad news. The doctor would tear up. His voice trembled. This was very touching. It was touching for us to have this personal relationship with this doctor.

And that is when you could see the tears in his eyes. You could tell when it was bad news because his eyes would start to water [long silence].

The physician is trained in the objective knowledge of the sciences, yet he reveals his subjectivity in nuances of emotion and gestures—a tremble of the voice, a movement bringing him to tears. By allowing the expression of his emotions he transcends the detached biomedical way of being-in-the-world. In their mutual eye contact Amy sees his eyes watering and in response she is touched by the intimacy of the shared moment. “You could see the tears. His voice trembled,” she said. Amy sees the doctor as a human being who is impacted by delivering the bad news. Through her father’s illness she feels a person-to person togetherness that restores their respective individual wholeness. Amy said:

And when there was bad news, that is how we knew. After all those years you picked it up. When there was bad news you knew because the way he fidgeted was different. He was very uncomfortable. His eyes got red and a bit watery. Sometimes, at first, he would try to avoid eye contact when delivering the bad news but then he would give you eye contact. You could tell that for him it was: “Oh, gosh, I don't know how to say this.”
The physician is uncomfortable and the brisk movements of his fingers show it. Amy notices his eyes getting red, and the avoidance of the gaze, and she knows the kind of news that gives rise to such bodily expressions. This is bodily knowing. She feels his nervousness and his pain. He attempts to avoid eye contact but he cannot. He cannot escape the eyes that face him. This is the permeability of the self taking the risk to reveal oneself (Marcel, 1964). Amy implicitly feels the anguish that permeates the doctor’s experience when disclosing “bad news.” She senses that he does not know what to say, or how to say it. In that moment of silence, she senses the incarnate quality of the doctor’s presence. Amy and her father’s doctor have spontaneously created an “intersubjective space” (Stern 1985, 2004).

“He is very uncomfortable,” Amy said. Amy senses the doctor’s discomfort, his lament in the movement of his fingers and in the moist red eyes. In that moment, Amy and the doctor both enter and feel the space of bad news. It is the genuine felt sense of each other’s experience. It is participation and co-participation in being (Marcel, 1964), a genuine openness to give and to receive the other. Amy senses how hard it must be for the physician to reveal bad news day after day. She sees him and she feels the pain of him doing his duty. He sees and feels her suffering as death hangs close. This is to “exist” and as Marcel (1967) writes, “to co-exist” (p. 205). It is co-presence in life that is all the more compelling given that the loved one’s life now hangs in the balance.

Ernie recalls the moment a doctor revealed his own vulnerability as person, beyond his profession as doctor:

I don’t blame them for anything. Doctors are what they are. The doctor is another professional like everyone else. But a caring doctor… it was just the way the other doctor said: “I can’t do anything.” And he couldn’t do anything but it was just the way he said it. It was like saying “I wish I could but I cannot do anything.” I find that caring because it was the meaning, “I wish I could do something but I can’t do anything,” and that was sad for him.

For this doctor, caring is to “lament, to grieve” (Online Etymology Dictionary) that there is nothing he can do. Ernie senses that this doctor’s way of being in the world is as one who feels the other’s anguish. When he cannot offer his technical expertise, he offers a sensitive self
to the others vulnerability. And she feels his sadness. This expression of caring is being with the other in suffering (Marcel, 1967). This is how Ernie distinguishes the “caring doctor.”

“A lived story unfolds within each present moment” (Stern, 2004, p. 16). The narrative above is a “moment of meeting” that stood out for Ernie (p. 16) where “something vital has been added to whatever had been said” (p. 19). Implicitly Ernie shares feelings of powerlessness and sadness with the doctor. “I can’t do anything so I guess I can just give him the intravenous,” the doctor said. No other words were spoken in this physician-family interaction, yet this moment became a space where “a particularly human contact had been made” (Stern, 2004, p. 21).

Amy also narrates such moments of vital contact, intimacy, and sensitive responsiveness:

When the news got worse he (the doctor) would stop and ask me if I needed a translator to come in. He understood the very hard position I was in. He would stop and ask me: “Do you need me to go and get a translator?” I was always given that option when it was bad news. And it was nice to have that choice.

Interviewer: I wonder, as a family member, what would be the message such that he stopped and asked if you needed a translator.

[Tears]. Oh. I knew it was BAD. He was thinking of me. Yes. He knew it was going to be very hard for me or for any family member to relate messages like that [silence, very quiet voice]. It was hard for him, too, to relate the bad news to me. [Long silence tears.] So, yes, this is caring. I don’t know if any other doctor would have offered me that. It wasn’t for my dad. It was for ME and I couldn’t take it any other way.

Anne remembered how the doctor went quietly about his business in the silence of a hospital room. She senses that he is aware of her presence. They are both there for her father. There are no sounds, no words spoken, and no need for them. Between them exists a sense of listening and being attuned to each other. Anne said:

This doctor, sometimes he was there in the room doing stuff for my dad [tears silence]. And I was there, he was there, and he was quiet and that was OK. He
didn’t have to talk to me. But he knew that I was there and he was there and the central focus was my dad.

We were both there for my dad. He didn’t ignore me because he was doing his things for my dad and I was doing things for dad and it was good! I knew that he (doctor) was caring for him, whatever he was doing it was about my dad.

In that moment, she senses his caring and that he senses her sorrow. Anne continues:

It was a sense of being acknowledged. Sometimes that’s all it takes…to be in the room quietly with someone. And you feel comfortable enough and the space feels comfortable enough because he [doctor] is not sitting away at the opposite end of the room trying to scribble something.

Two persons attuned to each other transform the space. Anne speaks of the quietness in the room, yet she feels “acknowledged.” Acknowledgement is “to admit into existence” and to acknowledge is to “take notice, to accept as legitimate, to regard someone as having a particular status” (Merriam Webster Dictionary, 2010, p. 9). The physician recognizes her status as someone deserving due acknowledgment. This physician recognizes her as a daughter, a caregiver, a human. The gift of oneself lies in one human being recognizing the inherent dignity of another. This recognition of beings allows for a simple meeting of moment-to-moment contact that opens relational possibilities (Stern, 2004; 2004).

This doctor is not bothered by my presence. Some doctors would come and say: “Do you think you could leave the room while we do our stuff?” But this doctor never asked me to leave the room. He saw me holding my dad’s hand and he kept on going about his business. He never asked me to leave.

Interviewer: So for you that was recognizing your presence?

YES!! It was like: “yes she is here and I’m here.” Yes, he recognized my presence. “I’m here doing stuff for your dad and you are here for your dad. We are both here for your dad [silence]. And I don’t want you to leave as the other doctors ask. And I’m not here talking to you with a massive group of students behind me and talking about your dad as if he is just a patient. I am here by myself and it is quiet between us [silence] but that is OK.” [long silence].

In the quietness of the room, presence is shared in “spontaneously co-created moments…the turning-points” (Stern, 2008, p. 180). Silent togetherness is a vital embrace in
the sterility of the room. There is no need to break the silence, (Bazzano, 2012). “By listening attentively to the silent presence of the other, fundamental messages emerge such as *Do not hurt me. Receive me, Receive my presence. Be kind to me. Listen. Look at me. Respect me*” (p. 30). Through silence Anne “sensed the experience of the other, and both sensed the mutual participating in the other’s experience…—a new state of intersubjectivity was created between them” (Stern, 2004, p. 20).

Stern’s concept of attunement opens the way to understanding these participants’ experiences. Stern (1985, 2004), a leading researcher in the area of mother-infant relationship, proposes that infants from early life have a certain readiness to be attuned to the mother’s mind in what he posits as “intersubjectivity” (2004, p. 85). Through careful observation of the mother-infant relational engagement, the infant and the mother came to know each other’s inner feeling states. He called this implicit affective knowing “affect attunement” within a “shared mental landscape” (Stern, 2004, p. 368). Thus, for Stern, implicit knowing is about expectations and feelings. Moreover, Stern suggests that intersubjectivity, “the shared mental/feeling landscape” (p. 368), is a survival need.

Stern (2004) highlights the notion of the present moment as “a transformative journey, taken together that starts with a moment of suspense, and transverses a landscape of emotions and intention where a world of change becomes possible” (p. 365). Present moments are always critical moments composed of “relational moves” (p. 368). “[A] spoken phrase, a silence, a gesture, or shift in posture, or a facial expression” (p. 368). A moment of meeting summons a response that is both authentic and spontaneous “where both partners share an experience and they know it, implicitly” (p. 370). Anne said:

*When my dad died he had been transferred to ICU. The third physician was a person who didn’t give up on us, even at the end. Even when we were in the waiting room the night before my dad passed, she was still trying and talking to us saying “this test result looks good, this test results was bad,” but she didn’t give up. She never stopped talking to me like a PERSON [emphasis]. We were involved. This was something that we were doing together.*
"The participants have created a shared private world’ (Stern, 2004, p. 371) where the intersubjective relational field has been expanded. In the voice of these participants, these lived moments in the cancer ward become expansive through a physician’s caring presence.

Life at the cancer ward is constituted by the sensitive attunement of self and other. Anne stated:

The doctors who really talked to me treated me like a person and not just a thing in the landscape. With them there was a sense of relaxed calmness that we were in this together, So you almost relaxed because you TRUSTED [emphasis]. There is a trust there that makes you think "Oh I can breathe now. There is someone I trust in charge."

Interviewer: What stands out for you in terms of those particular doctors who were helpful in building trust?

Anne: They had the capacity for emotions [long silence]. They could express how difficult it was for us. They never tried to hide how difficult it was for them too—that there was a bad disease here. They acknowledged it and they didn't hide. They talked to you. I don't know how to say it but they talked to you.

Two human beings partake of the space and time of cancer. Two subjectivities are committed to participate in the lifeworld of cancer care. This is a “shared feeling voyage” (Stern, 2004, p. 172), “a kind of journey …taken by two people, roughly together through time and space” (p. 172).

Amy notes that the fundamental condition of humanity is to feel, and feeling is connected to acting in a caring manner.

Maybe the doctors feel they need to be expressionless. But as a family member I appreciated the emotions in my doctor. I appreciated that he cared. It is nice to know that doctors care. It is was very nice to know. You don’t have to be best friends. How do you remove your emotions? If you see something like cancer you cannot not feel. You have to feel something.

Amy contrasted her doctor with others who delivered bad news in a detached manner. They had become “numb,” she observed. But her doctor offers himself and by participating affectively he is also for himself. She remembered:
This is interesting because I hear that some doctors become numb when delivering the bad news. But I don’t think that our doctor could become numb. He takes every patient who is going for cancer treatment personally [long silence]. If the treatment is not working it is also a blow to him. And you can tell that.

Amy’s account points to the ever-present possibility of being desensitized to the delivery of bad news within cancer care. Yet, at the same time, she categorically affirms that her father’s physician “could not become numb.” Marcel posits that participation and availability to the other arrives in feeling. The numb or unavailable individual is “internally inert” (Marcel, 1964, p. 50) or in a state of “somnambulism” (p. 51) and thus cannot be responsive. To respond is to feel and an emotion is about a motion, an act or action (Marcel, 1964). We feel the appeal of the other that “restores us to ourselves” (p. 51). To feel is to be moved by the other. Amy’s doctor is seen to be moved by the other to the point where a negative treatment outcome is a “blow” to him. Amy’s perception is that he is deeply, emotionally affected. Emotional numbness, however, is a symptom of burnout, a phenomenon that is now considered worrisome in medicine (Angoff, 2013; Thirioux, Birault, & Jaafari, 2016) and oncology (Shanafelt, et al., 2014).

To feel leads to an act, to an action (Marcel, 1964). Amy’s account reveals it leads to the investment of action in care. She said:

To see that the doctor has actually invested himself in his patients, that he actually cares for the patients’ life and what they are going through, and that he cares about what the families are going through, this is not something that you see every day.

“To be invested” is to give or to devote oneself. The doctor who is invested clothes himself in his vocation as doctor and within the quality of presence that he offers. Amy said:

Our doctor cared to listen to the person. He cared how to ask. You could tell that he cares. He cares that the patient has cancer. He cares that that person’s life is in his hands. He cares if the patient is going into remission or not. He cares if what he is doing is effective or not. And he cares that cancer is affecting all the family.

He acknowledged that this family member is experiencing pain. He acknowledged that this experience (cancer) is a bad situation for the family.
members as much as it is for the patient. That level of humanity makes you feel important [long silence-tearful]. He acknowledged that you as a family member were having a rough time too! [Emphasis].

Our doctor understood that the family member goes through just as much pain as the patient, even if the pain is different. He understood that connection. The other doctors did not understand. It is this understanding that makes it reassuring for the family.

The gift of oneself notes Marcel is the availability “of a consciousness capable of caring for another person” (Marcel, 1964, p. 88). It is interesting that Amy uses the word caring and care a number of times in her narrative. As mentioned previously, Amy described her doctor as “attentive.” It is worth noting that being attentive shares a related meaning with care and caring (Farlex Dictionary) which Amy connects to humanity. Humanity is defined as a “state of being human” as well as the quality of being kind and benevolent to others (Merriam-Webster Dictionary). Amy’s experience of a caring doctor is of one who is invested in being attentive, kind, and humane. He feels, understands, and expresses his sorrow of the emotional and physical pain that cancer brings to the patient and the family members. In the dispiriting room of the hospital, she sees the doctor caring for her father and she knows he feels her own pain. It is a comforting presence that gives Amy some solace.

To be invested is about revealing oneself through movements, stances, and motions of listening to the patient and the family carer. Other doctors were generally ‘dismissive,’ moving from one question to another without much care. But her father’s doctor is invested in caring. He “cares to listen,” Amy reflected. There is no automatic motion of going from one question to the next.

This doctor listened to you. When he asked question, he would actually be listening. Yes, he had a list of questions to ask but he cared to listen to the person.

He offered an invitation to call him should she need it. Amy continued:

And he would say: “If there is any problem, call me.” Like the other doctors you tell them there is a problem and they are “yep, next, yep.” They are dismissive.
To be invested is thus a form of caring as a solicitude and concern and responsibility. “How is caring experienced?” asks van Manen (2000). Experientially, “caring is lived as a worrying attentiveness” (p. 318) and “worry, it seems, is the active ingredient of attentiveness” (p. 318). This doctor cares about the patient, the outcome of the cancer treatment, and the cancer impact on the family. He knows the other is vulnerable and one whose life is in his hands. And he worries. This is the openness of the self to the other’s invocation. “This appeal is caring experienced as a vocation, as a calling” (van Manen, 2002, p. 270). It is to make oneself available. When I asked Amy whether doctors should make themselves available to the family carer as well as to patients, she responded:

They have to be available for the family member since we are the ones with the questions.

When I asked her whether her father’s doctor made himself available to her as the caregiver, she categorically affirmed that despite the doctor’s busy schedule he did so with readiness.

Oh yes. Yes. If we needed to talk to him, you would have to make an appointment. But the answer is yes. If we needed to have an outside consult other than the weekly or daily brief that you got, we could make that appointment. And he would be available. He made himself easily available. Doctors have to be available.

Kindness is thus revealed through physicians’ openness to give and to receive, to make themselves available and at the disposal of others (Marcel, 1964).

As a family member, you sit there and see what everybody is going through, what your family member is going through. It is very reassuring to know that the professionals who are caring for the patients are kind.

Interviewer: And in your opinion, kindness should also be extended toward the family member?

Yes, because it makes a difference. The experience that we have with the nurses and some doctors is that the little kindness you get from some medical professionals makes you feel better in that environment. When you don’t get that, it is frustrating. It is frustrating when the doctor is not listening to you and doesn’t seem to care.
kindness carries a sense of gentle compassion toward the family member and the patient. The physicians’ kindness “makes you feel better” when you witness “what your loved ones are going through,” Amy recalled. Freeman and Hoffman (2011) note that within medicine kindness was first conceptualized as a virtue, defined as “helpfulness toward someone in need, not in return for anything, nor for the advantage of the helper himself, but for that of the person helped” (p. 343). Youngson (2011) notes that compassion manifests itself in “simple acts of kindness” (p. 40) that are readily “observable” (Freeman & Hoffman, 2011, p. 343). Kindness reveals itself as a gift of presence from the physician who sees the other as a person (Freeman & Hoffman, 2011).

Kindness takes little time to implement in the doctor-patient-family interaction (Pickering, 1997). It arrives in the act of listening to the patient and the family, to offer time and caring (Pickering 1997). Kindness is also transformative in “how clinicians view themselves” (Freeman and Hoffman, 2011, p. 344). It restores physicians’ satisfaction in their own calling as doctors. Dykes (2004), a physician and medical school professor, writes:

I teach my students that medicine is a service, a sacred service in my opinion. I teach them the value of listening not only with our ears, but with our hearts, being ever mindful not to lose sight of the innocence and the wholeness of those we serve. I teach them the value of kindness. (Dykes, 2004, p. 82)

Amy related that when death came, her doctor did not stand aside or retreat. When the trials failed and bad news arrives, Amy does not feel alone. She said:

The doctor was there when my father died. And the doctor never pulled back. It was very emotional when he delivered the last bad news [long silence]. But it was sort of nice too. Because after all these years you have a relationship with the doctor. You felt connected when he was giving us the bad news. You sort of felt like we were sharing this news together. In a sense, it was almost as if he were a part of the family. This was really nice. It is really nice that way. It felt like a friend telling you bad news rather than from some detached guy in a white coat. It makes a big difference.

Affect attunement involves a relational way of being that entails a sensitive affective, corporeal, and experiential understanding of the subjective world of the other. It involves grasping the resonance of a person’s emotional experience in a particular present moment (Stern, 2004). The physician who is sensitively attuned to the subjective experiential world of
the other (Stern, 2004) offers an authentic presence where one human being sensitively responds to another being’s experience (Marcel, 1964). In the relational interaction, the attuned physician gently enters, attends, feels, and temporarily participates in the affective world of another human being, and with the family carers.

In the immediate, moment-to-moment interaction, the physician extends beyond the self, and approaches the complex inner world of another being. In death he offers his disponibilité, the very notion that defines presence (Marcel, 1964). He is fully present in being with the other, with Amy, ‘together’ in death. This physician is in tune with Amy’s bodily, emotional, and spiritual experience of living the reality of cancer care. He was not “just another guy in a white coat.” When two persons encounter each other in a moment of meeting, growth and change are, in turn, made possible (Stern 2004). The doctor is not just another provider of service. He is a human being who also shares in each family’s cancer journey. This is the “we,” the in-between space of being with the other (Marcel, 1967). It is in this sense that the encounter is transformative for both persons in the co-creation of their realities, despite the fact that the family member-physician relation can never be symmetrical (Stern 2004). The gift of oneself makes possible these moments of mutual connectedness throughout life and even past death.

It may be that the gift of oneself is restorative to what it means to dwell in an otherwise inhospitable space. Patients becomes more than cases, files, or diseased bodies. Families are human beings with histories, values, feelings and experiences. They are not ‘things’ sitting in a room. The doctors who give themselves to these participants, in the acts of giving, are also present to their own beingness (Marcel, 1964). Giving to the other restores their vocation as healers and opens the possibilities of an intersubjective space where two human beings can encounter each other as whole persons. “There is no closing off of oneself from communication and communion” (Treanor, 2006, p. 73). In the giving of their emotions, material and spiritual resources to the other, “the one that exposes me to, or better opens me up to, a reality with which I somehow communicate” (1964, p. 88), physicians “somehow make room for the other in” themselves (Marcel, 1964, p. 88). A physician’s recognition of the intense psychological, existential, and emotional demands of cancer treatment affords moments of contact where the
gift of time and oneself can alleviate suffering, and where grief and sorrow are recognized as our common bond.
Chapter 8.

Words from the family: A practice of embodied care

*Medicine is a collaborative effort, and the most important participants in the collaboration are the patient and family. (Savett, 2002, p. 22)*

The purpose of this study was to explore an area of research that remains largely unexplored by empirical research (Bevans, & Sternberg, 2012; Shin et al., 2013), which is qualities of the family-physician interactions during cancer treatment from the perspective of family members. My aim was to uncover the meanings that family members ascribed to their experience. This chapter encapsulates the family members’ perspectives on restoring wholeness to the patient, family member and physician triad, and provide direction for humanizing current medical practices.

Family members saw themselves as vital to their loved one’s well-being and overall medical outcomes. Participant family members stated that they saw themselves as part of the living context of their loved one’s illness. Devoted to their loved one’s care, they provided emotional and instrumental support to their ill loved one, from the initial diagnosis, through treatment, and to the end-of-life. Family caregivers spoke of being a crucial link in providing important information to the attending physicians and they considered this information crucial in terms of the patient’s health outcome or treatment management. Participants saw themselves as not only a resource for the patient, but also for the doctor, their presence enhancing the quality of life for their loved one during and after diagnosis.

Family members highlighted the importance of establishing and maintaining a partnership with the medical provider where the family is welcomed as a partner in care. Participants spoke of gestures, expressions, sounds, movements and motions as being essential in building caring interactions and relations amongst families, patients and doctors in the cancer journey. The family members underscored a loss of confidence, loss of empathy, loss of trust and respect toward the physician when such interactions were neglected.
One participant, Emma recalls the tremendous emotional toll illness takes on the family. She notes how upon hearing the doctor say the word cancer she wishes she could burst into tears. But she cannot. As the caregiver, she said, the family member must gather the strength even when left reeling emotionally. Emma notes how she felt the need to be strong to sustain her mother’s “spirit.” She said:

You know what they’ve just said, but you are still not sure what the prognosis is at this point...yet you are standing in the hallway and you have to have fortitude. You have to get yourself prepared to walk back in that room and act and pretend that everything is great. You try to keep the other person’s spirit up as well, and you are fearful, but you have to keep it together. You can’t walk into the room and burst into tears. It does not work. You need to wait and do that in a quiet way in the hallway.

Emma stands alone in the hospital hall. Cancer has disrupted the rhythm of her life. Emma uses the word burst, signifying “to break into pieces in a sudden and violent way,” “to give way from an excess of emotion or being full of emotions to the breaking point” (Merriam-Webster Dictionary) to describe the emotional impact of cancer. She knows the impact that hearing the word cancer has on her mother: “She is the kind who immediately shuts down.” Fear and uncertainty dwell in the hospital hall and disrupt Emma’s being. But she cannot break apart. She “has to keep it together,” to withstand the disruption, and to protect her mother from the overwhelming nature of diagnosis and treatment. Grief needs to be postponed when one is facing a loved one’s diagnosis.

Amy points to the critical importance of providing emotional support to the ill loved one. In the day-to-day living of the cancer treatment, Amy needs to be strong for her father as well as for her other family members. She does not speak of having a choice; she feels she must be there and be strong. There is no other option. As she moves through the cancer journey, Amy knows that she must hold herself up for her father’s benefit. If her father gives up psychologically and physically, then everything can collapse.

You HAVE to be strong!! [Strong voice]. You sure need to be strong for your family member who is ill and for all the family because if the patient loses it, then everyone else does too. So you have to be strong. It is like a spiralling down effect. Everything will fall.
Emma also knows that despite her own emotional pain she needs to support her mother by asking questions about treatment, relaying information to her mother and other family members, and attempting to understand the implications of the cancer treatment. The patient may have to rely on what the family member is saying as they face medical decisions. There appears to be a sense of having to *take charge* since the patient may not be able to do so.

As a family member you are trying to be cognizant through all of this. We, the patient and the family caregiver, converse back and forth in trying to find the truth. Hopefully you will have had contact with the doctor to tell him: “Here are the questions that we, the patient and the family caregiver, need you to answer at this point.

The role of the family carer is thus not only one of emotional support but also a support that is psychological and informational. Family carers in this study felt strongly that they mattered in terms of the patient’s well being. Alongside the doctors, they saw themselves as carers who were at “every moment” with the patient. Emma said, “The doctors are not with the patient every moment and neither are the nurses. But the family members are with the patients all the time and the family members are the ones who know the patients well.”

Amy also indicated how the family “provides a different set of eyes” thereby being able to offer additional information or more detailed observations. She notes that with “anything that is abnormal, it is the family member who will notice first.” Thus, for Amy, the family carer is a critical resource for the patient and for the physician. Amy reflected how important it was to trust the doctor treating the loved one. She said:

The family carer should be able to have that option where they can tell the doctors: “Listen, I think there is something you missed here.” Or, “Can I tell you that a few days ago this happened.” You as a family member do not know if it is relevant but you want to be able to disclose that knowledge to the physician. At least you want to let them know whether the information is important for the treatment or not. I don’t think the family member should be afraid to share any information.

Amy explained that sometimes the patient may not report critical information because of forgetfulness or because of being afraid to bring forward information. She relates how the family presence provided collateral medical information that afterwards was deemed to be significant by the doctor. Amy stated:
There are many times where the patient forgets. My dad, many times would forget about the problems he had. Or he brushed them off. He would say: “It is not a big deal.” But our doctor would say: “Oh, that is really important.” So he would always ask me and my sister, and we would add to it. We would say, “Remember the other day when such and such happened. “And that was in addition to what the doctor needed to know.

Interviewer: So you are saying the family is important medically?

Amy: Yes. Pay attention to the patient but also to the family member. They are not experienced in the illness but they see it and they see the patient.

Anne also attested to the importance of the family presence throughout illness. She described how during hospitalization the dental team would come to check up on her father. As she sat in the chair beside her father’s bed, the dental team entered the space of treatment. The head doctor addressed her personally and inquired how she was doing. This was a gesture that Anne emphasized as important. “What have you observed?” the doctor asked. “Anything else going on?” Anne recalled:

The doctors on the dental team came to check the state of my dad’s teeth. The chemo really erodes the enamel, it increases the decay on your teeth, and a lot of patients lose their teeth. That is my understanding. The chemo really burns you from the inside out. The doctors of the dental team didn’t just converse among themselves. The head doctor actually said: “HI, HOW ARE YOU” to ME [emphasis]. He asked ME what I had observed, what had been going on, and did I know anything more. He actually directed his conversation to me because my dad obviously was very ill.

Given their emotional bond to the cancer patient, and their day-to-day living at the cancer ward, family members’ observations were crucial in providing more data or information. “You can tell them better what’s going on with the patient than what the doctor sees from the chart,” Anne disclosed. Amy added, “We are giving you valuable information from a family who is seeing the patient every single second that they are there. Take what I’m telling you and use it!” Family members thus viewed themselves as vital partners in the provision of care. Participants pointed to the importance of a welcoming family-physician interaction where a partnership is “an acknowledgement that you as a family member are there and that you are a crucial link,” Anne said.
Illness unfolds against a horizon of living relations. The patient looks to the immediate and extended family as the very core of this relational system. Emma said:

The patient has a whole life, a family, and people who care. When you are given information such as “you have cancer”, the doctors should look to you as a family unit and then say “if you need to talk to someone here is someone to go see.” Not just “this is cancer” and then, “thank you for coming.”

Where Emma emphasized the need to treat the patient and the family as “a unit,” Amy points to the historicity and familial context in which the illness unfolds. The wholeness of the patient and the accompanying family is what should be visible to the doctors. Amy added:

Doctors have to see it as a whole. I hear stories where people said the doctors were cold because the doctors were only looking at treating the disease. And that just removes ALL [emphasis] the human aspect from it. That removes compassion too. Because they are not looking at the patient as a person but as a disease. It is a very sterile environment too. It is such a sterile environment.

Amy notes that physicians should see the “whole” illness, “in an unbroken or undamaged state, with no part removed” (Oxford Dictionary). Upon entering the caring space the disease is separated and removed from the larger context of the patient, and the patient from the family. The sole focus on the disease breaks the wholeness and soundness of Amy’s human existence. For Amy, physicians must focus on the humanity of those for whom they care. This is what sustains the other undamaged in the face of the disease. Amy also emphasized that the space of caring in the hospital is lived too often as a “very sterile environment”, that is, as one “free from living organisms” (Online Etymology Dictionary). One may speculate that such a space is also barren of the affectivity inherent in sentient beings. A “sterile environment” is one that “lacks colour (MacMillan Dictionary). It is “not comfortable.” Perhaps the sterility of the built environment, the sparse furnishings, empty spaces, and colorless walls serve as mechanisms whereby the disease itself can be separated from the human being, where disease can be detached from the lived world of the patient and family, and all who enter remain bare and anonymous.

Amy points to the danger in dehumanizing such a living experience and stresses the importance of not medicalizing the wholeness of the illness experience. While it is understandable that the focus of the physician is curative, it is also the case that disease is
inside a “person” who is part of a familial system of relations. For Amy the physician must acknowledge the family interrelatedness. She also reminds us of the perils of ignoring such familial interconnectedness:

You want to kill the disease, right? That is great. But the disease is inside a person and if you do not acknowledge your patient as a person you are definitely not acknowledging the family of the patient. When the patient is feeling unimportant, and does not feel treated well, they are upset and sad, and the family feels that. Then begins the domino effect.

Amy makes clear the importance of having a strong and open interconnection between the patient, family caregiver, and the doctor. When the patient feels that he or she does not matter to the medical gaze it has an impact on the patients’ well-being: the patient may want to give up and the family carer(s) are anguished by that. How the doctor treats the patient has an impact on the family carer. Similarly, how the family is treated by the doctor also bears on the patient. When one member of the patient-carer dyad loses confidence in the physician, so does the other.

I know that it becomes a domino effect. Because I know that if I were angry and frustrated, my dad would feel that. And he would feel bad on so many levels. He would feel bad that I am going through this. And you lose confidence in the doctor too. The patient feels bad seeing what the family member has to go through. If patients are not treated well by the medical profession, they feel bad. And you as a family member feel sad. It is already sad seeing your dad, and seeing that he is depressed by how he is treated. That has kind of a double hurt. Then I lose total confidence in the doctors.

If the patient is not feeling confident about the doctor the family will not feel confident either. And it goes the other way too. As a family member, if I don’t feel confident about the doctors, then my dad will have no confidence in those doctors.

Amy continues by emphasising the affective interconnectivity of the family and the patient: when her father is in pain, she feels his pain and she suffers. By her father’s side she must witness her father’s excruciating pain but she cannot help. In a tearful manner Amy relates her helplessness:

The pain does extend to the family. When a patient is not comfortable the family member suffers. When the patient is in pain the family member feels
the pain, not to the extent that the patient feels pain, but it is a level of pain you feel when you watch your loved one in pain. So you are also in pain. And you can imagine what it is to see your loved one feel such excruciating pain and you just have to sit there and see that [tears].

She continues:

If, as a doctor, you don’t care to give my father a little bit of comfort it is frustrating. And we have to watch that. We have to endure that. It makes a difference to us as family members because as family members when you see your loved ones miserable you feel worse.

Where Amy reflects on the need to see the patient and the family as a “whole”, Emma speaks of the need for “unity” between the patient and their family. Kate in turn uses the expression “the collective” to signify the affective unity of the patient and the family. Kate said:

I didn’t see in palliative care treating the collective—the family. What I appreciated with the hospice is that it completely contextualises the family. In the hospital and palliative care, trying to get information from the doctors was impossible.

Kate, who as an only child bore the whole weight of responsibility for her mother’s care, pointed to the recurring invisibility of the family member to the medical gaze, even in terminal illness. Kate suggests that palliative care should be family oriented. She noted that palliative care nurses or physicians should have the same attitude as the people working in hospice, particularly towards inclusion of the family.

The hospice perspective in terms of the patient and family was just magical. I think palliative care should learn from the hospice. The attitude of the palliative care staff shouldn’t be substantially different toward treating the collective, the family.

When we went to see L, his wife said she could take us on a tour of the hospice. She walked us around in this whole environment that is created to support the family, including us, the visitors. And it is so incredibly well thought out. When I looked at that, and at the work that I do, I see a real solid connection between the fact that you cannot just educate a child, you have to support them within their context. And in the hospital it should be the same: the family is part of the context.
The “family is part of the context” and should be treated as a “collective.” Yet a reductionist view of current western scientific medicine separates the ill person from the family, and the disease from the patient. Such a reductionist view ultimately removes dignity and vitality from human existence (Toombs, 1992, 2004). Emma added:

You know if you are going to put a person in the situation of cancer treatments and the person has full confidence in a loved one to come and be with them then it should be inclusive because you are there for the benefit of this person and want to help them. You are not there to reprimand or accuse. You are there only for the benefit of your loved one. You want them better, you want to help them, to do whatever you can.

The patient-physician relation is seen as the backbone of ethical medical practices by various medical associations including but not limited to the American Medical Association (2001) and the College of Physicians and Surgeons of Ontario (2007). These associations, furthermore, assert that physicians should recognize the interconnected bond of the family-patient dyad. To recognize the family carer is to see the patient and the one who is at the core of the sanctified physician-patient relation. Amy said:

There needs to be more of a reminder to the doctors that they are not just treating an illness, they are not just treating a patient, but they are treating a whole family. The patient and the family are a whole. Doctors need to understand that we are all connected. If the doctor acknowledges the family they acknowledge the patient too. And I think that when there is an understanding of that, then everything falls into place.

That is why I feel that our doctor had that understanding. That it was not just my dad he was treating, it wasn’t just my dad with whom he was having a relationship, but rather you are having a relationship with the family and the patient. It is that type of relationship that makes the experience less depressing.

The doctor understands her plea and he responds. He sees her bond with her father and recognizes the force of living bodies in living relationships with each other—father and daughter in unity in cancer care. Disease cannot and does not take away the family wholeness. Amy and her father are not separate, isolated entities. They are attuned to each other’s everyday experience in the cancer treatment. It is through understanding the importance of that dyad that a physician can restore wholeness and humanity to the physician-family-patient encounter. Amy knows that she does not need to travel the cancer journey alone. The patient, the family
member, and the doctor are together in this journey. This is what sustains Amy and what allows her to continue alongside her father. The lived space of care, despite the gloominess of leukemia, feels “less depressing,” she says.

Emma invites us to ponder the importance of the family carer-physician partnership in healing. “We have to find out how the health care world can open the door to let the caregiver in. And that is what is missing,” Emma said. “Doctors can help the patient sitting there who cannot absorb what is happening by allowing family members or a confidante to be a part of the treatment. Include them,” Emma insisted. She added:

A true partnership is needed because it is a team that is going to help. It’s not having a family member drifting around trying to figure out things in bits and pieces. And what does that say about only hearing things from nurses? They have their shifts and they leave, and every time it is a new person. And then the next person probably sees things differently than the last person.

Someone from the family has to be there at the hospital. There has to be a partnership involved. I did not have that. No, that would have been very nice but it did not happen. I don’t know if things have improved over the years. Now it has been about five and a half years since her passing. So I’m hoping that something has changed a bit for the better and that they see the family differently in terms of a partnership.

While different nurses may come and go, patients are often under the care of a designated physician. For Emma, creating a partnership with that designated doctor is crucial, and failure to do so can lead to angst in the family. Such angst pervades Emma’s day-to-day lived experience at the cancer ward. Without a partnership, the family caregiver is left to wonder and struggle “to figure out in bits and pieces” what is going on. One may wonder how this angst can ultimately impact the patient’s well being, the family’s wellbeing, and the trust they place in the attending physician, and the larger health care system in which they find themselves.

Emma stresses the vital significance of establishing a partnership, “a relationship which strives for balance, equality, and mutual respect, and in which information, power, and responsibility are shared between two or more actual persons” (Online Medical Dictionary). Given the importance of the family carer in terms of patients’ health outcomes and well-being,
how do we begin to envision a new relationality of care that embraces a patient-family carer-physician triad? How can relations of mutual respect unfold? “There has to be a partnership involved. A true partnership.” Emma recalled how doctors’ approaches have changed from those of her childhood.

A long time ago the doctor knew everyone in the family. The doctors knew the children, they knew if they had had chicken pox, what bone they broke, etc. I remember our old doctor. Right up to the time he retired he was from that old school who came to the house. He checked us all out and made sure that everything was good. He knew everyone in the family by their first name. And when the doctor walked in he said: “Hi Emma.” Right? And you don’t get that anymore. It was more intimate then. Doctors knew the family unit and they knew the history. They don’t anymore. You walk into the doctor’s office and they don’t even recognize your face. The doctor I currently have, in the seven years that I have been going to see her in person, I have seen more intern trainees in the clinic than I have actually seen her.

“He was from the old school,” said Emma, recalling an old way of being-in-the-world. The family was seen and understood, not as separate beings, but as a whole unit. The physician knew everyone in the family by their first name. They offered a welcome by naming you, creating the needed recognition in the space of caring. The physician knew the family as one and was attentive to the family’s well-being. “You don’t get that anymore” Emma sadly reminisced. Patients and family members are now mostly nameless, Emma reflects. Yet as Goldberg (1986) and Jagiela and Gebus (2015) remind us, to be named is to be recognized and welcomed. This is Emma’s experience of her family doctor as she grew up. The doctor named her and recognized each family member. Now, Emma says, you go to see your doctor only to find yourself nameless and faceless. For Emma, the partnership begins first with the family physician.

The partnership was not there for me. But it would be nice to have that right from the get-go. I think it should start with the family doctor.

Interviewer: Why the family doctor?

Why not? Why not start there? They are the ones who are passing the patient to the next guy who is higher up, the one with more experience, and directly to the oncologist. The family doctor has to make some kind of diagnosis, and then he sends you to the specialist. Even at that point it should be something
that as a doctor he can say why the patient is being moved to a specialist. That is the start of how everything begins. It is that person who hands you that piece of paper that says: now I need you to go and see the specialist.

Amy also sees the family-patient-physician partnership starting with the family doctor. She emphasized the important link between having a caring family physician in moments of heightened need and vulnerability. Amy relates how her family physician indeed attended to her and her father. He turned his attention to his patient and the accompanying family from the very moment that cancer entered their lives. Previously Amy described how her family doctor immediately picked up the phone and contacted the oncologist in their presence, bridging the patient and family transition to the leukemia ward. These are the turning points by which Amy and the physician are bound together to support her father. Life in the leukemia ward begins with an act of inclusion by her father’s family doctor.

Kate, however, notes how the hospital model continues to decontextualize illness and detach the family from the ill one.

What is missing in the hospital is the support of the family. I don’t see it as necessarily addressed. And the issue is that there are too many residents and the fact that family physicians don’t have hospital rights anymore. They are putting it on these others, hospitalists, and I haven’t seen that work. I have not been in situations where those changes have worked, or that it has been more effective. I’m not seeing that shift in attitude in the hospital in terms of recognizing the context—the family. I don’t think that is necessarily because doctors are evil nasty people in the hospital. There is no responsibility directed toward the family. There is no human responsiveness toward the family. And I don’t think you as a family should have to wait that long to get support, no thank you very much. You don’t have to be so ill, on the brink of death, to be seen.

Skirbekk, Middleton, Hjortdahl, & Finset (2011) indicate that within medicine, respect and trust make up the foundation on which to build a partnership in clinical practices. Our participants noted how feeling respected led to feelings of trust which were building blocks to having a partnership. In other words, mutual respect created trust between the three parties. It increased the sense of professionalism that a doctor displayed, and how invested he or she was in the loved one’s illness. Amy said:
It goes with the respect for the patient itself and respect for the family. But it also goes to say that when you are not showing respect for the patients and the families, you are also not showing respect for your own professionalism. Through my experience, I feel that that is not very comforting to know that this doctor lacks respect in all aspects. In the long run, and I don’t know about patients, but as a patient’s family member, when you are trying to make very important decisions, you don’t feel very comfortable having this professional involved. You don’t trust this doctor to do the right thing because it seems he is taking his job lightly.

She continues:

When you have no respect for the doctor or confidence in your doctor you don’t want that person as your doctor. It is a very scary thing to think that Doctor Y is treating patients. Because to be a doctor is not only about how knowledgeable you are but it is also about how much you listen to your patients. If you don’t care to listen then you probably are not going to give your patients the right treatment, or the best possible treatment or medications. There is also a higher chance of misdiagnosing. And I know that misdiagnosis happens a lot within the hospital and also with family practitioners.

In the narrative above Amy seems to highlight the dynamic link between respect, confidence, and trust, and the back and forth flow between the family-patient-physician triad. “You give respect to gain respect. And if you are not giving respect than you are not getting it,” Amy stated. Respect toward the one seeking care is a duty of the physician, posit McManus, Gordon, and Winder (2000). For Beach, Duggan, Cassell, and Geller (2007), it is an ethical obligation. Sokol-Hessner, Flocarelli and Sands (2015) state that physicians’ lack of respect toward the patient as a person is a “harm to a patient’s dignity” (pp. 550-551) and respect is about dignity (Sokol-Hessner et al., 2015). A lack of respect toward the patient and the accompanying family is a lack of respect for the profession. Perhaps this is what Amy refers to when speaking of a doctor taking “his job lightly.” This sentiment is echoed by The Working Party of the Royal College of Physicians who wrote that “patients certainly understand the meaning of poor professionalism and associate it with poor medical care. The public is well aware that an absence of professionalism is harmful to their interest” (2005, p. 5). For McManus et al. (2000) respect is an ethical standard of professionalism. The Working Party of the Royal College of Physicians further notes that, “Medical professionalism lies at the heart of being a good doctor” (2005, p. 5).
Amy noted how a loss of respect toward the physician undoubtedly led to loss of trust in the medical provider. Sadly, a loss of respect and trust in the physicians may impact patients’ outcomes (Bending, 2015). “The patient’s health may suffer following a betrayal of therapeutic trust vested where the patient may be not as likely to (a) accept the doctor’s advice due to skepticism, (b) disclose all the information that the doctor requires to make an accurate and timely diagnosis, or (c) seek future medical treatment except in cases of emergency” (p. 191).

For Emma, it had a lasting effect:

As a caregiver I look to the medical people very differently now then I did before. I don’t have the same respect for doctors that I used to have, and I question a lot more than I ever did before. I don’t like someone trying to manipulate me to do things in health care that either aren’t necessary or not explained properly. I demand an explanation. You have to convince me now that it is a good way to go. YES!! I think having gone through this experience makes you a bit more cynical about things.

According to Skirbekk, Middlethon, Hjortdahl, and Finset (2011), trust is established by such actions as showing interest in the patient as a person. It demands an attentiveness to the unique personal life narrative of those who are seeking medical care. Respect and trust are enacted by physicians not just by “being knowledgeable in modern medicine” (p. 1188) but by the manner in which they interact as human beings. Respect engenders a welcoming by offering time, attentiveness, sensitivity, and responsiveness (p. 1188). In the end, a partnership requires trust, and trust is built upon seeing one another, naming one another, and in the voice of the participants, by conveying a desire to know the other. The participants were very clear on how respect and trust could be embodied by the doctors providing care.

The partnership—the how: The practice of embodied care

Participants spoke of the importance of doctors’ gestures, bodily expressions, and movements in the unfolding of medical practices that engender caring responsiveness to the patient and the family member/carers. Amy attested to the power of gesture in treating illness. She said:

Communication is a very important thing in illness and for treatment. My dad did not speak the language but he could tell through gestures. Even with the
good doctors he would be more at ease with some doctors or more cautious with others. With other doctors it was: “I don’t think you should touch me.”

Smith (2012) who has written extensively on pedagogical practices calls attention to the power of gestures. He notes that “The basis of good teaching requires a more fundamental understanding of bodily sensibility that is lived, felt and experienced intensely” (p. 66). For Smith, a gesture “keeps the space of respect, affection, empathy and appreciation. It acknowledges not so much another’s place besides me, but rather the place we share alongside one another” (p. 69). Likewise, within medical literature, Toombs (1992) has written extensively on the what she calls “the body’s gestural displays” (p. 65) in the experience of illness. She defines gestural display “as an integral element in the many forms of social expression that we take for granted—standing, facing one another, shaking hands in greetings, gesticulation, and so forth” (p. 65), just as Emma, Anne, Ernie, Kate, and Amy remind us. These bodily gestures and actions carry powerful meanings (Toombs, 1992). Toombs notes that in the medical interaction a physician’s posture of standing up while the patient is sitting down emphasizes the asymmetry of the relation. More importantly, however, patients may ascribe meaning to such gestures as of one being “inferior.”

Toombs explains that a stance of sitting down side by side may diminish relational or status distances (pp. 62-64). Toombs writes:

Patients are likely to feel much less “inferior” if the physician sits down by the bedside, so that they are on the same level (eye to eye) when communicating with one another. (1992, p. 66)

Toombs (1992) also posits that in the physician-patient interaction such gestures may impact the patient’s dignity. She explains that while standing up by the patient’s side the physician has to ‘look down’ to communicate with the person to whom they are providing care symbolically emphasizing the helplessness or “dependency” of the one who is seeking care (p. 65).

We are situated beings, and as situated beings, we are always bodily connected to others (Marcel, 1964). Relatedness is our way of being in the world and this relatedness is always incarnated (Marcel, 1964, 1967). Embodied presence is always co-presence (Marcel, 1967). In
the face of cancer treatment, participants pointed to the importance of corporeal interconnectedness that was revealed in simple gestures, positions, movements, mannerism, and verbal expressions that we often enact in our day-to-day living. Emma said:

It only takes a moment to say to the person who is sitting beside their loved one: “We understand that you are in this process and you are in it for the long run and I’m glad that you are there.” I think that is what should happen. And I think that is huge. It is not for the doctors, but it is huge to the people on the other side of the desk. For the family unit, it is huge that they are receiving that kind of acknowledgment.

As Marcel (1964) proposes the other, the patient and family carer, should be received and welcomed by the physician corporeally. ‘Validate the person’ Emma says. To validate is to make another person feel “worthy, justified” (Merriam-Webster Dictionary) and “to recognize or affirm the worth of a person or their feelings or opinions (Oxford Dictionary).

What are the manners by which Emma as a family member is received by the doctor? What gestures affirm her worth, her value as a caregiver to the cancer patient? What are the manners by which Emma feels her affective experiences are recognized?

It is how doctors approach the family. So doctors: Introduce yourself. Shake my hand. Make me feel that I’m going to be part of whatever is happening in this room. And even if you put a hand out and even if it is not given to the patient, give it to the person who accompanies the patient, the person who is going to be responsible for the caregiving.

In the hand-to-hand contact, Emma perceives a welcome for her as the family member and the primary carer. To hear “I’m glad that you are here” is to be welcomed as a partner. To offer your name as you touch my hand, to extend your arm to reach mine, is to close the distance between you and me. As one hand reaches the other hand one feels the vital responsiveness in the skin-to-skin contact. These bodily connections say that you see me, you receive me, and you include me as a partner. Emma continues:

It is a case of just getting a chair! Sit down beside your patient. Make sure the drapes are closed, and do whatever is necessary to get in a more intimate space and say: “you know we really need to talk about this. Do NOT talk at them or pass them like you are not there. All the doctor needed to do was pull up a chair and say: “We need to have a discussion about our findings.” Not blurt out in a harsh voice: “You will never use your arm again.” Everyone has to be able to survive this cancer experience somehow including the grieving process.
Emma’s narrative suggests that the patient and the family member see themselves in the bodily acts of the physician. As the physician approaches the cancer patient, the act of grabbing a chair to sit by the patient’s side is an intentional movement that carries the meaning of nearness. It is a movement that creates a more intimate space where sensitive connections are made possible. As the physician approaches, he can move his arm to “close the drapes” ensuring the intimacy of the space where they meet. The physician’s motion of closing the drapes creates a sheltering space that surrounds and protects the family carer, the patient, and the physician. Such bodily acts carry a promise that the patient, the family, and the physician will move together through this journey.

Amy notes privacy is often scarce, yet tone of voice is crucial in conveying privacy. The low pitch and the quietness of the voice when important information is given demonstrates a quality of discreetness. The quietness by which words are uttered opens up a new personal meaning to the experience: caring and respect. The doctors cannot control how hospital rooms are designed, but they can control the pitch and loudness of their voices. Doctors can be touched by the patients’ needs, be aware of the limitations of the room, and offer privacy and respect by being discreet. Amy said:

Privacy is important. Oh yes, that curtain and lack of privacy [silence] is a level of respect. There were times when other doctors were there. But they were quiet, they were discreet because they know that they were only surrounded by a curtain and there were other people there. So they were discreet. Doctors have to be discreet because that is respect and it is something that the patient deserves and the family member does too.

To be discreet denotes care and respect. To lower one’s voice, to speak in a whisper or to change one’s tone of voice, is to realize that the situation requires something other than a normal conversation. It is a recognition that there is sanctity to that space, and reverence to that moment.

Sitting beside the patient, shaking the other’s hand, closing the drapes and being mindful of what is being said, are all actions by which the Other, the patient and the accompanying family, are seen and acknowledged as persons. For Amy, stances, gestures,
expressions and motions may convey respect toward the patient-family carer dyad, or the lack of it.

They have to address you as a person first of all! There needs to be a level of respect in acknowledging the person standing in front of you and that they are going through a very difficult time. And doctors need to know that because they are more knowledgeable about the illness than the family member or the patient, they need to be more respectful. You don’t want the doctors to talk down to you, right?

I think that anybody would like to know that they are important enough for the doctors to want to talk to them. We, the family members, are actual persons standing before the doctor. I don’t know how to explain it but sometimes on a day to day basis you can tell when the doctors are condescending and you feel less than a person.

It is significant that Amy uses the word “person” repeatedly in stressing the importance of being in illness. For Amy, physicians must view family members and patients as “actual persons,” that is, human beings who still feel and experience everything around them very intensely. It follows that physicians need to understand that the patient and the family member “are going through a difficult time.” For Amy, “to be treated as person” is to be “respectful” and to be attuned to what the cancer experience affectively means to the Other, to the family member of the patient.

Kay Toombs (2004) calls attention to this need to restore being into illness. At a societal level, as well as within technological biomedicine, the focus is on “‘doing’ as opposed to ‘being’” (p.194). Yet Toombs, a scholar living with a neurological disease for 30 years, asks the question, can we “just be” (p. 194) for the other. In illness, disability and disease, human beings are simply that—first and foremost” (p. 194). Yet how does a physician “just be?” asks Toombs. Perhaps, as she proposes, it is by being attuned to the affective experience of the other. Physicians can “be” by treating the family member as a person.

Family carers want to be seen as human beings, and in Amy’s words, beings “important enough that doctors want to talk to you.” Yet, Amy spoke of some physicians as “condescending.” She notes that some physicians “talk down to you” and being spoken to in such a “condescending” manner makes one “feel less than a person.” “To be treated with
dignity is to be treated with respect, to be considered worthy of the regard of the other” writes Toombs (2004, p. 193). “If, by your actions, you demonstrate that I am worthy of regard, no matter what the circumstances, then you affirm me in a powerful manner” (p. 195). Amy said:

I think that doctors should have patience with family members and be amenable because the family members are trying to process all the information. The doctors need to be available and have patience when educating the family member. I know there are pamphlets but it is not the same. And make the information available and have discussions, and inform the family member what is going on in terms of the cancer. The doctors need to have an understanding of what the family member is going through and know how to care for them.

Perhaps this is what Amy suggests in terms of being a person who is worthy of talking to, and in a manner that is not “condescending.” It makes her feel valued as a person and this restores her dignity.

The doctors and the family have something in common: caring for the cancer patient. For Best et al. (2015) an important goal of cancer medicine is the very “relief of patients’ suffering” (p. 1335). Amy believed it was important “to be patient with” and “available” to the family member. Family members must almost immediately assume the caregivers’ role at the same time they are trying to make sense of an acute cancer diagnosis, prognosis, and treatment. Cancer treatments can be harsh emotionally, financially, and physically taxing. Thus, for Amy, doctors should be attuned to the impact of cancer on the other person who is caring for the patient—the family carer.

Anne, suggests that dignity is to offer explanations in a manner that is not condescending. Amy’s narrative below is exemplified in Toombs’ words when writing about dignity in illness that “we are urged to clothe ourselves with compassion, kindness, humility, gentleness, and patience” (2004, p. 197); values that can be shown in acts, ways of being-in-the-world with others (Toombs, 2004).

Interviewer: What would you tell the doctors about the family entering the cancer experience?
[Long Silence from Amy]. It is hard to think. There is such a long list of things. There is not one concrete thing that you feel or that you want the doctors to do. It is not a list that says you should do this or do that. It is almost that you just want to say to the doctors: “Can you just care?” [Strong voice]. Maybe this is mean. Just tell doctors to remind themselves that even as a doctor this could be you.

Because all of a sudden when you see it in that light it is almost that compassion will come or at least you will assume that it will come. So yes, if you just place yourself in our shoes, what is it for the family member to go through this, and what it is it for everyone going through cancer treatment. Ask how would you like to be treated? I feel if the doctors have that experience then everything else will follow. If you have the experience you know how you want to be treated. You want to be treated with respect. You want to be treated with kindness and compassion and empathy. You want to be treated as a person. You want to be understood. That is what I would like to tell the doctors: Just start walking in our shoes.

In cancer the present is tied to an uncertain future that is almost instantly associated with images of death and “decay” (Gordon, 1990). The family member and the patient are together thrown into the space of illness unexpectedly and with little knowledge. Cancer has robbed the patient and family of temporal security. They live in a present without a future, and to offer them respect and dignity is to be aware of this loss. At the same time of this personal upheaval, the family carer also needs to provide support to their loved one.

The words of the family member highlight the need to see the family as a unit, as a whole, and as a partnership with all those caring for the patient. A partnership requires respect and trust. Foremost it requires a welcoming, being seen, and acknowledged as a partner in the care of the patient. Physicians must see the family as being there for the benefit of the patient. To build this partnership does not take much more time from the physician, or create an unbearable cost to the system. Anne, Emma, Kate, Ernie, and Amy remind us of the power of small, everyday, gestures by which we invite the other as Other to the medical space. “Look at them in the eyes” is Anne’s plea. Amy in turn said:

The doctors may not be able to control the disease as much as they would like to, but the doctors can certainly control how you are treated. And I don’t think it is hard to do this.
An ethics of service is embodied in concrete gestures and acts (Toombs, 2004). “Hold a patient’s hand,” said Anne. For it is in the holding of the hand that the patient and the family know they have entered a community of caring and service (Toombs, 2004).
Chapter 9.

Conclusion

My own long journey of learning suggests to me that we need to challenge existing models of professionalism. The Western model rests on foundations of biomedical approach, rational detachment, and objectivity...We need to encourage mutual support and shared learning among our different professional groups and between caregivers, patients, and their families. When we do all these things, we create a sense of togetherness. (Dr. Youngson, 2011, pp. 44-46)

The purpose of the present study has been to describe family member-physician interactions from diagnosis through treatment to end-of-life stages of cancer care. Family members have increasingly assumed a critical role in terms of treatment support, where the welfare of the patient is now entrusted to these carers’ hands (Longacre, 2013). It is thus natural that family carers seek a meaningful interaction with the physician whom they see as a resource and guide in the provision of crucial information and support (Dresser, 2011). Family carers spoke of this support as being vital to fulfilling their caregiving role. How the family manages the hardships that come with cancer and cancer care has important consequences for patient health outcomes. As a cancer carer myself, I was often left to wonder what it was like for the families around me to navigate the cancer journey. How might this crucial moment-to-moment interaction with the physician have taken place for the family caregiver? What was the moment-to-moment dialogue between the doctors and the family carers as they accompanied their loved ones through treatment? This thesis sought to explore these family carers’ experiences of physician care.

The study

My goal has been to understand the dynamics of interaction between the physician and the family caregiver. I am interested in making apparent to others the affects and effects of actual interactions between cancer caregivers and the attending physicians. Five caregivers—Anne, Emma, Ernie, Kate, and Amy—volunteered to participate in this interpretive, phenomenological inquiry. They were caregivers for periods of time
encompassing a few months to five years, until death, and for a variety of cancers (oesophagus, mouth, blood cancer, colon and breast cancer). My goal has been to attain rich and in-depth narratives of the qualities of family member and physician interactions. As stated in chapter three, methodology, I am not concerned with providing an hypothesis, seeking empirical generalizations or inferring causal explanations. Rather, using van Manen’s words (1990), my intention was to uncover the deep and lasting meanings of the everyday experience as lived by family carers and, in this way, extend the current and limited body of knowledge on the relational dynamics of extended cancer care.

The present hermeneutic, phenomenological inquiry involved thematic analysis of verbatim transcriptions of these caregivers’ recorded interviews. This inquiry stemmed in part from my own lived experience. Thus, my stance as a researcher was one of being deeply aware of my presuppositions and assumptions of cancer care. I engaged in a thoughtful process of reflexivity, journaling throughout the entire research process. I immersed myself in the available literature and kept notes of emergent themes throughout the inquiry. van Manen’s (1990) thematic analysis allowed me to identify themes and sub-themes that arose from the narratives of these participants. van Manen (1990, 2014) notes that phenomenology is a writing and re-writing process. And so, I immersed myself in the data, listening and re-listening to the participants’ voices, going back and forth as I wrote and re-wrote the text. “To write is to reflect,” writes van Manen (2014, p. 20). “Phenomenology aims to evoke insightful descriptions of the way we experience the world” (p. 66) and thus show how these family carers experienced the world of relational contact with the medical provider.

Cancer can be viewed as a defining moment in most people’s lives. This study gives access to these “nodal moments” (Stern, 2004, p. 173) in each of these five caregivers’ lives. The data gathered revealed rich, personal details of the day-to-day experience of these five family caregivers as they interacted with the physicians providing care for their loved ones. Through in-depth conversational interviews these caregivers could speak for themselves and thereby let us enter their private worlds and begin to understand what it is to be supported or not by physicians when a loved one undergoes cancer treatment. The use of open-ended questions allowed for the free exploration of the experience. I asked few questions and kept my probes
to a minimum since I was cognizant of avoiding interruptions. Consistent with van Manen’s guidance, I invited all participants to engage freely in conversation rather than in a formal structured interview. I left time and location selection to the participants so they would feel comfortable in openly sharing and exploring what the cancer experience meant to them. These are intimate narratives, deeply felt, deeply told by these five caregivers that invariably drew attention to the quality of family-caregiver-physician interaction.

These rich narratives may not have been captured had I used a methodology of data collection on a larger scale, such as a survey. Although quantitative research is valuable, such research would also not have tapped into the in-depth intimate accounts that these participants offered. The strength of this study lies in its ability to uncover rich personal accounts, allowing others to hear the voices of those who have already taken the cancer journey. These caregivers’ experiences speak to others who, when reading these narratives, may recognize the stories as their own and can say, “yes, I felt that way too.” Such personal and intimate details can only come through a small number of participants. I did not seek a narrow and positivistic methodology that would generalize the findings. My aim, rather, was to get into the emotional crevices and relational spaces of how one experiences the interactions between the attending physician and the caregiver. How are these interactions lived, felt, sensed, and seen during cancer treatment?

This study’s text not only speaks sonorously but also through the feelings and emotional tones the described gestures provide. Meaning is inherent to bodily gestures, actions, positions, stances, and motions. Our gestures are a source of expressive meaning. What loss, for instance, did these participants feel every time they were dismissed by the doctor, every time a doctor turned his back, looked away, or stared at a clipboard? What did they gain when a hand touched their shoulder, a smile greeted them, or a physician stopped to speak to them? These narratives are about personal gain and loss, of “defining moments” that shape these participants’ lives long after hospital, palliative care and hospice care has finished. These transformative moments, or turning moments show the potential for restoring healing, humanity and dignity to medical practices (Reid, 2012; Youngson, 2011, 2012).
My aim was to write an evocative phenomenological text (van Manen, 1997) that “summons” (p. 260) the reader to deep reflection on these participants’ experiences. “Evocation means that experience is brought vividly into presence so that we can phenomenologically reflect on it” (van Manen, 1997, p. 353) such that “words become ‘images’” (p. 261). It is through evocation that the text “speaks” through “images and sensibilities that are so crisp and real” (van Manen, 1997, p. 354). I call the family carers’ experiences into being through my writing in the hope that their stories will resonate with readers and thus bring about “an emotional sensibility of recognition” (van Manen, 2014, p. 262). This is the phenomenological power of such a dissertation: that is, it generates intimate, personal, embodied knowledge.

My approach to the study was also guided by the work of Daniel Stern (2004) who maintained that the work of the practitioner in the clinical relationship is situated at the “micro level made up of moments that occupy a subjective now” (p. 135). The practitioner in psychotherapy focuses “intensively on understanding intersubjective meetings in the present moment” (pp. 139-140) where “a world in a grain of sand” (p. 138) is revealed. Present moments are recalled as if they are lived presently and “are being verbalized almost as they are happening” (p. 139). As a practitioner, I am committed to being fully present in the session. My intention was to bring my whole self in connecting to the transcripts just as I do in psychotherapy sessions. I listened attentively to the participants’ voices and approached the narratives with an attitude of openness, presence and clinical sensibility. I was conscious of putting aside previous knowledge and biases as a practice that is essential to therapy. I was attentive to the text and the story being told. I asked myself how each narrative informs me of the present moments lived by these carers. What did the excerpt reveal? What did I hear? I contemplated the possibilities of human connection that the participants’ stories might reveal.

I was mindful of “the smallest remembered happening, feeling, thought, or action” (Stern, 2004, p. 229) that were implicitly or explicitly revealed in the excerpts. What do these narratives tell me of the “shared intersubjective field” (p. 243) between the carer and the physician as it was being enacted by these carers? How was the interaction lived within “affectively charged moments” (p. 245)? In the space of meeting one another, just as I have
experienced with my clients, the family caregiver and the physician “are both pulled forcefully into the present” (p. 245). It is in this space that they “work together and are together” (p. 245). I listened carefully and became attuned to the sentient registers of carers and physicians in being together-with-one-another. Would the participants’ voices reveal moments of “crisis” that “resolve into moments of meeting? (p. 245). Or would they unveil moments of “missed or failed opportunities” (p. 245) to expand the intersubjective space of relatedness?

Stern (2004) highlights the crucial importance of implicit knowing and nonverbal nuances in clinical situations (p. 145). Implicit knowing not only involves gestures and movements but also “affects, expectations” and “what lies between the lines” (p. 114). “All present moments involving intersubjective contact involve actions, a mutual gaze, a postural change, a gesture, a facial expression, a respiratory change, or a change in vocal tone or strength” (p. 145). As I immersed myself in the transcripts I was mindful of the “paralinguistic contouring” (p. 145) conveyed by the narrated subjective lived experience. What is implicitly revealed? What would these carers tell me of the mutual gaze as they interact with physicians? What gestures or facial expressions are revelatory of caring responsiveness? What gestures of sensitive receptiveness come to life from the text?

[Life between people is directly lived to a relatively small scale: a sentence, a pause, a facial expression, a gesture, a feeling, a thought…We call this small scale the local level. It is where present moments emerge. (Stern, 2004, p. 149)]

As I read the text I was mindful of the “small scale, micro, local level of the interaction” (p. 135). I reflected on the nuances of action, motions, and interactions that may be revelatory of compassionate understanding. I paid attention to sentences, pauses, implicit and explicit feelings that might be revelatory of heightened responsiveness, or simple nuances of presence. This approach guided me throughout the present inquiry and brings me to the findings of the study.

**Summary of the findings**

The narratives of these participants reveal that a cancer diagnosis and the treatment that follows brought drastic changes to these participants’ lifeworlds. The cancer diagnosis
was a sudden, unexpected event for all the participants. Most participants recounted that their loved one had until that point enjoyed reasonably good health, without symptoms suggestive of cancer. Still for most participants the diagnosis was one of advanced or metastasized cancer, that is, cancer in which treatment protocols are likely to be harsh and highly complex. Then, once the daily realities of cancer treatment set in the family carers sought guidance from the physician in order to provide emotional, physical, and instrumental support to their loved one. They sought support, acknowledgment of their presence and recognition of the turmoil and hardship that cancer brings. They sought an interaction with the physician that would provide them information about prognosis, treatment alternatives, or other information they considered crucial to decision making.

Despite their daily presence at the hospital cancer ward, and the impact of cancer, most participants said they felt “invisible” and that their presence was “unrecognized” by the attending physician. Family members came with an expectation that the attending physicians would acknowledge them, their role as carers, and their need for help in an unfamiliar environment. The patient and their caregiver “look for reassurance and kindness from their physician, but what they receive often feels impersonal” (Nyima & Shlim, 2006, p. 4). Most participants in this study said the physician-carer interaction was characterized by distance where they, the family members, were neither “seen, “spoken to” nor “heard,” even when the physician saw their daily vigilance by the patients’ side. Some family carers used expressions such as “I was invisible,” “I did not exist,” “you are of no consequence” or “I did not matter” when referring to their interactions with many physicians. There was for the most part, “no contact.” Participants described being objectified and dehumanized: “you are just a number,” “you are nothing,” “you are just a figure” or a “category: a daughter.” This objectification and nullification seemed intentional to them.

Most participants noted that there was little or no eye contact, no smile, no gentle touch, or any movement towards them. Cancer care was contained mostly to brief and abrupt physician interactions. Given the catastrophic nature of their loved one’s disease, “compassion is assumed” in the space of healing, write Nyima and Shlim (2006 p. 2), yet many participants used expressions such as “no compassion,” “no empathy,” and “no humanity” to describe
their interactions with physicians. They spoke of the cancer journey as a “lonely journey” in which they sought someone who might guide them through a landscape where “everything becomes dark” and “the world goes down.”

Too many physicians turned away from the family members, creating situations and spaces that were tense and stressful. Turning away included not providing even the most basic of information. Participants’ narratives revealed an unwillingness of the physicians to share crucial information that would help the family be effective caregivers. Participants used words such as a “wall,” a “block,” and a “closed shop” to describe the physicians’ responses to their appeals for information. When information was provided it often came filled with jargon, was kept brief, had little regard for the privacy and sensitivity necessary and, as some participants noted, was given in a dismissive manner. The perceived unwillingness by the physician to collaborate with the family carer was seen as a form of intentional disrespect from the physician. This disrespect in turn created distrust, hostility, and disrespect towards the attending physician(s).

It is also the case that in the inhospitable space of the hospital, three participants spoke to the power of a doctor turning towards the family members’ appeals. Participant narratives highlight the power of small gestures and the nuances of caring presence: smiles, eye contact, a touch, or a handshake. These small but powerful offerings say “I am here!” (Marcel, 1967, p. 205), close the distance between family member and physician, thereby acknowledging the former’s presence, distress, and vulnerability. “It doesn’t take a lot” voiced one participant, “but for the family it is huge.” These common bodily expressions and gestures engendered a caring attentiveness and sensitive responsiveness to the patient’s and the family carers’ cancer experiences. These gestures created bridges to true moments of meeting between human beings. These participants speak of the power of embodied actions, motions, stances, and facial expressions in enacting compassionate care. Their effect creates the perception of a physician either turning away from caring or turning towards in an act of compassion.

Participants spoke of how some doctors gave of their time to explain results, to stand with them, or to simply be with them, thereby creating the “in-between space of you and me”
Participants spoke of physicians offering the gift of compassionate presence that allowed them to be emotionally open and available to the family. In this act of giving, a co-presence is created that is an unfolding of the “we” (Marcel, 1963, 1964). It is in those moments of the “we” that the physician is attuned to the suffering of the family, and the family members are attuned to the emotionally challenging work that oncologists and other medical specialists face. This develops a mutual recognition and compassion for the other, relieving the strain of the situation for all those involved, even if just in that moment.

Limitations of the study

My goal was to provide an opportunity for family caregivers of cancer patients to reflect on their experiences and, in this way, to build knowledge through the stories that people tell, particularly because the voices of the family members are so infrequently heard in cancer literature. I was concerned with bringing to life, as much as possible, the lived experience of those interactions that routinely take place between family member caregivers and the physicians.

Participants in this study were comprised of a sample of five women, and thus the study reflects only the stories of these five women. Several scholars have pointed to the importance of the ecological and historical context in which cancer unfolds (Cox et al. 2012; Longacre, 2015; Zaner, 1990, 2015). The descriptions of these family caregivers are complex and reflect a specific time in which they lived the cancer experience. At the time of the five interviews, all the participants’ loved ones were deceased. As such, the participants all shared the experience of loss. Had the treatment outcomes been different, say, where the patient had gone into long-term survivorship, I wonder if their narratives might have been different? This study’s findings encompass only the lives of five participants in a precise temporal horizon and within the limited interview-time of ninety minutes to three hours with the researcher. The findings are thus unique to these women’s lifeworlds and cannot be extrapolated empirically to other populations.
The participants were of very similar socio-economic status (SES), gender, ethnicity, educational background, as well as having a similar quality and type of relation to the cancer patient. All participants were from a middle class social background. Four of five participants had post-secondary education and one had only completed high school. All participants were caregivers of a parent. Consistent with the extant literature, all participants were women (Kim et al., 2015). That is, caregiving continues to be largely shouldered by females. It would be interesting to explore whether the experience is lived differently by men. In terms of ethnicity, except for one participant, all other carers declared their ethnicity as Caucasian or of western European ancestry. In terms of the quality and type of the patient-carer relationship, all participants were daughters and all disclosed that they had strong emotional bonds with the patient prior to the diagnosis.

Given such an homogeneous background, one may wonder how this experience might be lived by caregivers, for example, from a lower socio-economic status where additional financial constraints and stressors might exist. I wonder whether the act of approaching the physician, seeking information, and the quality of the interaction might be different if participants had come from a lower educational attainment. Cox, Nackers, Young, Moreno, Levy, and Mangione-Smith (2012) noted that SES impacts the level of physician-family engagement in terms of “relationship building, information exchange, and decision making” (p. 319) and such impacts were independent of ethnicity. Yet, generalizability of findings is not the aim of phenomenological research, nor of this study (van Manen, 1990).

As the research question came, in part, from my own experience as a family caregiver in cancer treatment, I attempted to bracket my previous personal knowledge, suppositions, pre-assumptions and beliefs. But total bracketing is impossible (Kleiman, 2004; van Manen, 1990, 2014); interpretations are always subjective. The hermeneutic-phenomenological inquiry assumes the subjectivity of the interpretation and recognizes that interpretation and understanding are always subjective and personal (Gadamer, 1989). Accordingly, I tried to keep a stance of openness and naïve curiosity to “see” things as they appear; however my stance as a researcher is justified by van Manen (1990) who argues consistently that the
researcher’s biases can never be totally excluded from the research process. My own experiences with cancer, my background as a counsellor, and my experience as a family caregiver, might have influenced, for example, the organization or interpretation of the text.

Though I used clear methodological guidelines as proposed by van Manen (1990), almost invariably and indisputably it is I, the researcher, who decides, for example, the phrases, expressions, words and phrases of key significance and who determines the themes that best express such significances. Hermeneutic phenomenology does not claim objectivity or assume that the reality out there can be captured independently of social and historical considerations, and personal beliefs, assumptions, and prejudgments.

Van Manen (1990) reminds us that phenomenology is “discovery oriented” (p. 29), yet our discoveries are always incomplete. Recently, in October 2016, the British Columbia college of Physicians released a policy paper titled *Circle of Care: Supporting Family Caregivers in BC* outlining the need for medical practices that recognize the personhood and humanity of the patient-family caregiver and physicians. It calls for physicians to provide leadership and advocacy to recognize, acknowledge, and offer emotional support to the patient and the family carer affected by illness (Doctors of BC, 2016). Considering this focus on humanizing medicine, it would be worthwhile to explore physicians’ own voices in terms of the potential barriers they encounter in cultivating compassion in medical practice. What systemic barriers might be identified? What role does the hidden curriculum play and how might it impact the quality of the medical interaction and how it is lived?

It is quite possible that hearing from physicians themselves may help us to gain further insight into how we may begin to enact compassion in the biomedical space of care. As stated in the introduction, this phenomenological study is the starting point for a larger conversation where differing perspectives may be explored, namely, those of health care professionals, patients, caregivers, and all who take part in the medical interaction. It is the hope of this researcher that going forward we may explore, from the physicians’ vantage point, the barriers they may face in reconciling their biomedical way of knowing with the
healing aspect of medicine that incorporates compassionate care in medical practices and that, in turn, fosters a true patient-centered and family-centered care.

**Implications for practice**

*To be technically right, a decision must be objective; to be good, it must be compassionate.* (Zaner, 1990, p. 315)

van Manen (2014) writes that a “phenomenology of practice” is about “the everyday practice of living” (p. 15). Entering into the private lifeworld of these five caregivers points to both the need for a new gaze and a new clinic, and highlights the shortcomings of the clinic as it currently exists. As Foucault reminds us, the Cartesian clinic is alive and well, and thriving in current biomedicine. Within this Cartesian clinic, the medical gaze continues to abstract and dissect. The first to be dissected are those who accompany the patient, namely, the family members. Patients remain cases reduced to body parts in need of repair. The clinic continues to separate those who have the power to speak and to know from those who do not, and this is enacted daily through physician actions, patient treatments, and consideration for family members. Clinical physicians are, in turn, reduced to performing the functions of their profession which are long removed from the personhood of the healers to which they once aspired.

Yet these five caregivers’ stories speak to the possibility of real change within the very definition of the clinic, and of the cultivation of practices that are respectful of the wholeness of all human beings affected by the illness. Their stories speak to the power of small, everyday gestures, of body positions that afford relational dynamics suggestive of a deep sense of presence, and expressions of welcoming invitation. These caregivers envision a new clinic that transcends the objectifying gaze and embraces intimacy and togetherness in healing.

This present study uncovers possibilities of a new paradigm in healing and understanding illness—a new way of being as a patient, a family member, and a physician within a clinic that is both hospitable and humane. A different gaze is required and one that illuminates the lost art of medicine. It is a gaze that seeks healing even when cure is not
possible. Respect, compassion, and humanity are found in the luminosity of this new gaze. In the everyday living of cancer treatment, how do we, as practitioners develop this gaze? How do we begin to enact sensitive, compassionate and responsive relationalities of care that dignify the space of illness?

Dr. Anna Reid points out that change must begin with the physician.

I have seen both as a doctor and as a family member the consequences when care revolves around providers, rather than the patient. What those experiences crystallized for me was that, yes, we must advocate for change, yes, we must speak out on the issues, and yes, we must partner with others. But Health Care Transformation begins with us – physicians. (Dr. A. Reid, Canadian Medical Association, 2012)

Below I propose the following implications for physicians, for other health care providers, and family members themselves:

**Implications for physicians**

*Acknowledge the family caregivers as partners in care*

The family is critical to the unit of care and must be acknowledged as key to the overall health outcomes of cancer patients. They are entrusted with, and shoulder much of, the caregiving throughout cancer treatment (Pennbrant, 2013; Ekstedt et al., 2014; Shin et al., 2013). The family will ultimately carry out the complex care of dispensing medication, feeding and maintenance of medical equipment, wound care, emotional support, physical therapy, transportation, and end-of-life care and arrangements. Physicians should be sensitive to the impact of not acknowledging the caregivers as a “crucial link.” This may create a “double hurt” for the patients in facing a catastrophic illness while also witnessing their families receiving little support or guidance in the caregiving, even as they face numerous emotional, physical, and financial hardships along the cancer journey. Furthermore, the exclusion of the family as a vital collaborator can have negative ramifications for patient care in terms of quality of life, treatment, adherence, misdiagnosis, ineffective pain management, as well as family and patient satisfaction with physician care (Mazor et al., 2013).
The participants in this study spoke to the importance of being ‘seen’ as ‘true’ partners in care. Family carers see themselves as the voices of the patients when the patients cannot speak, and as the eyes of the doctors when the doctor cannot be there (Riley et al., 2014). Thus, the role of the family as partners and collaborators must be recognized by the physician right from the first interaction between physician, patient and family member.

**Acknowledge the interaction**

I propose that physicians must acknowledge and be mindful of the power of the interaction. As Stern (2004) reminds us, the interaction is the moment of possibility where sensitive actions can open the door to partnership. From the first moment of meeting, physicians should be mindful of how their gazes, gestures, and stances affect the tone of the interaction between themselves and the patient and family. The quality of the interaction is critical because good patient care requires a recognition that family carers take on complex caregiving tasks with no prior knowledge of how to do it (Longacre et al., 2015). Physicians should be sensitive to the fact that the carer is likely to be undergoing considerable stress and turmoil, while having to project a stance of strength to support the patient (Thomas et al., 2002). It is thus the duty of the doctor to support the family carer with compassionate guidance.

**Provide information in a timely and sensitive manner**

Little attention has been paid to caregivers’ specific informational needs...Yet a caregiver is expected to learn new illness-related terminology, enter the new treatment setting with the cancer patient, and participate actively in treatment decision making. (B.C. Ministry of Health, 2015)

An important finding of this study is that families see the provision of information as imperative to the tasks of caregiving. I thus propose that central to an ethical clinical practice is the duty to provide comprehensive information to the family. Although physicians’ time is scarce, physicians should be mindful that families place great importance on receiving information directly from the doctor, and not from other health care providers. In this study family carers spoke to the importance of being able to speak with their physicians about treatment options, prognosis, quality of life, and other variables that impacted their loved ones’ outcomes. Some of the participants spoke of rarely seeing the physician or feeling that they
were barred from speaking to them. Physicians should be mindful that their physical presence and availability to the family is critical to the provision of information and compassionate care.

Physicians should be attentive of the family’s need to receive information in a timely manner and that information should be provided in a language that is clear and free of jargon. Physicians Kearsley and Youngson note, “Hospitals are large, impersonal places… where staff often have too little time and often speak with the foreign tongue of medical jargon” (2012, p. 458). Information should also be given in a manner that gives dignity to the gravity of the situation and to the depth of the trauma that patients and families are facing. Physicians must be sensitive to the physical space where information is being disclosed, when possible ensuring a private space for patients and families to receive potentially dire information. Information provision in a manner that is tactful is perceived as bringing compassionate understanding to the medical space that patients, their caregivers, and the physician inhabit.

Physicians need also to be mindful that when the carer’s informational and compassionate needs are not met this may lead to a sense of heightened distress in an already highly distressed circumstance. Heightened distress, in turn, can lead to hostility in the caregiver-physician interaction which in turn increases distrust in the medical provider and can potentially impact the patient’s outcome. When information was provided in a manner that was compassionate, it led to trust, respect, understanding and appreciation of the emotional and spiritual demands that physicians working in oncology face day-to-day.

**Show compassionate gestures in everyday practice**

*Over time, I have gradually reconceptualised my role as that of a caring human being first, and an expert second. That enabled me to be much more humble and respectful, to listen patiently, and to bring much greater compassion and humanity to the relationship. (Dr. Robin Youngson, physician, 2011, p. 43)*

An unexpected finding from these participants’ narratives was the importance of intercorporeal affectivity. Physicians’ compassion was lived and revealed corporeally. The perception of a physicians’ caring presence and of compassionate understanding was enacted through gestures, facial expressions, touches, tones of voice, and motions such as a handshake or by gestures that accompany verbal cues of attentiveness and kindness. In the words of these
participants, compassionate caring is embodied in a smile, a touch, a handshake, a bow, a nod, eye contact, a caring movement, and these motions humanize the space for those living in it: the family, the patient and the doctor. Gestures, utterances, movements, and positions are perceived as the physician being present for the family. Such gestured interactions allow for the creation of a collaborative space where family members feel seen, listened to, understood, valued, and treated as human beings. Gestures of presence also engendered feelings of trust, caring, togetherness, and compassion.

Importantly, these gestures take little time to enact, yet they carry great power in the interaction. As Tardy (2015), a physician contends, “eye contact, listening, touching” (p. 230) are an “effective, inexpensive, and easily administrated medication to employ in both the sick and those who simply experience foreboding in medical interactions” (p. 230). Compassion can also be evident in attitudes of attentive listening to the family and the patient. In the voice of the participants, it is a particular way of listening and one where the professional does not rush or is dismissive of the interaction. Active listening not only has a powerful healing effect (Mazor et al., 2013), it also carries the message that the physician does “care.” It is important to add that physicians’ compassionate bearing becomes critical when disclosing bad news, which is frequent in the cancer trajectory, and even more so as death approaches. Gestures of presence may facilitate the grieving of the family when death occurs. Doctors should be mindful that through gestures of compassionate presence patients can have a peaceful death as they observe that their accompanying family is being seen, acknowledged, and supported. Moreover, compassionate gestures facilitate the bereavement and future well-being of the surviving caregivers.

I propose, therefore, that physicians working in specializations such as oncology make themselves aware of the importance of their own corporeal bearing. Physicians should be cognizant of the power of their voices, their motions, attitudinal attentiveness, and the affectivity enacted through their gestures. A perceived lack of compassion can also be enacted through the body, even when the intent might be the physicians’ self-protection and ability to cope with impending patient deaths. Subtle or overt gestures—an averted eye gaze, lack of eye contact, or physical and emotional unavailability such as showing up late for patient/family
meetings, or not showing up at all, may make the family perceive the physician as uncaring and in turn foster distrust in the physician. The lack of a corporeally compassionate presence leads to lingering resentment and lingering distrust of the medical profession by the family members long after the loved-one has died.

A different clinic and a new gaze are enacted through gestures of compassion. Beyond the biomedical knowledge that permeates current medical education and practice, bodily expressions of welcome, of reaching out, of support and care, create the possibility of human contact beyond the pathology of the disease. The worth and dignity of all those meeting in the space of cancer care are respected. Physicians play a crucial role in the enactment of gestures of presence, availability, and sensitivity responsiveness in illness. Yet in cancer treatment the presence of allied health care professionals cannot be over-emphasized. Ancillary health workers are part of the relational milieu in which illness and suffering unfold. Therefore, in proposing implications for practices I widen the circle to include not only physicians but also ancillary workers such as nurses, clinical counsellors, social workers, etc. Including these other health care providers draws attention to a more distributed agency, to a shared response-ability for cultivating gestures of compassionate response to suffering in the context of serious illness.

**Implications for physicians and all health care providers**

**Be present in the moment with the family and patient**

*Now I have learned to be still and to listen. Sometimes, quiet presence without anxiety is the most profound intervention...We don't need to fix it or hide it, just be present and share our common experience of humanity. (Dr. R. Youngson, physician, 2011, p. 44)*

Stern (2004) proposes that we "look...through the magnifying glass of the present moment and from a phenomenological perspective. This altered vision will lead to changes in how we think about our work and what we do from moment to moment" (p. 135). I am mindful that a lived story unfolds in the counselling session. As a therapist my clinical and philosophical commitment heightens my awareness of the power of being present with-and-for-the-other. For Marcel presence involves openness and availability. I am aware that to be open is to receive the client and the affective story that unfolds. This openness demands no
pre-conceived assumptions, theory, but an attitude of non-judgement. As I enter the counselling session, I fully immerse myself in the experiential world of the client. I offer my resources, but I am also open to receive what the other offers. I listen deeply and without pre-judgements, to the person’s unique subjective experience, and I respond sensitively. I participate fully in-the-moment with the client. Such engagement requires personal commitment and an attitude of reflectivity: mindful awareness of the humanity of the person who faces us. It requires calling the other, the one who suffers, into presence (Marcel, 1963).

The therapist may say something very minimal…But the therapist says it in a special way with a special tone of voice that has overtones of empathic understanding, of dipping into their own world experience and expressing that, of standing alongside the patient in this moment of painful reappraisal…In other words, the therapist creates a moment of meeting…Sometimes this takes the form of an affect attunement. (Stern, 2004, p. 189)

I need to be attuned to my inward bodily sensations. It follows that before I receive the client, I turn inward. I pay attention to my body. I am aware of my sensations and emotions. For a few minutes, I turn my awareness to my breathing. As I walk the hall to greet the client I place my attention on my steps, attuned to let go of any mental distraction as I press my heels into the ground. I turn my attentiveness to what my stance, my smile, the tone of my voice, my posture, might reveal. I contemplate how my bodily enactments might impact the “intersubjective field” (p. 124). As I sit with my client I turn my awareness to my body and “what meaning my movements and actions” (p. 145) convey to the one who faces me. What is “carried in the tone of [my] voice, [my] gaze, and [my] manner of moving” as I greet the client (p. 146). Are these expressions of responsivenes and sensibility and fundamentally of being present? Or do they convey a presence of absence, “missed and failed opportunities” with negative therapeutic consequences” (2004, p. 176).

Cultivate presence daily

I practice daily a few minutes of such reflectivity and grounding so I can feel centered. Reflective, mindful breathing allows me to be centered in myself and to be more in tune with clients’ bodily cues. It also allows me to enter into the power of the “now” (Stern, 2004, p. 3). “We are subjectively alive and conscious only now. Now is when we directly live our lives”
“That is where and when mutually aware contact between the minds of the therapist and patient takes place” (p. 3). In the present moment, where real human beings meet, we have opportunities to simply be present for the other. “You have your own experience plus the others experience of your experience as reflected in their eyes, body, tone of voice, and so on. Your experience and the experience of the other need not be exactly the same” (p. 125). Yet, it is in this moment of presence, that I as a therapist share the “rich, emotionally lived” (p. 172) world of my client. Presence makes the “moment of meeting” possible. Being in the moment with my client does not demand a “technical response” (p. 168). Embodied presence summons a deep contemplation of what it is to be open, available, and attuned to the other (Marcel, 1967).

[They] found themselves look[ing] at each other intently. A silence prevailed. The therapist, without knowing exactly what she was going to do, softened her face slowly, and let the suggestion of a smile form around the mouth. She then leaned her head forward slightly and said, “Hello.” The patient continued to look at her. They remained locked in a mutual gaze for several seconds. (Stern, 2004, p. 168)

Presence is what is remembered writes Stern (2004). It constitutes the nodal point” (p. 169) in therapy where the client sees the therapist “truly open to her” (p. 170). Presence, reflectivity and mindfulness is what I, as an instructor, pass on to my counselling students.

**Provide somatic awareness, reflectivity, and mindfulness training**

To step aside from the expert role and to bring the quality of compassionate, non-anxious presence requires a great deal of inner work. Humility and non-judgement are important qualities. As the inner resources are cultivated, so one develops greater mindfulness, presence, patience, gentleness, and a powerful sense of meaning and purpose. (Dr. R. Youngson, 2011, p. 44)

For Nyima and Shlim (2006), compassion can be cultivated. Contemplative traditions affect and change neural/brain activity (Youngson, 2012). Like the study of medicine, a cultivation of compassion involves a commitment (Nyima & Shlim, 2006). The cultivation of compassion requires awareness, “some effort” (p. x) and is “a lifelong pursuit” (Nyima & Shlim, 2006, p. x). “Compassion is a result of consistent daily practice” (p. x) and a state of awareness where the mind can let go of thoughts. Yet, “[s]imply feeling the desire to be more compassionate is the first, powerful step toward achieving this goal” (Nyima & Shlim, 2006,
It may be that by a simple change in the awareness of the present moment, of our own mental state, our own bodies, and our thoughts we may begin to change how we embody our practice of compassionate care for ourselves and for others. From a moment of awareness may come a simple gesture that has the power to create connection.

In his writing about the present moments as moments of possibilities, Stern (2004) suggests that the clinical practice of medicine is also about “having a different vision of the clinical process” (p. 223). It is about being mindfully attuned to the “shared present moments” (p. 227), momentary now moments, in which real human beings in illness interact. Such mindfulness awareness gives rise to “different clinical sensibilities” (p. 223), to new “ways-of-being-with others” (p. 227) in the illness that “they are now living” (p. 220). This new-way-of-being-with-the-other is “beyond a technically acceptable response” (p. 168). It is about a clinical action—“a moment of meeting” (p. 168)—an authentic response of working together and a full appreciation of the other in the interaction, in a process that Stern notes is largely non-verbal (pp. 220-223). It is a moment of meeting, of “appreciating the experience of the patient more deeply, of feeling his experience and sharing with him so there is an enriching of who he is, what it is like to be him, and what it is like to-be-with-him” (p. 226).

Youngson (2012) and Nyima and Shlim (2006) note the importance of present moment-mindfulness. Mindfulness and cultivation of compassion can be fostered simply with a deep awareness of “starting each day with the desire to help others” (Nyima & Shlim, 2006, p. xvi) or, as Youngson (2011) posits, being fully aware that compassion is realized in “simple acts of kindness” (p. 40) that take little time. Nyima and Shlim (2006) note that compassion can be cultivated through meditation. An embodied mindfulness approach incorporates somatic awareness, observation and noticing bodily sensations, as well as a greater sensitivity to one’s postures, gestures, stances, and motions. It involves being aware, sensing, being in tune and evaluating the feedback that we receive from our own body. Counsellors who work in the area of embodiment can be invaluable partners in creating mindful medical training, and thus in supporting the development of physicians whose work is immersed in caring environments that have high potentiality of ‘feeling’ and ‘seeing’ death.
For Nyima and Shlim (2006) medical practices cannot be restorative of the wholeness of a patient and family’s personhood without the cultivation of compassion (Nyima & Shlim, 2006). When patients, family caregivers, and health care providers feel that their emotional experiences are recognized, a new “healing dialogue” becomes possible between the human being who “appeals for help and the other of whom professes the ability to give it (Zaner, 1990, p. 322). Within this healing dialogue lies the potential for the unfolding of the we, which as Marcel suggests, indicates a co-presence—a mutually responsive two-sided connection between those needing care, and those providing it. It is a mutual recognition and co-participation that can give rise to a communion in caring and create a wider community of compassion for all those present in suffering. This brings us to the final implications of this study.

**Implications for practice–The family members**

Compassionate gestures from the family towards the physician can humanize the physician’s daily experience of cancer care. Just as a physician may walk in the family’s shoes and be available to their suffering, a family member may also walk in the physician’s shoes and come to appreciate their hardships, their losses and their suffering. This appreciation may be seen in what Amy offers as the last gift. It is a gift of enacted gratitude and long-lasting acknowledgment for the physician, given not for the ability to cure their loved one, but for having been present alongside the family member in the journey.

Many years after her father’s death Amy speaks of remembering the doctor who cared for her father. She recounts how her family sends him a Christmas gift every year, never expecting a reply, yet always receiving one. Even in this small act of response this doctor still remembers her, her family, her father. Through tears and smiles she recalls:

> We still now send gifts every Christmas. We send him chocolates every year [laughs], little treats just to thank him and to acknowledge him for all his hard work. It is a gesture for us to say thank you, and that you are a good doctor. And always, always, within a month or two, he takes his time to hand write a thank you card to send to us. And we don’t expect a card back from him. But he takes his time (smiles) in hand writing his postcard.
And I think it is important to remember how well you were treated by him. We think it is important to acknowledge that, because we know there are a lot of people out there who are lucky enough to have him as a doctor. It is just a gesture from us to say thank you. Thank you for your hard work. And it is not just a thank you from us, but also for the other people who are benefiting from his care. I think it is probably nice for doctors to know that. There is a sense of satisfaction in what you do. Because that doctor has a long-lasting impact on the family members after the loved one has passed away. We still appreciate the level of care and professionalism my dad received and that we received too. This has a lasting impact for us.

And for those doctors who think that caring is not important, or that this experience does not have an impact on the family members: it is not true. Your patient can go but the family member stays. They are the ones who remember you. It is the family member who remembers whether you were a caring doctor or not. It is kind of scary to think, as someone who went through this experience, that other family members should have to go through all the frustration when the doctor is not listening. During the time my dad was still around, I felt bad and so did my dad, because for other family members there was no comfort for them from certain doctors. My dad joked about it saying: “Thank goodness we don’t have that doctor.” But you felt bad for anybody who did. You feel bad. There is a sense of guilt too, because everybody should have a caring doctor.

Compassion not only benefits the “receiver but also the giver” (Nyima & Shlim, 2006, p. x). “Physicians also suffer from the dehumanisation of modern medicine” (Cole & Carlin, 2009, p. 1414). “Doctors are less satisfied with their careers than ever before” (Nyima & Shlim, 2006, p. 3). Physicians in oncological wards work under extreme conditions of stress, witnessing suffering as they face their own vulnerability alone (Youngson, 2012). “Unmourned losses; unrealistic expectations; uncertainty in relating; unasked questions; and unexplained suffering and death” are common to the physician’s experience of working in hospitals, write physicians Cole and Carlin in their article The suffering of physicians (2009, p. 1415). Doctors face working conditions that are “routine, day-in and day-out…at the end of the shift you go home feeling exhausted and dispirited” (Youngson, 2012, p. 16).

There is now a tension between practicing the ‘calling’ of medicine as healing while being prisoner to the objectified, reductive, medical gaze that “can limit the ability of physicians to live up to these requirements and ideals, which in some individuals creates a
cognitive dissonance that leads to cynicism, disillusionment, self-doubt, dis-ease, and a retreat from ideals” (pp. 1414-1415), and to poor coping mechanisms such as addiction, depression, suicide, and abandonment of the profession (Cole & Carlin, 2009; Shanafelt et al., 2012; Shanafelt et al., 2014). In avoiding the interaction for the sake of clinical objectivity, by detaching themselves from the moment where eyes can meet, where there can be the warmth of a hand, or a nod of the chin in shared recognition of pain, physicians rob themselves of the richness of the we, the healing relation.

“How can we humanize the experience of doctoring?” ask physicians Cole and Carlin (2009, p. 1415). Compassion from the doctor may lead to compassion from the family towards the doctor, and may create the very protection from distress that doctors face daily (Youngson, 2012). The family caregiver enters the world of the physician, who each day works under conditions of witnessing pain, suffering, and death. In cancer care, each recognizes and affirms the other. Each is sensitive to the other’s experience and it is in this way that there is mutual participation in suffering. They are being with each other. A physician who is truly mindful of the present moment may find in turn that the other partner in care—the family member—also sees the challenges that the physician faces. When physicians feel they are recognized, this may ward off the heightened distress that permeates the day-to-day work of cancer care. This person-to-person recognition as humans ultimately redefines the space of illness and compassionate caring.
References


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Appendix A

Participant Recruitment

PARTICIPANT RECRUITMENT FOR RESEARCH STUDY


I am looking for adult volunteers interested in taking part in a research project that I will be conducting as part of my Ph.D. work at Simon Fraser University. I am interested in exploring the experience of cancer patients' family members of their interaction with physicians during oncological treatment of their loved one.

If you are a family member of a cancer patient who have been involved throughout your loved one's cancer treatment and would like to talk about your lived experience of your interaction with the physicians providing care, I would appreciate your participation.

If you are over 19 years of age, had a family member who was diagnosed with cancer and you were involved in the care of your family member throughout the oncological treatment, I would appreciate your participation.

Participation involves taking part in a face-to-face interview lasting 1 to 2 hours. You are asked to reflect on your experience, your thoughts and your feelings, in as much or as little detail as you feel comfortable with. Interviews will be audiotaped. Audio recordings will be later transcribed. All audio recordings and transcriptions will be erased two years after completion of the study. Your name will not be used.

The Office of Research Ethics of Simon Fraser University has approved this study.
Appendix B

Consent for Participation in Research Document


Researcher: Carmen Almarza MA (Couns.Psyc.), Ph.D. candidate

Supervisor: Dr. Stephen J. Smith, Associate Professor, Faculty of Education

The present study is being conducted by Ms. Carmen C. Almarza, a doctoral candidate at the Faculty of Education, Simon Fraser University. This research is being conducted under permission of the Simon Fraser University Ethics Board. This study is part of my doctoral dissertation under the senior supervision of Dr. Stephen Smith. Dr. Smith is the Director of Professional Programs of the Faculty of Education at Simon Fraser University.

We are interested in hearing from family members of cancer patients who, as part of their loved one’s illness have had interactions with the physicians providing care for their loved ones. To be included in the study family members of cancer patients need to have been actively engaged in the care of their loved one. The goal of our study is:

To hear, in your own words, about your interactions with the physician(s) involved in the care of your loved ones. I am interested in exploring the experience of doctor-family interaction in advanced cancer diagnosis and treatment, from the perspective of the cancer patients’ family members.

Understanding the family’s voice with regards to how physicians embody and respond to the family’s needs in the family-physician encounter, as well as the meaning that families assign to their experience, has important implications for the formation of British Columbia doctors and medical students. The knowledge gained from this study will inform pedagogical practices that are responsive to the patient and their family’s needs.

Participation in the study requires taking part in one face-to-face interview. The length of the interview will be left open, but each interview is expected to last anywhere from one hour to two and half hours. In the interview, I will ask you to reflect on, and share your lived experience at the cancer ward in as much or as little detail as you feel comfortable.

Interviews will be conducted solely by Carmen Almarza. With your consent, face-to-face interviews will be audio-taped. Audio recordings will be later transcribed and assigned a unique code number to ensure confidentiality and anonymity. All audio recordings will be transcribed solely by me, Carmen Almarza. The information that is gathered will be kept confidential and anonymously stored. Analysis of the data will be made available only to the Principal Investigator and my senior supervisor Dr. Stephen J. Smith. Audio recordings and transcripts will be kept locked until they are destroyed, two years after the completion of the study. To ensure anonymity, we will not use your name or initials. Your name will be replaced with a pseudonym.

Your participation in this study is entirely voluntary. It is up to you to decide to participate or not participate. You are also free to decide to withdraw from the study at any time. If you decide not to participate or to withdraw from the study once the study has begun, you do not have to provide any reason for your decision and your decision will not have any adverse effect on you.

This study does not involve potential foreseeable risks or discomforts to participants. We adhere to strict procedures to ensure your confidentiality and anonymity and to safeguard your rights as listed below.
• You have the right to confidentiality. Any information that is obtained in this study will remain confidential to the full extent allowed by the law.

• Your identity and personal information will not be available to anyone but the principal investigator, Carmen Almarza, and the study’s senior supervisor, Dr. Stephen Smith. Any identifying information will be removed. Participant names and/or initials will not be used. Pseudonyms will be chosen by the participant or assigned.

• The participant can choose, or we will assign a pseudonym for any persons mentioned in your interview.

• You will have full access to your interview transcripts at anytime that you deem necessary before transcripts are destroyed.

• As the participant you have the right to withdraw at any time without penalty or prejudice.

• There are no consequences for choosing not to participate in this project, or for withdrawing from the study at any time.

• You have the right to request copies of any reports associated with this study. The results of this study may be available to you by contacting the Principal Investigator, Carmen, C. Almarza. You may also contact my doctoral supervisor, Dr. Stephen Smith.

This study has been approved by the Office of Research Ethics of Simon Fraser University. If you have any questions, concerns or complaints relating to this research study, you may contact, Dr. Stephen Smith, Associate Professor, doctoral Senior Supervisor. As a secondary point of contact, you may also direct your questions, concerns and complaints to Dr. Hal Weinberg, Director Office of Research Ethics.

The results of this study may be submitted for peer review and publication in journals. Results may also be presented at conferences.

We greatly appreciate your support for this study.

Participation in this study requires your voluntary consent. After reading this document, if you choose to participate please sign the document that follows on the next page.

Warm Regards,

Carmen C. Almarza, MA (Couns. Psy), PhD (c).
Faculty of Education
Simon Fraser University.

Dr. Stephen Smith
Senior Supervisor,
Director Professional Programs,
Faculty of Education
Simon Fraser University
I understand that I may withdraw from participation at any time without prejudice or penalty. I understand the risks and benefits of participating in the study. I have read and understood the Informed Consent document above and I freely give my consent to voluntarily participate in the study entitled "The clinical practice of embodied care: A phenomenological investigation of physician-family interactions in oncological treatment".

Participant Name (please print): ____________________________

Signature: ____________________________________________

Date: ____________________________

Principle Investigator: ____________________________________

Signature: ____________________________________________

Date: ____________________________