

Organizing Transitions in Palliative Care:

Outside/Inside Cancer Systems

By

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B.S.N., University of British Columbia, 1990

M.S.N, University of British Columbia, 1992

A Dissertation Submitted in Partial Fulfillment of the  
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**Abstract**

This dissertation explores the question “how does a person who is a cancer patient find their way to being a dying person?” Through the lens of modernism (Giddens), discourse analysis (Foucault), and philosophical hermeneutics (Gadamer) the author examines how the institution of cancer control is constituted, and how the cancer patient is co-constructed by this system and people entering into it as people needing cancer treatment. Language is explored to uncover meanings and discourses which help shape this experience and self-narrative of the cancer patients who face leaving the cancer control system and do or do not find their way to palliative care systems. From this perspective the more solitary and less shaped experience of ‘unbecoming a cancer patient’ is explored for those cancer patients whose treatment has failed. The liminal space between the expert systems of cancer control and palliative care is what is revealed and problematized. What is explored is what this liminal space between these two systems is, and how people who find or lose themselves in this space at this time might be met, without succumbing to the modernist temptation to create yet another expert system to manage

what is explored. What is at stake for people at this time is their own self-narrative going on, and it was found for some people in a liminal space this self-narrative faltered. It is revealed that nurses are best positioned epistemologically to support people at this time, and the question of where this support ought to happen is explored in terms of the ideological fit within current health system alignments. This work adds an important theoretical rendering of the term liminality and has important implications for person centred nursing care and health system redesign.

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The second acknowledgement I wish to make is to my supervisor and committee. Mary Ellen Purkis, for taking on the demanding job of helping me to see another way of understanding after so many recalcitrant years in positivity and doing so with grace, wisdom and humour; Anne Bruce, for bringing her lightness of being and indomitable enthusiasm to the fore especially where I faltered in my own humour and zeal; Helga Hallgrimsdottir, for asking the hard questions in such a gentle way, and trusting in my confidence that she was the right sociologist for the effort; Lynn Stevenson, whose mentorship and friendship has supported me not only in this effort but in the many many years I have had the privilege to know her; and the last but not least the fifth unofficial but critical member of my team Madeline Walker, who taught me to honour and retain my voice as I wrote my story into a thesis.

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### **Dedication**

This project is dedicated to three nurses who have each in their own special way mentored and supported me towards my career in nursing and this penultimate and final degree.

First is my own mother, Norma Helene Syme, who becoming a nurse in 1940, framed for me for all times the grace and intelligence of the nursing discipline. It is her essential being-in-practice that I have always aspired to, and I believe that she would no doubt have seen herself in this work had she not died so early in my life.

Second is my first and ever-best nursing instructor, Robbie Rich, who so clearly saw in us beginning nurses what would flower in our practice and careers as we became full-fledged nurses. I will always recall and have ever sought out in nurses I have mentored what she referred to as “the bloom” that beginning and growing nurses have - Robbie Rich, first class nurse, teacher and mentor.

Third is my first and ever-best head nurse, Anita McCaw, and the team of nurses I first joined in my emerging nursing practice at Toronto General Hospital, 6 Eaton South. Anita set the bar for excellence in nursing practice for which I was forever shaped in terms of what I considered acceptable and further, stellar nursing care for patients. It was Anita who taught me to think of each person I cared for as my partner, my child, my brother, my father, my mother – never allowing the human connection we all share with one another to escape my thinking about and caring for people.

Which returns me to my first mentor, my mother. Finally this work is dedicated again to her, this time not as nurse, but as mother – and all mothers like her who die alone and lost in liminality as a now see her death as having been. May this work bring to light their loss of

narrative and lead nurses to better recognize and support those so bereft in their finding a way to be a dying person.

### **Chapter One: Organizing Transitions in Palliative Care**

...and I have been spending quite a bit of time figuring out what the aim is and what my aim is at this point and I find myself um, I find myself finding that difficult finding what that goal is. Um because when you're healing that's a thing to look forward to and it moves you forward to your future. Um, but if um, you're not moving that way, you're not moving towards a future that um, is being without illness, I don't know how you can say what direction that is? I'm not sure I have the vocabulary for it. It's ah, sort of stalled, sort of static.

Jane, who spoke these words, has died of cancer. The day she uttered these words she had just learned that the cancer she had was incurable. I open with this account to introduce the concern and focus of this study. This is a space I call a liminal space. This person came to this space after being through the cancer treatment system – learning what it was to be a person with cancer, learning how to be a cancer patient with colon cancer, learning that the chemotherapy, surgery and radiation therapy she had could not rid her of her cancer, and now being faced with learning to be a person who is dying of cancer. This person and those facing this liminal space and emerging liminal self are the focus of this study.

Liminality is a concept arising out of anthropology, describing a betwixt and between place and personae between a past and future state (Turner 1969; van Gennep, 1960). Meyers (2008) explores liminality through the lens of existential philosophers Sartre and Merleau-Pontys' reflections on being and nothingness. Liminality is also taken up in sociology in terms of inter-polar spaces between cultures (Fanetti, 2005) and in thinking about porches as thresholds and transitioning spaces (Walker, 2005). Liminality is also explored in health care literature relating to chronic illness (Frankenberg, 1986), and as a space experienced by people facing life limiting diseases (Bruce, et al., in press), Finally, liminality is explored for people with cancer in terms of a process (Little, Jordens, Paul, Montgomery and Philipson, 2006) and as a life-long way of being after being diagnosed with cancer (Navon & Morag, 2004).

This study explores liminality as a particular space that opens up for some people leaving cancer treatment centres and being faced with dying because of their cancer – how they go on. As a concept liminality is rooted in the betwixt/between living/dying and expressed by people like Jane, as an ambiguous space and self. I will also demonstrate that, in some particular and observable ways, it is a space shaped by the cancer treatment system and how people are constituted and constitute themselves as cancer patients and subsequently as dying persons. This will be carefully explored as liminality itself is a rather ineffable concept particularly as this applies to a dying person, and difficult to *expose* in an empirical manner. However, liminality is also a space which lies between two expert systems, and is therefore shaped by and experienced through how these systems are and how these systems are taken up by people who find (or lose) themselves in a liminal space. Therefore, while liminality is not a new term to be used in cancer or other life limiting diseases, the ways in which liminality is positioned in this study is new territory for cancer palliative care research and nursing.

There are two questions leading this study and shaping and forming what this research addresses. The first question is *how does the transitional patient organize a self that engages with the liminal space between cancer treatment and palliative care?* My interest in this question is how the self takes shape and is shaped for people who find themselves liminally situated after unsuccessful cancer treatment. The answer is sought in the language they, their family members and the oncology clinicians who care for them use to express this self and space, and in the shaping forces for this self and space that can be seen in the discourses. The second question presumes on this first liminal space being made visible, and asks *if question one can be understood, then where ought this transitional space (between cancer treatment and palliative care) to be located – inside or outside the cancer treatment centre?* Again, both options are

brought into relief by language and discourses that come both from the patient, their families, oncology team members who experience this liminal space and selected text surrounding the organization of these two areas of concern. In weighing these options consideration is given to the benefits for patients and their families and the goodness of fit for both or either cancer treatment systems and palliative care as to where liminal support may be provided. These are questions which have disturbed me over my many years in cancer/palliative care nursing practice. This is the first reason I have for doing this work.

As a qualitative inquiry, this study not only contributes to a specific body of knowledge, but is, after Peter Reason (1996) “a living inquiry in the lives of all involved” (p. 15). The aims of the project are reviewed in light of Reason’s “reflections on the purposes of inquiry” in terms of (a) personal knowledge – fulfilling the inner self of the researcher vis-à-vis the topic, (b) working with people in the world – how to change people’s experiences working from their needs, and (c) disrupting/interrupting patterns of power in knowledge acquisition and dissemination (1996, p. 15). The next few paragraphs will explore and anchor this study in terms of Reason’s thinking.

First, there are two foci of personal interest in this study. The first is a real interest in the answers to the questions posed. Something is missing in “cancer dying systems.” There are cancer treatment centres, with expertise about how the disease can be modified or eradicated, and emerging expert palliative care systems to where people dying of cancer can take their needs and concerns. There is, however, very little explicit support for cancer patients as they leave cancer treatment systems and find, or do not find, their way to palliative care systems. I call this the in-between problem, or in application to the care system, a liminal space. I have struggled with this concern for years, and with my clinical experience and systems understanding I have not been

successful at solving this problem. Finally it occurred to me that perhaps I was not finding a solution to this in-between problem because I was not able to see this in-between problem in ways that would likely lead to different understandings and thus different solutions. I was like a fish in water, not seeing water as anything except what I am used to seeing and knowing (May, 2009). This self-reflection is crucial because as researcher, I cast my shadow over my work (Crapanzano, 1986). I select and present those texts and questions which speak to my own history, my soul, and my intent in my work: I story my data. As such, I cannot claim impartiality as *I am* the research instrument. My partiality is evident in the research I have chosen to do. My work is cancer palliative care, and has been cancer palliative care for over 25 years. I have a way of seeing dying patients and their families, of understanding them, of helping them. This is my clinician/professional self – in the story and telling the story. I also have lost a mother to a cancer death. This is my personal self – in the story and telling the story. Finally, I am a palliative care advocate – trying to retell and reshape the story, in ways that are supportive and sensitive to dying people and their loved ones. This is who I am and consequently how I make meaning.

This leads to my second personal interest which is to “actualize the capacity of the self” (Reason, 1996, p. 19). I first looked at this in-between problem in terms of a cancer patient’s *readiness* to engage in palliative care or palliative care conversations. My idea was that if we might be able to identify patients’ readiness to engage in these conversations, we might be able to be more suitably supportive when they came to their end of cancer treatments. This idea of readiness was conceived in a framework of linear thinking and positivism. This unidirectional and simplistic framework did not in any way fit the complexity of my questions. People are more complex and varied than this simplistic way of thinking of readiness would capture, so a

notion of selfhood (Cohen, 1994; Giddens, 1991) was introduced into my thinking. Systems are also more complex and difficult to understand in this linear fashion, and so the notion of interests, power, and the exploration of the abstract expert systems were introduced into my thinking (Foucault, 1980, Giddens, 1990). This new turn in thinking and understanding served as impetus for this work, with the prime focus being to explore the in-between problem and define a liminal space, along with the simultaneous focus of using this opportunity to apply my newly changing mind to the problem, being mindful of reflecting how I think, how I make meaning, and how I approach problem identification and solving.

In terms of Reason's (1996) second focus, or how I might change people's experiences working from their needs, I was very clear that this study was a *nursing* dissertation. That is to say, it is important that what knowledge this study produces must in some way add to the disciplinary knowledge about what a nurse might need to know to practice to support people if and when they experience being/not being in a liminal space. As a practice discipline, nursing has so many questions it faces that it is not enough to just try and answer those questions just for the sake of knowing something new, but also so that this knowledge will lead to making a difference for people in liminal spaces and the nurses who care for them. Thus, this study will frame the knowledge it produces to change practice and also provoke nurses to think about how best to recognize and serve people they encounter in their practice who are in a liminal space. But, similar to the personal aims outlined, this study does not only aim to provoke individual practitioners to change their practices, but also to invite the discipline to reflect on the nature of nursing knowledge that differs from and augments orthodox science by exploring knowledge that is situated, provisional and embraces heterodoxy as a way of being (Reason, 1996).

The third interest is political. This study aims to explain data to reveal dominant and subsequently subordinate discourses. This revelation is a first step towards “interrupting the patterns of powers that define issues in the service of the powerful” (Reason, 1996, p. 15). In this way, the study seeks to pose and address questions that are routinely excluded from social awareness. The initial notion of “readiness” that I had first thought of perusing would have presupposed the notion that people leaving the cancer system as dying persons would necessarily access palliative care, framing the questions and concern in terms of system alignment and system interests. The assumption that would be made is that *this is how it is because it is*, failing to provoke a new understanding of the world and the needs of people in liminal spaces by looking at, shifting, prodding and exposing power relations (Reason, 1996). This study has been conducted to answer the research questions and in doing so to meet Reason’s three aims. The dissertation has been assembled to provide a framework and pathway for this work to help readers understand how I think about things, worked with the data I collected and made the meanings that I did. What follows is a précis of the subsequent chapters.

Chapter two explores the context of the study and what needs to be known by the reader to reflect upon and eventually situate the author’s perspectives about the constitution of the self who is the incurable and dying cancer patient, and the discourses and systems which contribute to shaping this. This research project attempts to explore how some people exiting the cancer treatment system after unsuccessful treatment find or lose themselves in a liminal space as a sort of parenthesis between the expert systems of cancer treatment and the emerging expert system of palliative care, and between a self as a living self and a self as dying. In this space meaning becomes diffuse and self as dying is ill defined. Although the preceding sentences describe this space, they do not, as this work seeks to do, add the layer of problematizing the liminal space.

What is the problem with liminality? This chapter will explore this question with the aim to contextualize the space of liminality and the problem it poses from the perspective of the individual who finds or loses themselves in this space, and explores the features of the expert cancer system that contribute to liminality in the particular ways that I will argue cancer systems do.

It will be shown that while the biologic/cellular and bodily stories give meanings to cancer, the voices that attend these stories are not equal. The biologic/cellular story of cancer is caught up with the science of the disease and with this in the dominance of medicine over the person as patient's bodily and personal experience of the disease. In this weighted meaning-making space, there is a person with cancer trying to make sense of their situation – who they are, what is becoming of their bodies, and how their narratives will be indelibly shaped and ultimately truncated through their experience. These narratives and sense making spaces are ones that are shaped by medical dominance and the institutions that lay claim to understanding how this disease is manifest and how, when it appears in a person's body, it is addressed. When this institutional and medically dominant interest is withdrawn, people may tumble into liminality – a space between expert systems. This is a space which seems to be, so far, beyond the reach of expert institutional shaping, and is the living/dying space where people may lack a narrative to take themselves forward.

Chapter three sets out how this qualitative inquiry has been pursued in relation to expanding disciplinary knowledge and by utilizing three frameworks which were chosen to meet the aims of the study and work well together. Additionally, this chapter shows how the study was accomplished so that credibility and trustworthiness of the research can be assessed. First, the study design is explored and explained – why research questions were chosen, how

participants were recruited and why, what and how data was collected, how data was analyzed in relation to the chosen frameworks and questions, and how issues of ethics were addressed. Next, the notions of authorship, voice and reflexivity are explored. In terms of frameworks, first and foremost Giddens' work is explicated in terms of his arguments about expert systems in modernity as these relate to the nature of cancer institutions and the ways in which patient persons interact with them and reflexively create their self-narratives. Giddens' work concerning the reflexivity of self-narrative in modernity is also used as a lens on people's experiences of being cancer patients and becoming liminal persons. Next, Foucault's thinking is explored as it relates to unearthing the power effects in discourse and how these effects will be sought out in the accounts and data. Here the notion of disciplinary dominance, as it relates to becoming and unbecoming a cancer patient, is explored. Finally Gadamer's philosophical hermeneutics is explained and its use explored as a means to understand the complexity of meaning in language used by participants and found in writings about cancer care and liminality. Additionally, Gadamer's notion of how language forms and shapes the self is explored, as it is through conversations that the support for people in liminal places will be shown to be a critical nursing skill. In concluding this chapter, trustworthiness of this qualitative inquiry is explored and the project is positioned in relation to the practice and discipline of nursing.

Chapters four to seven set out the major findings of the inquiry. The findings are organized according to patient participants' accounts of how they became cancer patients, how they were discharged from the cancer system, and how they found/lost themselves after their disengagement with the cancer system. This temporal way of presenting these findings reflects the patient participants' accounts of "first this, then that, then this." Each portion of the findings is thought of in terms of this progression and also conceived in relation to three themes in terms

of the notion of aggregation, with chapter four focusing on how people became *aggregated* as cancer patients. Chapter five explores how, after some very deliberate shaping was taken up to become cancer patients, people became *dis-aggregated* – un-becoming cancer patients as they left the cancer system, and how their story line was altered and altered them, and ultimately how they managed to go on. Chapter six then explores the third major finding in this work, how some people became *un-aggregated* as they lost/found themselves narratively and bodily in a liminal space. Implications of these findings are first explored in terms of how they support/contradict/or extend what is already known in the literature about this topic, and the extent to which the data up to this point has answered the first research question.

Chapter seven extends this notion of liminal space in terms of who might be well placed to support people finding/losing themselves in this space and where this support might be located. Nurses are found best suited to this work, and the work of liminal support is framed in terms of being-in practice and conversations. The question of *expertise* is addressed in terms of the seemingly inexorable modernist tendency to so position knowledge and skills. Finally, this chapter focuses on answering the second research question and suggests potential changes to nursing practice and system alignment.

The eighth and final chapter reviews and reflects on what this study reveals and what its findings suggest to changes for nursing practice education and health care policy. What will be made clear is how this work contributes meaning(s) about peoples' experiences in the liminal space after cancer treatment is ended. Here also the aims of the introduction are revisited in terms of Reason's reflections on the purposes of human inquiry: (a) the actualization of my self-capacity through this project, (b) the contribution to knowledge in terms of changing people's experiences working from their needs as this relates to being in a liminal space, and (c)

disrupting/interrupting patterns of power in knowledge acquisition and dissemination as a research project in itself, and as this knowledge factors as a policy lever to disrupt and transform cancer care systems.

Again, the research questions that this research is perusing are *how does the transitional patient organize a self that engages with the liminal space between cancer treatment and palliative care and if question one can be understood, then where ought this transitional space (between cancer treatment and palliative care) to be located – inside or outside the cancer treatment centre?* In order to understand how cancer patients might reflect on how they are transitioning to be a person dying of cancer, it is first necessary to understand what a “cancer” means in the first place, as well as what the system of cancer treatment is all about, else it will be difficult to understand *from what* these people are transitioning. Consequently, the next chapter explores both cancer and its systems of care so that the reader will understand what these concepts are, and how they may effect or shape a person who has cancer and has been through the cancer system for their treatment.

## Chapter Two: Context

This chapter explores the context of the study and what needs to be known by the reader to reflect upon and eventually situate the author's perspectives about the constitution of the self who is the incurable and dying cancer patient, and the discourses and systems which contribute to shaping this. This research project attempts to explore how some people exiting the cancer treatment system after unsuccessful treatment find or lose themselves in a liminal space as a sort of parenthesis between the expert systems of cancer treatment and the emerging expert system of palliative care, and between a self as living self and a self as dying. In this space meaning becomes diffuse and self as dying is ill defined. Although the preceding sentences describe this space, they do not, as this work seeks to do, add the layer of problematizing the liminal space. What is the problem with liminality? This chapter will explore this question with the aim to contextualize the space of liminality and the problem it poses from the perspective of the individual who finds or loses themselves in this space. In doing so I will explore the features of the expert cancer system that contribute to liminality, particularly in terms of medical dominance.

I begin with another of Jane's accounts to portray the intersection of the self or personal interests with institutional or expert systems interests.

That was a, a really big bump too. There was a meeting when ... the results of the CAT [x-ray computer tomography] scan and the CEA [carcinoembryonic antigen] numbers were going up and so the oncologist said that there was a recurrence but I was asymptomatic and then after that I was symptomatic and that was the other shoe dropping. The minute that you are symptomatic, you're in you're not on that same path. You get sent home with a book from the palliative care centre that has a DNR [do not resuscitate] ..... which is hard to look at ... (crying).

Note first Jane's tone – we feel a sad, bereft feeling space. Jane is on the threshold of a liminal space. The deliberate focused shaping of her self as cancer patient is coming to an end, not because she is moving away from this self, but because her incurable cancer is not of interest

to the oncologist – the shaping gaze is withdrawn and she is left to her own self. This one-sided disconnecting can be seen through the intersecting discourses. First, there is the biologic story, the medical discourse – Jane is told she has a recurrence of her cancer. The signs are there, the CAT scan and the increased markers. But Jane’s story relates to her bodily attentiveness which tells her she is not getting worse, she does not feel different, and she has no symptoms, and then, unrelated to the biological markers she feels unwell and symptomatic. Jane seems aware that her bodily story does not fit with the medical one, and moreover she understands that her accounting of things is not the prevailing story: her bodily discourse has no relevance. It is the medical discourse that shapes the encounter, and it is this discourse which ends in Jane being sent home, discharged. All this happens for Jane in one meeting and looming ahead of her is the next expert system with the intrusion of the palliative book and the DNR. Jane is tumbling into the liminal space between expert systems – she cannot go back and she cannot go on – and as we learned from Jane’s account opening chapter one, she is narratively stalled.

When I explore what Jane’s sadness and bereavement is about, I realise two things. One, Jane knows she is dying, and two, the oncologist’s clinical rejection is personal for Jane. Jane feels the oncologist not only rejects her because there is no further interest in her cancer, but also because the oncologist is not interested in her symptoms and in her suffering, and ultimately is not interested in Jane anymore. Jane’s biologic cancer story has ended and so too has the clinician’s interest. Giddens (1991) is helpful here. Jane’s impending death for the oncologist is “a technical matter, its assessment removed to the hands of the medical profession: what death is becomes a matter of deciding at what point a person should be treated as having died” (p. 161). Jane has not arrived at this point yet; she has not caught up with the medical fact of her death. Yet for the cancer system and her oncologist – Jane has for all intents and purposes already died.

This is the problem of the liminal space. What will be shown in the research is that the expertly and deliberately shaped self as cancer patient can be brusquely and unexpectedly jettisoned into a shapeless and diffuse space which leaves people like Jane lost for words and direction – ultimately lacking a narrative way to go on with the self.

It is the contrast of these two spaces – cancer treatment and liminal – that make this unwanted and unlooked for release unique for cancer patients, and I will argue that the pre-eminence of medical dominance contributes to the starkness of this contrast. What has given the medical discourse the ascendancy it appears to have over Jane’s experiential and bodily stories? I propose that this medical truth about cancer is related to the voice that claims it: it is the cellular and biologic truth that is uttered almost exclusively by medicine, and it underpins the way medical dominance is exercised in its relative exclusivity in cancer treatment systems. I will draw upon health sociology literature concerning medical dominance that explores the articulation between the experiential body stories of illness and the cellular scientific ones. It is from this place that I will argue that the biological/cellular story of cancer has ascendancy as it aligns with the scientific and medical interest in cancer and that this has meaning and contributes to the problem of liminality.

A survey of a 2006 issue of *Health Sociology Review* devoted to medical dominance shows evidence for both its decline and its stronghold—and ultimately shows that such dominance remains prevalent in cancer treatment systems and is crucial to the shaping of the liminal space. Writing the introduction to this journal, Willis (2006) reviews the historical context of medical dominance, the evidence for its decline, and the evidence against its decline. In terms of its history, Willis writes that the golden age of medical dominance lasted from 1930 to 1970, peaking in 1960 and following a steady decline since that time. The sustained pre-

eminence of the medical profession was accomplished through (a) the state's underwriting of this position in health care, (b) medicine's autonomy in the regulation of its own work, and (c) medicine's authority from (a) and (b) to assert dominance over other health care occupations (p. 422). Evidence for decline of medical dominance is cited as restriction of autonomy – internally in terms of greater transparency of the medical profession to institutional and legal scrutiny, and externally in the proliferation of medical procedures and the need to standardize these procedures against what was seen as “accepted medical practice” (p. 423). Physicians were no longer free to practice as they wished. In Australia, further waning of medical dominance was seen in the reduction of physicians in administrative roles and the erosion of physicians as gatekeepers to the health care system by giving certain “medical functions” to other health practitioners – as in provision of sickness certificates. Evidence against the decline of medical dominance is cited in the medical profession's active resistance to the main-stream introduction of nurse practitioners which, at the time of Willis' writing, had been successful in Australia.

Willis' introductory essay is followed by others which indicate that medical dominance is being eroded by its replacement in political discussion by political struggles about neo-liberalism (Coburn, 2006); the domination of a health policy agenda and introduction of state sponsored regulatory measures (Allsop, 2006); the greater emphasis placed on patient wishes in the terms of the “responsibilisation” effort of publically managed care (Dent, 2006, p. 458); and the effects of consumerism and managerialism (Tousijn, 2006). Countering these arguments for erosion are Bourgeault and Mulvale's (2006) study about primary care reform in Canada and the United States which showed that the embeddedness of medical dominance impinged upon these policy changes to create collaborative health care teams. Similarly, Long, Forsyth, Iedema and Carrol's (2006) research highlights the “depth and complexity of enculturated medical dominance”

through their study of multidisciplinary teams attempting but failing to “work in a clinically democratic way” (p. 506).

Oncologists enjoy a relatively uncontested dominance in policy and clinical structures in the cancer treatment system. In accordance with Willis’s key observations, oncologists regulate their own practice (no one else would know how to measure their skill and knowledge), and cancer treatment centres are medically led organizations dis-integrated from other health care sectors, resisting the state’s interest in undermining medical pre-eminence, the success of which can be seen outside of cancer systems in the establishment of primary care teams and the introduction of nurse practitioners. Consistent with Long et al.’s (2006) observations, oncologists practice in relative isolation, drawing on other teams members to support their medical treatments and work, rather than looking to the patient’s needs.

Medical dominance in cancer systems is also supported by institutional structures. While there are no federal unifying institutions directing the delivery of cancer treatment across Canadian provinces and territories, there are exceptionally unifying federal institutions for cancer research. This is significant because much of what is offered for cancer treatment is either research based, as in evidence-informed standard protocols and care guidelines, or is actual research itself in terms of clinical trials (British Columbia Cancer Agency, 2009). So while there is no federal structure unifying the delivery cancer *treatment* across Canada per se, provincial cancer treatment centres are unified in their *conduct and uptake of cancer science* and this focus is what also supports and intensifies medical dominance in cancer (Clarke & Everest, 2006). Provincial cancer institutions organize their structures, care processes, and funding according to the scientific cancer cell or biology of the tumour. These are called tumour groups, or sometimes disease site groups (British Columbia Cancer Agency, 2009). This is an organization fitting only

with the biologic/cellular story of cancer, embedding scientific and medical dominance in the structures of cancer institutions. The cellular/biologic story relates to how oncologists specialize, how treatment protocols are applied, and how cancer research dollars are distributed. It is a pervasive and powerful way of organizing an institution and delimiting its focus, and is a way of being that sets cancer out as a system of health care different from any other. It is also a way of organizing that places medicine in an undisputed place of dominance. I would also like to note that these features make cancer treatment and care systems unique amongst other illnesses.

There is a measure of control through application of scientific evidence that is not seen to such a degree in other diseases. On the one hand, this control could be said to represent a high degree of consistency and, alternately, could be said to regulate the field in such a way as to leave little room for other ways of conceiving cancer and to limit the choices that patients and their families may draw from to consider themselves with this disease.

This portrayal of medical dominance as one aspect of control resonates with Sontag's (1978) seminal work, where she explores the historical and literary renderings of cancer from which she claims the constraining notions of militarism and shame arose. With both frames Sontag sees these images being imposed upon the person with the disease and notes them as images which are distinctly restrictive and negative. Sontag argues that these ways of seeing cancer limit and control options people have for understanding and patients have for experiencing this disease. This observation is echoed by Sered and Tabory (1999) who found that women with breast cancer who enter the cancer system experience "a kind of culture clash" where the powers of the two cultures are not equal and it is the medical culture that dominates those who enter it (p. 246). This too will be seen to have an effect when patient choices are

explored in the accounts I later lay out, and very much shapes what judgments patients make in terms of their access to cancer expertise.

Looking more specifically at medical dominance in cancer, Clarke and Everest (2006) conducted a content analysis of the portrayal of cancer in magazines published in Canada or the United States in 1991, 1996, and 2001. This analysis focused on the “framing and content of cancer stories” (p. 2591). Their study showed the persistent dominance of the medical story when contrasted to frames of lifestyle or political economy. Their analysis also revealed an emphasis on fear of cancer in cancer literature and linked that fear with the contextualization of medicine as the solution to that fear.

The notion of medical dominance is central to this study, as it is through the lens of power effects that research participants’ narratives will be explored (Foucault, 1989). Foucault explains in the *Birth of the Clinic* that physicians develop a “clinical gaze” not merely from theory, but from the direct observations of patients. This gaze ascribes to physicians the wisdom and power to penetrate the body and see the underlying physical reality (or truth) of organs and bodily processes: “For the clinic, all truth is sensible truth” (p. 120). This knowledge is passed between medical practitioners through an esoteric and expert language that codifies the wisdom and power they claim, and it is through this wisdom and power that we can understand how Jane’s discourse is subordinated, and in fact irrelevant to the oncologist’s interest.

Deborah Lupton uses Foucault’s notions in her exploration of medical dominance as she investigates with Australian physicians how consumerism may have eroded the dominance of their powers. While affirming that there is a greater sense of “shared responsibility” between patients and their physicians, Lupton asks provocative questions about who is sharing with

whom, and observes that the giver (physician) is “the upper hand in this new conceptualization of the medical encounter” (1997, p. 492). Lupton also questions the notion of “whole patient care” to be rather than the antithesis of a body-part gaze, but an even more encompassing gaze which compels patient-subjects to reach “further and further into their thoughts, feelings and everyday lives in unprecedented ways”(1997, p. 492). Similarly, Peterson (2007) cautions that “confessional practices and care of the self” ostensibly beneficial for the person and society as a whole “may reinforce power relations between experts and lay people and inequities in health provision” (p. 30). Medical dominance may be complicated by modern notions of consumerism, whole person attention, and self-care but it is by no means eroded, and very much contributes to the problem of liminality as it is conceived in this study.

Following the notion of inequity of voice and concomitant medical dominance, a second cardinal feature of liminality in this study is that it is not only a parenthetical space between two expert systems, it is also the space or narrative pause between Jane’s perception of self as cancer patient and what she senses is the new story line and self as being a dying person looming ahead. This self-oriented feature gives existential meaning to the notion of the liminal space as the living/dying space. Jane resists the icons of the next expert system, not as *any* expert system but as the expert *dying* system. Jane does not want to, nor yet can she think of herself as a dying person. Again, Giddens (1991) is helpful here stating that death poses a particular problem for the continuation of a narration of the self, because we become unable to sustain our habitual forgetting of the inescapability of death. Death interrupts us. Death transforms our sense of self from one of a continuous living being, to a being experiencing a haphazard truncation of our potentiality-for-being. Jane is trying to continue her habitual forgetting of her death and is faltering.

Liminality after cancer treatment and a living/dying space is also made problematic by modernity and the consequent lack of guides and supports. Mellor and Shilling (1993) contend that the organization and experience of death is a feature of high modernity (after Giddens). This reorientation to death has resulted from a) the increased identification of the self with the individual and physical body as opposed to the social body (Elias, 1985); and b) the erosion of the sacred (Berger & Luckmann, 1967). The result of this reorientation has left individuals “alone to construct and maintain values to guide them through life and death” (Mellor and Shilling, 1993, p. 429). Liminality is an utterly different and strange place for Jane after the highly structured experience of cancer treatment and she pauses in self and movement to catch her narrative breath. It is this parenthetical space that this research explores and problematizes.

To sum, while the biologic/cellular and bodily stories give meanings to cancer, the voices that attend these stories are not equal. The biologic/cellular story of cancer is caught up with the science of the disease and with this in the dominance of medicine over the person as patient’s bodily and personal experience of the disease. In this weighted meaning-making space, there is a person with cancer trying to make sense of their situation – who they are, what is becoming of their bodies, and how their narratives will be indelibly shaped and ultimately truncated through their experience. These narratives and sense making spaces are ones that are shaped by medical dominance and the institutions that lay claim to understanding how this disease is manifest and how, when it appears in a person’s body, it is addressed. When this institutional and medically dominant interest is withdrawn, people like Jane tumble into liminality – a space between expert systems, lacking in shaping forces, and bereft of narrative. This is a space lacking expert institutional shaping, and is the living/dying space where people like Jane lack a narrative to take themselves forward. But it is also significant that forward from this space is dying, and the

dying self and narrative is not necessarily one effortlessly re-ravelled and woven. It is not easy to be in liminality.

With the context of medical dominance in the cancer system and the problem of liminality outlined here, this next chapter explains how this space is explored and how meaning about this space is made, preparing the reader for the rendering of accounts collected from patients, family members and clinicians that underlie and give truth to these claims about liminality and the problem it poses for people living with and dying from cancer.

### Chapter Three: Methods

This chapter sets out how this qualitative inquiry has been pursued. The trustworthiness of the study design and credibility of the study results will be enhanced by an explicit description of what particular research questions were developed, how choices were made about the data to be collected related to the research questions, and how the data analysis was undertaken in a thorough and systematic manner so that choices made about what data were used is transparent and justifiable.

Accordingly, the research questions are set out again – this time for reflection with both the research approach and design. Following the questions, the research design is explained including choices about what data to collect and what choices were made about interpretive frameworks to support full description or explanation. Finally, this section reveals how issues of ethics were addressed.

Next, I will reflect on the nature of meaning-making from the perspective of social constructivism and knowledge as it relates to my ontological positioning in relation to the work, and the groundwork laid for my reflexivity. The relationships between language, discourse and knowledge will be examined as preliminary to exploring the theoretical frameworks. Then, the theoretical underpinnings of the analysis will be explained, outlining the three approaches utilized, why these approaches are chosen and my argument for why they work well together and are suitable to the research questions posed.

Giddens' work is first set out as a platform for understanding the problem people finding/losing themselves in a liminal space face in terms of *going on*, and how it is that modernity, as this relates to the nature of cancer institutions and the ways in which patient persons interact with them, affects this. Giddens' ideas concerning how the self is constituted in modernity is central

to this platform in terms of this *going on* as I analyze people's experiences of being cancer patients and becoming dying persons. I then explore the second and related Foucauldian lens on the nature of the self and the concomitant understanding of the disciplinary powers associated with the self-ensconced in cancer treatment and subsequently released. Third, I will explore Gadamer's philosophical hermeneutics and its use as a means to understand the complexity of meaning in language used by participants and found in writings about cancer care and liminality and how language can be said to form and shape the narrative self. Finally, the conclusion of this chapter positions this work as a qualitative inquiry related to the discipline of nursing

### **Research Questions**

Something is missing in cancer control systems. The cancer system focuses primarily on the biologic/cellular story of cancer and, even more restrictively, only attends to the biologic/cellular story for cancers that it deems to be curable. It is clear, however, that peoples' stories about cancer are more elaborate than just the biologic story. It is also clear that half the people who get cancer will die of their disease. What about these peoples' stories? How do they story themselves forward as people who will die of their disease? And what does the cancer system have in place to listen to and support this dying-from-cancer variation on the cancer patient story?

These are the questions my life and my work has centered on, and which I have pondered for many years in my attempts to change the healthcare system. It has occurred to me that perhaps the only way to change the system is to change how I look at the system, to take another perspective on how the system's problems seem to me. This way of approaching this project is fundamentally my own quest towards changing my mind – how I see these questions and problems and how I think about these questions and problems. Therefore, my choice of

approaches was a novel way for me to reflect on these questions, and so I began by shaping my research questions so that they lend themselves to my new and emerging view.

My questions were formed to try and capture what patients' experience of the cancer system when their disease is no longer treatable to a curative goal and the space they seem to encounter when they consequently begin to think about what happens next. One day they are coming to the cancer centre to speak with an oncologist about treatment options and they come with their hopes to be a person cured of their cancer. Another day they come to the cancer centre to be told that there are no options to cure their cancer, and they leave the centre (mostly for ever) to consider how it is that they are likely to die of their cancer. It is this space where narratively *going on* after the "no cure" message is delivered that I wished to explore and ultimately problematize. I saw this space being poorly defined in the nursing and oncology literature and poorly supported institutionally. I also saw this space and the incurable self that moves into it being shaped and then cast adrift by the cancer control system. So there was both the interpretive lens of meaning and experience, and layered onto this interpretation is the problematization and thus critical exploration of the effects of the cancer system in shaping these meanings and experiences: hence my three-fold framework. My hope was that by understanding liminality through peoples' experience of being in this space, and understanding how the cancer system contributes to the constitution of this space and self that people find/lose themselves in, I could open up yet another space to begin to explore how to support people when they move or are moved into it. I began this inquiry with the following research questions:

1. How does the transitional patient organize a self that engages with the liminal space between cancer treatment and palliative care?
  - (a) What contributes to this organization of this self?

- (b) How is this self and space made visible through language and/or narratives that are used around this transitional self and space?
2. If question one can be understood, then where ought this transitional space (between cancer treatment and palliative care) be located – inside or outside the cancer treatment centre?
- (a) What are the benefits for patients (and families) with either locale?
  - (b) What are the benefits for the contributing sectors of the health care system from either locale?
  - (c) How is either option brought into relief by language and discourses that come both from the transitional patient, their families, oncology team members and selected text surrounding the organization of these two areas of concern?

### **Study Design**

In this section I explain how the research project was accomplished, including describing the site of data collection, how access to the site was gained, how considerations of ethics were addressed, how the recruitment of participants occurred, what data collection instruments were used, how the data were handled, and how questions of trustworthiness were addressed.

Here, I describe the structure of the cancer institution where this research was conducted, with provision to protect its identity. The cancer institution has responsibility for cancer treatment and care for the people in one Canadian province. This responsibility is accomplished through multiple full-service treatment centers, a distributed network of satellite and community oncology clinics delivering or dispensing chemotherapy, and as well as through a program of research, education and data registry.

Cedar Clinic is the first established cancer treatment centre of this institution and has the specific feature of including surgical and inpatient care, as well as housing most of the provincial program leadership and the staff ancillary to this purpose. The other four centers are strictly ambulatory cancer clinics, each with a regional administrative structure that articulates with the provincial leadership at Cedar Clinic. This study was conducted at Cedar Clinic and Maple Clinic, one of the four ambulatory cancer clinics, as a means to broaden the resource for participant recruitment, as well as to explore what differences, if any, people coming to the clinics might sense of the two areas. Cedar Clinic and Maple Clinic are pseudonyms to protect anonymity. One participant had indeed visited both clinics and so some comparisons were available.

#### **Access to participants.**

Gaining access to research participants can be a difficulty in conducting health related research as potential participants can often be too ill or too concerned about their disease to have energies or interests to engage with researchers (Wolf, 2007). Researching participants who are dying from their disease is particularly difficult as, not only are people very sick, they often become even more sick and can die before they can be recruited (Addington-Hall, 2007). My research was focused on people who are cancer patients and who are leaving the cancer treatment system, their family members, as well as the oncology clinicians who had thoughts about how this happened, but also had a role to play in shaping the sorts of experiences people had in the clinic and how they were discharged. I focused on these people as my interests were to understand how this after-treatment-and-before-palliative-care space was shaped and had shaping effects for people in it. Cancer patients still *in treatment* would still be considering themselves persons of interest to the cancer system and its practitioners. People with cancer

*taken up into in palliative care* would likewise be considered a person of interest in the palliative systems and to its practitioners. I was interested in the in-between, non-institutionally located people and the liminal space they found/lost themselves in.

In my recruitment efforts I was in the interesting position of being an employee of the institution where I was conducting my research which had both enabling and confounding effects in terms of access. While I had no direct access to the patient and families, I had very good access to the clinicians, and was in some cases their supervisor. My recruitment strategy also did not focus on any particular tumour group, or any one discipline, distinctions which very much structure relationships within the institution. From the one perspective, this broadened my recruitment pool, with no restriction to a particular disease site, or a particular discipline. On the other hand, I was restricted by not being able to focus attention on a particular group of patients or clinicians as they are grouped within the cancer treatment centers. Consequently, my communication strategy was broad and necessarily quite detailed, explaining all things to everybody.

Orientation to my proposed study involved several meetings with many different groups who could either further or fetter my access. At each of the two cancer centers I met with the administrative leadership groups and explained the research so they would know that I would be recruiting staff and patients from their center. Being a research organization, this access was fairly easily granted, yet being the administrators of the centers, these groups carefully examined my research proposal to ensure that my project would not disrupt centre operations and to be satisfied that I had done due diligence with the ethical aspects of the project. These groups also vetted any advertising for participants, in terms of what could be said, in what format and where announcements might be posted. At the same time, I asked to have the discussion of my research

added to the agendas of the provincial Nursing Advisory Committee and the provincial Regional Nurse Leaders meetings. These meetings were attended to accomplish two purposes. One was to share with my nursing colleagues how I was progressing with my nursing research, to explore and share my new knowledge about nursing research, and to prepare an interest in eventually hearing my findings. The second purpose was to ask my colleagues to assist with my recruitment of participants. Other regional meetings I attended were each center's medical and radiation oncologists' regular monthly meetings, each center's Patient and Family counselling team meetings, each center's Nursing Integration groups, and each center's Pain and Symptom Management/Palliative Care (PSMPC) teams. Each of these provincial and regional groups could enable or hamper my participant recruitment. At each meeting I circulated recruitment flyers (2), as well as two corresponding letters of invitation (2), attached as Appendix A, B, C and D, respectively.

Three points of note here. One is that being a member of the organization, I had personal knowledge of the groups from whom I would need endorsement and support, and was in a position to access them without insider assistance. Two was that there were an inordinate number of people I had to consult, and consequently, there were an inordinate number of people who could either support or impede my project. It was complicated. A third point is that it was important to understand when and how I was acting in my researcher role and when and how I was acting in my role as a member of the organization. Using the self as a research instrument requires reflexivity and contemplation about the constituent selves engaged in the process to understand how the selves' biases and values shape data collection and analysis, and indeed become inseparable from the data (Sheldon & Sergeant, 2007). I was conscious of this combinative aspect of myself and tried very much to be transparent about this complexity with

myself, my research participants and with my data analysis and making of meanings, both at the beginning of the project and throughout my engagement with it. For instance, in situations where I could clearly see that my questions were disturbing people I was interviewing, I had to resist my own urge to intervene to soothe and comfort the person, thus interrupting their own train of thought and feeling and my own interest in understanding their plight. It is the weaving of Reason's sense of inquiry being "directly connected to our lives and the questions we bring to our lives" into what he terms a "living inquiry" (1996, p. 16). Moving through consideration of access to participants, this next section will explore who the participants were in this study and how they were recruited.

### **Participants.**

This research required the recruitment of cancer patients, their family members, and oncology clinicians. A different strategy was required to reach each group which is detailed here. Cancer patients who might be approached were people being seen in any part of the two centers, but not people, as I noted, to whom I had direct access. The above-noted patient recruitment flyers were posted in each of the two centers on their patient information bulletin boards. With this recruitment strategy alone, only one patient and separately one family member approached me. Five other patients were recruited to the study through clinicians who were aware of and interested in my research and were caring for patients at their point of leaving the cancer treatment centre. Total patient participants numbered six.

The process I followed as I recruited patients was to telephone each potential participant and explain the project and the commitment required of them, and if they expressed an interest in participating, to schedule an appointment to interview them in person. Interviews were carried out wherever people preferred, in their home or the cancer center. It was important to me to

bring this work to a place of participant choice as I very much appreciated their vulnerability and frailty. Only one patient and one family member wished to be interviewed in the cancer center, and all others wished to interview in their home. At the time of the interview I took the first five to ten minutes to introduce myself, explain the study and how their data and anonymity would be safeguarded and secured their signed consent (Appendix E). This time was important to conduct the ethical aspects of obtaining consent, but equally important to give and take a bit of conversation so that participants might take my measure and I theirs. From this exchange I could begin to adjust my approach and language to build and support a relationship with the participants. This was crucial to the interview as the questions I would ask I expected would disturb people, and I found it important to build their trust that I would support and honour them in their vulnerability. I was acutely aware of being a clinician-researcher in these moments. After this introduction, the actual interviews of single cancer patient participants took about one hour. I qualify this single status as some patients were interviewed along with a family member which I will explain below. Patient participants' names have been changed, and in this work are called Tim, Sam, Margaret, Jane, Janet and Mary.

Family members' perspectives were also sought, as it was my belief that they would have important but potentially different accounts for the experience and work of leaving the cancer center. The original strategy to include family members was to first interview a patient participant and from their narrative identify if there might be a family member whose perspective I could seek. If there was, I explained why I wished to speak with both family and patient participants and gave the patient my family member recruitment letter (see Appendix F). This occurred with three patient participants and yielded only one emailed no thank-you response.

Another way a family member became a participant was when a husband of a recently deceased cancer patient heard about the research and wished to be interviewed. This was not a situation I had anticipated, but I felt that his perspective might yield an informative view of transitioning and liminality, and so included him. What was surprising was learning from him that we had previously encountered one another when he had connected with me for assistance with a difficult transitional situation a year previously. When he made contact with me as a research participant, he reflected on this previous encounter, and I will admit I could not in any way recall when we had met nor what that meeting was about. Telling him that I was mystified about our connection, I asked him when this had happened. He recounted a telephone conversation we had had, and that I had answered his need some time, he said, when I was in Toronto. Thus located in my recall, the proverbial penny dropped. I was trying to remember him in a corporal way, when we had connected quite differently through the telephone. It was peculiar to be both the researcher and a character in the participant's account – another layering of self in the constitution and interpretation of the data of which I was becoming aware through this research project.

A third way I was able to acquire family members' accounts was to find myself in joint interviews with the patient and family member when I arrived at their home. As with the above unusual situation, I wondered how this combined narrative might affect the structure of the research. One choice I had was to ask the clearly curious or interested family member to step out. This choice seemed rather insensitive, these situations being very difficult for both patient and family – they were both there because it was important in some way to them that they were there together. Consequently, when faced with a duo, I interviewed both patient and family member together. These interviews were admittedly more complex, but yielded a rich interplay of

accounts which were harmonious at times and discordant at others. For instance, I had questions which were similar for patient and family member, but which changed only the subject of reflection – for example for patients “how did you feel” whereas for family members, “how do you think your loved one feels.” When I was interviewing couples I would start with the patient person, and then turn to the family member with a question asking them their positioning on what I had just asked the patient person. In a couple of situations the family member was “jumping in” and answering before the patient person, and the patient person was mute. I was thinking that this was the way family members might “take care” of patient persons, and would reflect on this sharing my observation with them, but then reframe the question to the patient person. This interplay added another layer of meaning to the accounts as will be seen when they are explored in the findings. In total there were five family member participants. The interview of single family member participants took about 1 hour. Interviews of duos took 1½ - 2 hours, and all interviews occurred over a ten month period. Family participants’ names have likewise been changed and are called Susie (wife of Tim), Steve (husband of Margaret), John (husband of Jane), Fred (husband of Mary), and Hugh (widower). As with patient participants, at the time of the interview I took the first five to ten minutes to explain the study and how family members’ data and anonymity would be safeguarded, secured their signed consent (Appendix G), and created a “safe place” for the conversation.

The third group of participants was oncology clinicians. Four of the eight clinicians who volunteered were members of the PSMPC teams which I clinically supervised. This was not unexpected as this study is about concerns central to their work and how they conceive of themselves as practitioners. I had anticipated these practitioners would respond for three reasons that were instrumental to this research. First, this is their work and they have an interest in

seeing it accurately profiled – they had insights that could inform my understanding of the after-treatment space. Second, I expected that some of these practitioners would see this as an opportunity to give voice to their concerns that their work is not well supported in the cancer treatment centre. In this, their concerns added veracity to my claim that the biologic/medical voice dominates and often obscures other ways of approaching and enacting the care of people diagnosed with cancer. Third, I anticipated that these people would want to participate through a sense of fidelity to me. I was their clinical supervisor, but also their comrade in their work and in their beliefs about this work. However, ethically this is considered a power-over relationship, and with this feature about my relationship with them, I could not directly seek the consent of people whom I supervised. Instead I worked through a proxy who took up this activity using a modified consent form and according to a prewritten script (see Appendix H and I). The other four participants were clinicians who I did not supervise. In all, disciplines represented were (a) three RNs – Kate, a member of the PSMPC team as well as Chris and Kathleen, who are Advanced Practice Nurses; (b) three physicians – Edward, medical oncologist, Paul, a General Practitioner Oncologist, and Simon, palliative care physician; and (c) two other interprofessional team members – Sally, a social worker and Gwen, a nutritionist. As with patient and family participants, these are pseudonyms, not actual clinician names.

All of the clinicians who agreed to participate were known to me and also were known to be sympathetic to palliative care. That is to say, they were all supportive of me, all interested in my work of exploring patients' needs at this juncture, and all shared hopes of seeing something come of this exploration. These interests very much weight the accounts in the following ways. One, these clinicians know of and think about patients' needs at this transitional point in their care. They are knowledgeable about this area of care and it bothers them that there seems so

little done to support cancer patients at this time. Two, these clinicians want to see things change about how transitioning patients are supported. The clinician interests that are not represented in this study are those who do not share this interest. This weighting of interests is epistemologically important to note as the accounts that are presented and analyzed are ones aligned with an interest in this aspect of patient care and in changing how it happens. This study cannot represent other interests, except as a reflection of what participants say about those who do not share this specific focus. This weighted-ness will be considered in the analysis of the accounts.

Clinicians at the Cedar centre were interviewed in the clinic where they worked, with the exception of Edward who asked to be interviewed off-site on his day off. Interviews were done during clinicians' workday, except for Edward. Interviews took forty to fifty minutes, and occurred over a four month period at the beginning of the data collection.

### **Ethics.**

Ethical approval was obtained from both the University of Victoria Research Ethics Board and the Cancer Institution's Research Ethics Board (Appendix J and K, respectively). Renewal was sought and gained from both ethics boards as the research process spanned longer than the calendar year (Appendix L and M, respectively).

### **Data collection processes.**

Interviews were conducted roughly following a script, each slightly different for patient and family members, and a distinctly different script was used for the clinicians (Appendices N, O, P). While these scripts served as prompts for me to cover the breadth of my inquiry, they

were applied in a flexible manner according to participant style and to where the conversations seemed to lead.

Interviews were taped and later transcribed into computer documents by a research assistant. Immediately after this, I reviewed each transcript for accuracy. Notes were taken during the interview capturing the setting and salient non-verbal elements that accompanied the participants' verbal text. Afterwards, these notes were entered alongside the transcribed text in the computer documents. On several occasions after the interview appeared to be concluded and the tape was stopped, patient and family participants said additional un-taped but important things. This was interesting: on the one hand, these after-tape revelations might be a reflection of participants having "warmed up" to talking about their experiences, leading them to other thoughts and ideas. On the other hand, perhaps participants found the taping a restrictive feature and strategically spoke to their "off-the-record" thoughts after the tape. Either way these accounts seemed important and so after leaving patient's homes these ideas were dictated into the tape and transcribed as "afterthoughts."

### **Process of analysis.**

Directly following the interview, observations were recorded: sitting arrangements, where we were, how the space felt to me, what the participant wore, what the participant's emotional posture felt like to me, how participants gestured, and whatever else was called to my attention that would not be captured by the taping. For instance, one couple I interviewed in a furnished apartment they had rented to be closer to the cancer clinic. The space felt bare and it was clear that the couple were not "at home" as they spoke of their "real home" and their real lives as being elsewhere, and had difficulty locating things (pens, teacups) in this "not home" space. It was also in this interview that the phone, resting on the edge of the couch where I sat, rang eight

times over the course of the interview. At first I thought this was distracting to the process I was following. Afterwards I thought about how these calls were part of the fabric of the network of support these people had fashioned – people called because they were interested, they were concerned.

Next, following each interview a short reflection was written to capture impressions. These impressions often described what was said and what I speculated was not said, in terms of looking for what lurks outside the conversation and asking why. I paid close attention and made notes about the language – or what leapt out in the form of metaphors, or what seemed particularly astonishing portions of the account. In these impressions I explored with myself what these metaphors seemed to be saying, and began making connections between this dialogue and what the prevailing discourses are about cancer treatment and care. For instance, one patient participant used several war metaphors to describe his experience of being offered treatment, and his expectations of the cancer system. Writing about him, I explored his selection of metaphors and their meanings and called him a “soldier patient.” Additionally, I noted responses I had to being in the interview process with participants, noting how my own selves were called forth in the exchange, and what meaning I took from that. These reflexive observations are woven in with the data analysis, as this is where this reflexivity happens and has implications for how I interpret and represent the data and address the issue of voice (Duffy, 2007).

The transcribed accounts were uploaded into NVivo® so to make use of this program’s coding functionality. Each transcript was read and re-read identifying words or phrases that captured what I felt participants to be saying and then grouping similar sayings together. With each grouping, a provisional label was applied, stamping on the data a first level of analysis. Examples for patients were “feeling abandoned” and “reaction to palliative care.” Examples

from clinicians were “journey talk” and “seeing the individual.” These initial labels were very close to the words that participants used, or closely accounted for what seemed to be their ideas. It was here that I reflected on the Gadamerian (1975) way of reading and hearing these words, listening to what meaning these words conjured in my imagination, seeking out the history of the word’s meanings that they seemed to express, and wondering what might lurk unseen at the edges of these meanings, what might be unsaid. For instance, one expression the soldier patient used was to look to his oncologist to see “what else he might have in his quiver.” I felt the battle imagery in this expression, even though it lacked the usual language about hero patient or courageous battle, and explored this expression as resonating with this type of imagery. Then I asked myself why he used the notion of an arrow in his imagery? And why not say arrow, but just refer to the quiver in which one might or should find an arrow? This was a very much a creative phase of my analysis and one which was helpful in weaving the narrative of the accounts.

Next, when all the segments of text which could be labelled in this way were, a listing of codes was generated so that it might be seen how they group together or stand apart from one another. These groupings represented a level of abstraction from the accounts and were reflected in more roomy terms like “trust” or “shaping effects,” and together constituted what is referred to as a mind-map connecting ideas that seemed to affect each other together (Buzan, 2000). Meanwhile, as I was reviewing the data in this way, I began to write about the accounts – to sort through the passages which seemed to embody important meanings and mapping what felt like the story these passages were etching out.

It was here that I began to shape the accounts around and within the analytical frameworks I had chosen. For instance, I could begin to see how some segments seemed to fit with Giddens’ notion of facework, and explored these segments in that way. Or another segment might seem to

exemplify the limits imposed by the clinical gaze, and so I explored this narrative with a Foucauldian lens. In this way I was able to foreground the data and explore the data with these lenses, making my own meanings with this interpretive exercise and theoretical framing.

Finally the accounts were reread and explored for abstractions formed from the labelling. This back checking was done to confirm that the interpretations continued to be grounded in the original accounts. It is these abstract groupings that form the subheadings and ultimately organize the accounts with themselves and with the organizing lenses I employed, and at my highest level of abstraction are as follows in term of cancer patients' experiences of what Giddens (1991) would refer to as narratively *going on*: Becoming a Cancer Patient-Aggregation; Unbecoming a Cancer Patient-Disaggregation; and Becoming a Liminal Person-Un-aggregating.

### **Philosophical Lenses/Analytical Frameworks**

My lens on this work is that of social constructivism, which “understands human reality as socially constructed reality” (Berger and Luckmann, 1967, p. vii). This lens counters a realist view that reality is out there and thus separated from our apprehension of it – a reality that can be separated from the world it exists within and can become the topic of a thing or a truth that everyone will agree exists in some specifiable form. Instead, social constructivism is considered by some as anti-foundational as it denies any criterion by which truth can be universally known (Schwandt, 1996). As observed by Nietzsche (1873) “Truths are illusions one has forgotten as such, metaphors which are habitual and have lost their sensory force...[and therefore] precisely because of the unconscious and this forgetting, man (sic) arrives as a *feeling of truth*” (p. 182; as cited in Forrester, 1989, p. 145, emphasis added). The meanings about cancer fit this ephemeral, interpretive notion – cancer exists as a reflection of how oncology scientists, clinicians (the biological/cellular story) and everyday people (the bodily and metaphorical story) are affected by

and affect what is currently understood about the disease. As science changes or language develops, meanings metamorphose rendering new truths which are equally situational and ephemeral. Agreement about what people experience will be a place of contestation. It is the researcher's role to offer as much supporting evidence as she can muster from the interviews she conducts and the observations she recorded to offer a defensible interpretation of how participants experience the liminal space between cancer treatment and dying.

As knowers we constantly make decisions and revisions about the versions of reality we hold. These decisions are neither conscious nor unconscious but are both at the same time, and are the ways in which we live our lives in the routine. Giddens (1984) reflects on this notion of practical consciousness in his thesis *The Constitution of Society*

Human agents or actors...have, as an inherent aspect of what they do, the capacity to understand what they do while they do it. The reflexive capacities of the human actor are characteristically involved in a continuous manner with the flow of day-to-day conduct in the contexts of social activity. But reflexivity operates only partly on a discursive level. What agents know about what they do, and why they do it – their knowledgeability *as* agents is largely carried in practical consciousness. Practical consciousness consists of all the things which actors know tacitly about how to “go on” in the contexts of social life without being able to give them direct discursive expression (xxii-xxiii).

As well, my practical consciousness is mediated by my constitution of self, itself not a static project as the powers that influence the self are always at play, not the least of which is was research process (Cohen, 1994; Foucault, 1988). For this reason I have paid attention to my roles and the responses I bring to the shaping of the data. That is to say, if there are a range of perspectives (or truths) which are possible, it follows that our situatedness shapes what we claim as truth, and all truth claims are embedded not only with the self, but also within relations of power the self is ensconced in. In relation to knowledge, language is also an instrument of uptake and dissemination of knowledge (knowledge's voice), and therefore becomes inextricable from knowledge and, in fact, mediates what is taken up as truth. This clearly has implications

for knowledge production (what this report sets out of the accounts), truth claims (how accounts are interpreted), and their dissemination (how this report positions those truth claims). In this work, this conception of language focuses the analysis not merely on what words are used in the accounts, but to ask why, and why others are not used, and what effect word choices may have.

Within this situated and language informed space, I chose three analytic lenses to shape the analysis of the accounts I gathered. First and most prominent is a framework advanced by Anthony Giddens where he explores the nature and effects of abstract systems and the reflexively created self and self-narrative as an explicit form and expression of modernity. Second is the use of Foucault's discourse analysis framing the conception of body and the analyses of both power and resistance in the context of the cancer institution. Third is the use of Gadamer's philosophical hermeneutics to explore the subtleties and nuance of language as it relates to cancer patient's self-narrative and how meaning is derived in the context of people's situations and selfhood. These three approaches are explained.

Giddens claims that a cardinal feature of modernity is the distancing of time and space and concomitant disembedding of social systems, compelling a new emphasis on risk and trust in the context of the impersonal organizations that replace local community and tradition (1991). Not only is modernity discerned at this societal-institutional level, it is also understood in terms of how it alters everyday social life and how it influences the most personal aspects of our lived experience. Thus, self and society have become "interrelated in a global milieu" (p. 32) where the individual reflexively creates the self within the external influences of modernity and concomitantly contributes to social influences. As this thesis explores the person who becomes a cancer patient and their subsequent reflexively-made self as dying person, Giddens' concept provides a suitable interpretive framework through which to understand this experience of

becoming and going on. The concepts of place and space, trust and doubt, and the work of reflexively making the self are briefly explored to anchor the reader in this analytical frame as it relates to the research interest of liminality.

Place is geographical, local and person-present. Space is what is left of place when relationships are taken up in the absence of present persons, and allows for local places to be infiltrated by ideas and beliefs from other places distant from them (Giddens, 1990). As well, with removing relationship from the person-present and located place, there is curiously a unitary framework of experience which at the same time underpins the dispersal or fragmentation of the individual experience (Giddens, 1991, p. 5). Intimacy is transformed in modernity from the anchored person or kin-centred social connection to the reflexive cultivation of trust against the background of abstract social systems: modern institutions impact relationships by “lifting them out” from local conditions, and disembedding them (Giddens, 1991, p. 18). Expert systems are one modern institution and mechanism that fosters this disembedding.

Expert systems “bracket time and space through deploying modes of technical knowledge which have validity independent of the practitioners and clients who make use of them” (Giddens, 1991, p. 18). These systems pervasively penetrate social life: our food, transportation, homes, and communication. The cancer patient does not know what the oncologist does. This is expertise that is highly specialized and to which a lay person is required to reflexively orient or re-skill themselves when they encounter it. This reflexive re-skilling is the work of becoming a cancer patient and is the space where the institution and the self are interrelated. The unattainable esoteric knowledge of the oncologist is also what sustains medical dominance in this encounter.

Trust in expert systems also does not require either a full apprehension of these systems or a mastery of the knowledge on which they are based. Relying upon modern expert systems is, according to Giddens (1990), an act of trust combined with a leap of faith. Trust in abstract systems comprises two sorts. One is trust in the known person – the long-standing relationship, the clarity of bona fides between and among people. Consider the family physician and his or her lifelong patients. The other is trust in the abstract system where expert knowledge does not passively frame the reception of lay person trust, but actually creates the conditions for the investment of lay persons' trust through the reflexive execution of expert knowledge. This second type of trust is a faceless impersonal trust which is centred on faith in the expertise about and within the system. Because of the person-less nature of trust, “facework” must be undertaken at access points where lay persons and abstract systems connect (Giddens, 1990).

Facework is what assists lay people to place their trust in expert systems: it is when an operator within an expert system takes time and effort to put a personal “spin” on things for an uninitiated layperson. Expert knowledge is considered part and parcel of the abstract system, and while this is where faith is placed, it is within encounters with the operators of the system where trust relations are often taken up. This is where operators must appear consistent with their expert claims – secure in their knowledge, manifestly trustworthy and reliable. Consider the airline pilot, the judge, the specialist oncology clinician. Consider the role played by the airline pilot's uniform, the judge's gown and the oncologist's white coat in marking these encounters as ones different from encounters with the general populace who occupy the streets and cafés beyond those uniquely expert spaces of cockpits, courtrooms and clinics.

Giddens (1991) conceptualizes the self as a reflexive project for which the individual is responsible but which is shaped by and shapes the post-traditional modern world. The

reflexively made self is thought of in the lifespan where there is a path of development from an earlier period to probable futures and includes reflection on the thinking and embodied self. The work within this lifespan is to continuously and reflexively formulate the self in a sort of self-interrogation of the lived experience. Answers to this self-interrogation form the narrative that underpins self-identity. The narrative itself is comprised of a series of passages: from child to teen, teen to adult, woman to mother, person to cancer patient, cancer patient to dying person. Note the present to future axis of this reflexive self-narrative: it presumes a now-and-then-to-come biography, a *going on* of the story line. It is in the capacity to keep the self-narrative going where a person's identity is found – not their behaviour or the perspectives of others (Giddens, 1991, p. 54). *Going on* is blocked by death, and it is in the losing or loss of the self-narrative that the cancer patient experiences liminality.

Finally, Giddens (1991) states that the reflexively made narrative self is embodied, and that “regularised control of the body is a fundamental means whereby the narrative of self-identity is maintained” (p. 57). In the context of *going on*, daily social life entails assiduous attention to self-in-body of all participants – this way of knowing self becomes central to the self-narrative. People at the end of cancer treatment and facing the next narrative stage of dying can experience a bodily unravelling where trusted and controlled behaviours come to lack regulation, and as well experience a narrative unravelling that together may lead to finding/losing themselves in liminality.

The concern of body has been analyzed by Foucault (1979) as it relates to mechanisms of power and the internal mechanism of self-control, and how medicine particularly shapes how a body is seen and how a person comes to see their self. Additionally, Foucault's writings reveal text as contextual, not with the thoughts and perceptions of the individual who produced the

statements, but rather with the rules and regulations with which the original speaker unwittingly conforms, and what Foucault calls a “discursive formation” linking Foucault’s thoughts with those of Giddens’ reflections on practical consciousness (Gutting, 1989, p. 231). Foucault’s work outlines what constitutes human knowledge and attempts to lay bare the institutions and norms which privilege particular knowledge claims and subvert others. I have argued in Chapter 2 that the “voices” about cancer are unequal, and so it follows that I should seek out how medical dominance plays out in participants’ accounts, using the process of discourse analysis to bring forth other interpretations of accounts which claim equivalent if perhaps not normative claims to validity. I am guided with this framework to think about the personal experience of the cancer patient after treatment as not merely a place of meaning to and with that person, but also as the effect of the structures and processes that the person who is patient moves with and is moved by to come to this space. I am interested in noting the layers of discourse that are at play – who says what to whom, how discourses might intersect (or not) and to what effects.

Finally, with a philosophically hermeneutic lens, words themselves become very much the focus of interest. To be a word, in Gadamer’s conception, is to be a word that speaks, and to do so from its historical and collective social meanings. This is the way in which the meanings associated with the word cancer were reviewed as context to this study – to understand how cancer stories speak to us about what cancer means. Gadamer (2002) warns us, however, that not only do words reveal meanings, words also hide and shelter other meanings. In using this approach, I am guided to look at not only what is said, but also what is not said: what meanings words seem to conjure and what other meanings lurk but remain hidden from utterance, and how these words convey the self-narrative of the people I speak with, and how they reveal or conceal power.

In sum, the framework of modernity elucidates the nature of time, space and trust relationships in the context of abstract expert systems, the process of reflexively narrating the self, two very pertinent aspects of the cancer control system described in Chapter 2 and the problem about how people connect with, or disconnect from it. Discourse analysis contributes a second layer of meaning, decentring the subject and seeking to understand the power effects at play in the discourses that comprise cancer treatment and subsequent liminality. Finally, hermeneutics is a philosophic lens that illuminates the word and the meaning conveyed by words, allowing access to what is present and evocative in the language that people use to convey their self-narrative and their experiences of liminality. Each approach offers a perspective on the accounts and other data I have gathered: together they form an anchor for the interpretive process, and allow me to detail for the reader how I make meaning, and so argue for a meaning made trustworthy. It is this notion of trustworthiness that I will now turn.

### **Trustworthiness**

Trustworthiness in a qualitative enquiry entails the following elements (a) clearly identifying the research question, (b) revealing the sources of the research data, (c) identifying and recounting the steps in the analysis of research data, and d) noting the issue of voice in the “re-storying and re-presenting” of the accounts, sorting out which self is (or selves are) speaking at which time (Duffy, 2007, p. 417). Each element will be briefly reviewed.

Here in accordance with Reason’s (1996) essay on the purposes of inquiry, I have identified the research questions and their relationship to my interests in my personal fulfillment as a clinician-researcher, my concern to change liminal cancer patient’s situations working from their needs, and my purpose to disrupt power relationships in cancer systems. My sources of data in terms of choice of participants, attention to language and silence, and consideration of

sensory input are revealed and explored as commensurate with the questions posed. The steps in the process of analysis are clearly set out, and my awareness of voice, for myself and my participants, is given an account of and will be revisited and reflected upon throughout the presentation of the findings. Finally, as meaning was being made of the data, interpretations were shared first with my supervisor and subsequently with the entire doctoral committee where my explanations were scrutinized to assess the soundness of my arguments and to ensure that these arguments were commensurate with the questions posed. With this study's design, approach and trustworthiness articulated, I will now turn to how I situate my work in the discipline and knowledge of nursing.

### **Situatedness within Nursing Knowledge**

Knowledge production, dissemination and application are the core business of disciplines. Disciplines develop knowledge as a means to progress or change and without knowledge would cease to exist (Toulmin, 1972). The aim within a discipline, like any other form of governance, is to strengthen itself. It is important, therefore, to situate any knowledge production activity associated within a discipline: its epistemological structures and ethos, as well as its governance objectives.

The discipline of nursing has a long history and tradition of articulating conceptual frameworks and models; practice, middle-range and grand theories; and metaparadigms which, for the most part, have been permeated by a logical positivist essence. The persistence of the discipline's adherence to logical positivism can be comprehended if one appreciates that these particular claims to knowledge were and are also claims to disciplinary power, very much modeled after and seeking territory from medicine. It is ironic however that there has been such a large investment in these disciplinary structures and particular uptake of knowledge when so

very much of the interest of nursing practice is not easily accessible through a positivist frame. I would argue that this focus is more about disciplinary power than the practice of nursing.

Foucault (1972) links discourse with power as both a productive and a restrictive force, and one which is inextricably linked with the production of knowledge: limiting, in nursing's case, as it has to some extent eclipsed the disciplinary lens to what can be measured and counted, and productive as the same exclusionary frame may perhaps have encouraged what was otherwise forbidden. Perhaps, despite these disciplinary structures and metanarratives, a major reason for advancing nursing knowledge is for the sake of understanding and improving nursing practice through knowledge.

Exploring that which refuses to be measured and counted, some aspects of nursing have been seen through, and grounded in, an expression of nursing philosophy. It is through this lens that the discipline has become exposed to the questions and concerns that characterize philosophy. These are not the "how many" questions, but the "how" questions. This postmodern attention to plurality, situatedness and power considerations in nursing has had some limited effect on the discipline. Lather (1991) characterized this turn as "a response to the contemporary crisis of profound uncertainty brought about by the crash of modern hope of rationality and technology to solve human dilemmas and quest for a description of "Truth and Reality"" (p. 20). I think a small portion of those working within the discipline of nursing are aware of this contemporary crisis, while a majority of nursing scholars remain unconscious in this regard. That the discipline is affected by a postmodern turn is evident in some attention being given to different kinds of knowledge which focuses on how meaning is constructed. This knowledge is characterized as that which goes beyond the physical, material and technical orientation of modernity to a link with truths that reflect context, connections, interpretations and social

constructions of reality. This attention to meaning construction is not mainstream in the discipline and remains somewhat fringe to disciplinary interest, but it is a feature of the discipline that I am newly aligning myself with. This approach has the potential to place nursing knowledge in the realm of plurality, provisionality, and criticality: to hermeneutically seal the covenant between nursing knowledge production and situated nursing practice as it seeks to relate to the experiences of health and illness of those whose presence generate opportunities for the activities and ethos of nursing.

This chapter has set out how this qualitative inquiry has been pursued in terms of how it was conducted, the frameworks used and how the trustworthiness of the project is demonstrated, and defines the place of this work as a qualitative inquiry related to the discipline of nursing. The research questions are articulated and demonstrated to fit with the methodological approaches selected. Access to participants and recruitment strategies are explained, and data gathering strategies outlined, revealing how issues of ethics were addressed. Finally, how data were analyzed, perspectives applied and meanings made are explored, linking the study design with the analytical frameworks and the ultimate aims of the inquiry. With this fore structuring of how the research was conducted I will now turn to share what was seen in the data, and what meanings were made of the inquiry.

#### **Chapter Four: Becoming a Cancer Patient – Aggregation**

This chapter sets out the first major finding of the inquiry. The findings are organized according to patient participants' accounts of how they became cancer patients, how they were discharged from the cancer system, and how they found/lost themselves after their disengagement with the cancer system in what I will argue is a liminal space. This temporal way of presenting these findings reflects the patient participants' accounts of "first this, then that, then this," as well as the interpretive findings of how patients self-narrated these spaces in their experience. Alongside patient perceptions clinician perspectives are explored to better understand how they see their own behaviours shaping the discourse surrounding cancer patients' care, paying attention to clinician language and clinician perspectives of how people become constituted as cancer patients. Accordingly, each portion of the findings is thought of in terms of the patient participants sense of progression or going on, and also conceived in relation to three themes in terms of the interpretive concept of aggregation: people becoming aggregated as cancer patients, becoming dis-aggregated as they leave the cancer system and becoming non-aggregated as they lose/find themselves in a liminal space.

The concept of aggregation is used here as this theme was the highest level of abstraction discovered in the accounts. People becoming cancer patients were gathered in, grouped and labelled in different ways which will be explored. This gathering in was not merely a disciplinary activity or system effect, but also how patients rethought about themselves and their self-narrative as they gathered in new perspectives of being not only a person with cancer, but a cancer patient. This going-on-after-the-cancer-diagnosis is what seemed to be a mutual partnership between the person needing the cancer system and the system being the appropriate expert system to meet this need. Going on was thoughtful and deliberate. However, when

treatment ended, the notion was that after being so attentively shaped, cancer patients were disbanded and let go, un-becoming cancer patients and leaving a sense of uncertainty and unravelling of the self. This new space was labelled as dis-aggregation. Going on in this space was not felt as mutual, but rather a one-sided orchestration of “moving on” on the cancer system’s part with an opposing self-narrative of “staying ensconced” from the cancer patient and family member’s sense of the narrative. Finally, some of the people with cancer, after leaving the cancer treatment system found/lost themselves in what is referred to as a liminal space and one where there was, from their perspective, no aggregating or shaping occurring and a consequential loss or interruption of the self-narrative. This third space has been labelled non-aggregation, and is the liminal space that this work newly uncovers and will be most extensively explored. Going on in this space was truncated for some, and fraught for all.

This section explores first how people come to be diagnosed with cancer and then when entering the cancer system what subsequent labelling, aggregation and shaping happens, and how this activity informs the self-narrative of the person becoming a cancer patient. As well I explore what countering energies of individuation and resistance are manifest as patients interact with the expert cancer system, crafting a note of person-in-treatment narrative. This section includes not only how people and their family members experienced this first transition, but also explores what oncology clinicians said about how patients coming into the system and are subsequently shaped by their experiences of being cancer patients. Understanding the work of entering the cancer system is foregrounded so that I may eventually appreciate how the system is exited, and how the self-narrative changes and why, which is what the next two sections will explore.

What is it to become a cancer patient? Cotter (1999) writes in her guide for people recently diagnosed with cancer that when a person is diagnosed they join the cancer movement:

“You’re one of ‘them.’ More accurately, you’re one of us” (pp. 6-7). There is a gathering in here, an aggregation which will be seen reflected in the accounts, not simply as a matter of being passively herded, but in a more complex manner of being aggregated and complicit with participating in the aggregation. Cotter goes on to instruct people what they can expect to be a cancer patient, and how they might behave to do well as cancer patients, and I would suggest how they might ultimately gather in a self to be brought under the medical gaze of their oncologist (pp. 6-7). How is this revised self-shaped for and by the person who has discovered this disease in their body? The accounts I gathered from people becoming cancer patients indicated that they were compelled by the diagnosis to learn and add a new self with cancer or cancer patient self after enduring an in-between transitional or becoming space filled with testing, waiting, uncertainty, anger, grieving, yearning and learning, and all things people are likely to experience when mortally endangered as they are with facing a cancer diagnosis.

People I spoke with began their narrative with a once upon a time of their cancer experience: the lump that was noticed, the cough that didn’t seem to get better. There was a cognitive and perceptive shift to making visible a previously ignored bodily function or, I would say, a reorientation to their body as one harbouring cancer. It is something we have all experienced in illness: the headache that reminds one constantly of the size and weight of the head, the cold that brings the nose and sinuses into relief in a way wellness never emphasizes. It is a heightened and focused bodily attentiveness that illness or novelty portending illness (the new lump or cough) brings about. People who noticed these telling symptoms take notice of their bodies in a very different way. There is a start somewhere where people were healthy in a body-inattentive way, and in another moment in time they become unhealthy in a very body-attentive way. People become cancer patients by being compelled to notice the bodily changes

that ultimately changes their sense of the world in which they live. Two participants spoke clearly to this transition: Mary and Sam. Both experienced the bodily changes, how their discourse about this intersected with the medical discourse, and how they came to narrate themselves as a cancer patient. The accounts are quite interestingly different, but lead to strikingly similar conclusions. First, Mary's account details her bodily discovery and how this changed her life and story.

... my doctor sent me for an x-ray after a long time of wheezing and kept saying it was my asthma and finally sent me for an x-ray and it came back and it had a nodule on it. They didn't want to explain the nodule until I came into see the doctor ... And then we were told to wait, this was in early May, we were told to wait until July 4th for a CT scan at (name of hospital) and we phoned the private health clinic in Vancouver and had one done there and that's when we knew. He said, the radiologist took some time with us, he put his hand on my shoulder and said, "I'm very sorry" and I knew, I just knew. I knew what it was. I knew I was incurable and that we were on a trip.

Mary is being self-surveillant about what seems to be happening to her. She knows something is wrong, but she cannot seem to get the satisfactory attention of anyone in authority. Her body was signalling that there is something wrong, as her coughing won't go away. She receives a sinister but inadequate label (nodule) and she pulls strings to get at the expert opinion she feels she needs as quickly as she can. She knows that the experts know something, but she just cannot seem to get them to tell her. And when she finally gets the expert opinion she is looking for, she says that she already knew. Gathered under the expert clinical gaze of the radiologist, Mary gains proof that her self-surveillance was accurate – the discourse of her bodily account and the expert medical discourse intersect. What is interesting is that Mary feels reassured, like knowing she has cancer is better than worrying about whether or not she might. Here is a clear rendering of the becoming space filled with testing, waiting, uncertainty, anger, grieving, yearning and learning. With learning her diagnosis from the right medical expert, Mary now has a legitimate place for herself and her body, somewhere from which she can begin her

“trip,” and I would suggest a major alteration of self from well-but-worried to self as cancer patient but now comparably medically safe and grounded.

Mary, and most of the patients and families I talked with, had on hand their notes about what happened when – a chronicle of the medical events (for example CT scans, cancer treatments) and bodily measures (for example, blood assays) that had happened since the discovery of their disease. They were notes specifically about events and measures, not responses to events as a journal might be. These notations about events are a mechanism patients and families used to keep things straight when so much seemed to be happening, and are also a means of maintaining control. But as these notes were only about the medical events and body responses, I would also argue that this chronicling is an example of a technology of self-care that places the onus on the cancer patient to record their medical progression as it is a record only about the biologic story. A number of Foucauldian scholars have highlighted the relationship between risk, governance and an emerging morality consistent with the project of neoliberal self-surveillance (Castel, 1991; Lupton, 1995; Petersen, 1997; Petersen & Lupton, 1997; Rose 1993, 1999). Neoliberal rationality highlights the entrepreneurial person who is expected to take up their own self-governance through practices of “endless self-examination, self-care and self-improvement” (Petersen 1997, p. 194). Certainly these chronicles are a practice in self-attention and self-care – but focused on signs of the disease’s progression in the body and the medical interventions. These chronicles are also not incidentally chronicles of the biologic story of the cancer. It is a journaling of the medically-rendered bodily self and becomes a major underpinning for how people becoming cancer patients relearn their narrative to fit a medically dominated space: to become a cancer patient is to enter into a medically dominated *going on*.

Also interesting in Mary's discovery account is the lack of regard for the family physician. I see this as an account of the infallible found fallible. This was a story that surfaced in several of the patient and family accounts, as well as in the clinician accounts of how their patients took up what they referred to as community care. It has meaning here when we think of how patients frame their cancer discovery accounts in relation to inexpert community systems, and recurs later as they are asked to leave the cancer system to go back to these community systems, as all cancer patients eventually do. Note also Mary's response to the perceived inefficiency of the health care system as a whole. It seems that people differentiate between the expert cancer system and what they construe as the less than expert community system. For Mary the family physician was "okay," or maybe even "pretty good," until things became serious. Then, the family physician's diagnosis of asthma does not seem to convince Mary – she knows there is something more than asthma is wrong with her as she pays attention to her bodily story unfolding. She presses to get into the expert system where her bodily story can be vindicated. The family doctor was wrong and worse, *he wasted time being wrong* while Mary was working to obtain the expert medical or biological truth of things. I wonder how often cancer patients' narratives of diagnosis alienate them from their family physicians, not just in the discovery of their disease, but once and for all after experiencing the acumen and confidence of the expert oncology clinician? This alienation has meaning here, and reappears later as we examine how patients narrate their transition out of cancer systems.

A general diagnosis is usually conveyed to a patient by a family physician who has received some feedback from a screening test (for example blood test, mammogram, fecal occult assay) that indicates that there is some cancerous process occurring. Mary's story illustrates this process, but she was neither trusting of her family doctor nor what she saw as the health system's

inefficiency, so she circumscribed the usual steps making her diagnostic waiting period shorter and rather more efficient: she took care of herself (Foucault, 1988). Stepping back from Mary's specific situation and the general observations about how the diagnostic process happens, there is no doubt that concerns about how this discovery happens are fuelled by the media portrayal of the fractures in our health systems, with stories of mistakes made by pathologists and extended wait times for tests and treatment (Canadian Broadcasting Corporation, 2010). But what I wish to draw attention to here is how this background perception of ineptitude is part of how people's expectations are shaped, and how their self-narrative alters as they enter the cancer system.

To contrast Mary's rather efficient process of accessing the expert system, Sam describes a very different feeling story of discovering he had cancer. It is a long and rather winding narrative, as in contrast to Mary's becoming experience, Sam's was far less efficient, less straightforward.

I had been having pain with my hip for some months and also I had pain underneath my arm for some months. I had been seeing a GP trying to sort out what the problem was. It went on for ages, I thought I had pulled a muscle or broken a rib or something like but on examination they found nothing. The hip thing was going on, this was like from the summer. I developed an increasing limp and it was agreed eventually I was going to come back at an annual medical time and if this thing hadn't gone away then they'd check it out thoroughly and see what the problem was. They did finally, and I eventually got into significantly enough pain that I couldn't stand up and I went into a clinic without bothering to wait for my GP, and he ran tons of blood tests over a two week period and looking for markers and goodies like that and everything came up negative. And then, in early December, I put my weight on my left leg and I heard a discernable pop and thought I had dislocated my hip. So, I writhed around in pain for, I don't know, 10 or 15 minutes and got up and went walking around again. I went to the doctor and he had prior to this done an x-ray of my hip to determine if there was any early onset or arthritis or something like that and it came out negative. I went to the doctor and he had been prescribing physio for me and so I went out there and I explained that I thought I had dislocated my hip and he said no, it's too robust a joint you couldn't have dislocated it and not only that if you had you would've been in such pain, as much pain as if you broke your hip and if you had broken your hip you wouldn't have been able to walk in here.... And then finally it was taking me 10 to 15 minutes to get into the seat that I use and 10 or 15 minutes to get out and the pain was getting worse. Oh and he also, my doctor also did a cortisone shot but that didn't fix the broken hip. And eventually I decided that I was going to have to go to

emerg and get somebody else to take a look at this. I went into emerg and after they tossed me around like a bag of potatoes they said, oh you don't move, you did break your hip, the ball had broken right off the top and then from there they decided to go ahead with the hip replacement operation. While doing that I guess the bone was sufficiently compromised that it broke again, the leg broke further down so they got a longer pin, and fixed it. Then they said, and now for some good news, the good news is you've got a broken hip and the bad news is you've got stage 4 metastatic cancer that's spread around to at least four, five parts of your body and uh, they give you 50/50 chance of 3-6, 3-9 months.

Sam's account is what I would call Mary's nightmare made manifest. Like Mary, Sam knew something was bodily wrong. Like Mary, Sam started with his family physician. But unlike Mary, Sam believed and trusted in his family physician whereas Mary did not. Sam lived the pulled-muscle-not-broken-hip diagnosis narrative for months. Mary waited on the asthma diagnosis narrative for a few short weeks. Both Sam and Mary did due diligence in terms of self-surveillance, Mary over the short course, and Sam over the longer. Sam's was longer, not because he failed in any way to take care of himself, but he just could not seem to get anybody to notice and accurately medically pronounce his ailment. His bodily story did not seem to intersect with the medical story, or when it did, it had lesser weight and the medical story prevailed, *even though it was wrong*: Sam had no way to go on as a cancer patient. He was in his own words "a bag of potatoes they tossed around." But for both Sam and Mary the becoming self-narrative has a familiar close. It was only when their symptoms and experiences are gathered together under the expert medical gaze did they have any weight or measure. The domination of medicine in their cancer patient self-narratives provided a way to be and a way to go on.

There is also something very different about how Mary and Sam engaged with the cancer system which I think reveals the potency of selfhood for the person becoming a cancer patient. Mary and Sam both worked within a framework of expectations and experience which they brought to the situation. Sam seemed to rather passively allow the health care system to direct

him unlike Mary who was ready for calamity and incompetence and quickly took the situation very much in hand. Mary's going on was medically dominated, but personally forceful; Sam's going on was also medically dominated but much less personally forceful. These accounts indicate that there is an interrelationship between the person and their going on to be a cancer patient narrative, and as collective as we might like to think the experience of becoming a cancer patient may seem to be, the person's history and sense of self very much shapes this first transition.

Self is a very interesting concept, and certainly has been given much thought: I will examine three theories of self as they each give meaning and context to what a cancer patient self means. First Cohen (1994) proposes that the individual is a "basket of selves which come to the surface at different social moments as appropriate" (p. 11). Each self owes its origins to some experience or situation the person has encountered that shaped it. Mary's very quick rendering of her self as cancer patient suggests, according to Cohen, that her basket contains a similar self based on similar experiences. In a second conception, Giddens (1990) treats the self as a reflexive project, "not as a passive entity but rather one that needs to be reflexively made" (p. 2-3). This calls to attention the notion of purposive engagement of the individual in the formation of the self, drawing on the past to organize a self which can adequately respond to present and future requirements (1991, p. 75). From Sam's account, we have a sense that his passivity reflects some sense of his self in relationship to expertise, or perhaps authority. Foucault (1980) also rejects unitary views of the self calling specific attention to the danger of thinking of identity as "quite deep and quite natural and not determined by political and social factors" (p. 4). From this notion the self can and does consist of multiple shifting identities which are externally and

internally co-created. This notion of self directs us to look at what externally may have shaped Sam's and Mary's sense of self as cancer patient. What interests were being served?

With these notions of self, I reflected on who Mary and Sam were as the persons I had come to know in our conversations. Mary revealed that as one of her many constituent selves, she was the mother of a boy with asthma.

We went through a lot of that with our son, he had asthma and that was before asthma became popular and no one really knew what it was at first so every time we took him to the emergency ward we had a new doctor, we had a new resident, we had a new intern, we were telling the same story. You know we were saying he doesn't need a new x-ray, we just ... the fight went on with different doctors every time so I think that's why... We learned to become advocates for and of care.

In this self-narrative, Mary learns that the health care system is imperfect, and through her experience as mother of a chronically ill child, she learns to speak out, to be an advocate. And so when faced again with the ineptitude of the system (interestingly enough surrounding yet another diagnosis of asthma), Mary brings her mother-as-advocate self out of her basket of selves to the foreground in a way that seems to eclipse almost any other way she might respond to her initiation into being a cancer patient. She is signalling that she is prepared to do battle with the system, that she's got experience of doing that, and that she sees the situation she is in now as similar in some ways to the situation she has faced before. She is experienced, even though she has not experienced cancer before. It is the sense that she holds of her situation that shapes her encounters with the world she engages with, and how she narratively goes on.

Mary's advocate self was a known and trustworthy self who could deal with the vagaries of the situation. Sam, on the other hand, drew on very different reflexively made self in his situation.

Ann: What did you expect?

Sam: I would expect the doctor's attitude to be, what can I do for you ... I have a bag of tricks and I have a great deal of medical expertise and they're constantly developing things

and I'm on top of it and I'm the expert and I know you're going through a tough time and it's difficult coping and things like that, but I'm here to help...and you know it may look a little grim at times but, you never know. Or, I have this experience you know and things have looked grim, I've seen it before and things have miraculously turned around and whatever.

Ann: Now, from your own perspective what do you think about Sam makes you better able to cope with what you are dealing with right now?

Sam: I'm a fighter.

Two things of note – a respect for expertise and authority in the situation and the corresponding posture of a warrior or soldier. I was not at all surprised to find that Sam was retired from the navy. His soldier self was what is reflexively incorporated into his self as a cancer patient – do not question orders; those higher up have more information and we soldiers are subject to need-to-know measures. Both Mary and Sam are fighters, but Mary reflexively relates to an advocate self who was very aware of the terms of engagement, and Sam reflexively relates to his soldier self, assuming that the experts in authority will signal if and when he needs to fight.

Clinicians too were aware of the “baskets of selves” people had that shaped their sense of themselves as cancer patients. Clinicians paid attention to how individuals expressed themselves as distinctive in terms how they made decisions about treatments:

Sally: [patients' decisions]...probably has to do with the developmental stage they're at in their life and what their roles in life are ... are they a parent, or are they a grandparent... do they need to be perceived as fighting this disease in order to maintain a role as parent, and a caring parent who's going to do whatever they can to be around for their children. You know, like ... So, I think their, their process is impacted by, and the decisions they make for maybe more aggression treatment or more risky treatment or clinical trials or whatever might be offered to them is dependent on all of those things.

Here we see Sally, a counsellor, understanding and interpreting people in terms of their life stages and roles and in so doing clearly honouring the patient person's sense of self in her interactions with them – she is giving voice to the patient's bodily experience of having cancer,

their self-narrative of being a person with cancer. She is making a genuine attempt to understand them as people and as constitutive selves.

We can see from these accounts how a person begins their transition to becoming a cancer patient with the pinning down of the diagnosis: not arthritis, not a broken hip, not asthma, but cancer. It is interesting how important it is for people to know what is happening, even if finding out what is happening is as distressing as a cancer diagnosis certainly is, and how very distressed people must feel with their sense of uncertainty to latch onto such a grim certainty. As a way of understanding this, how might these uncertain and certain situations be construed in terms of control? That is to say, is the appeal of the grim certitude of a cancer diagnosis associated with a feeling of being in control that perhaps the uncertainty of not knowing what is happening comparably lacks? I would argue that it is, and that while both Mary and Sam were unhappy with their cancer diagnosis, it was better than the dread of suspecting but not knowing: the ambiguity of the situation, the ambiguity of the self-narrative. It was as if they sensed a liminal space of “being/not being a self with cancer” opening up which was quickly closed with the definitive narrative thread of “cancer patient” that allowed them to go on. Armed with their legitimate cancer diagnosis gave them their beginning status as cancer patient. They were on a trip which brought them both to the threshold of the cancer system; they could narratively go on as bona fide cancer patients.

### **Access Points to Expert Cancer Systems**

Once the diagnosis of cancer is established people are engaged with the formal cancer system through the only portal available to them, the provincial cancer organization (PCO). Referral to the PCO can only be made by a physician (as there is the necessity of the medical prerogative of diagnosis) and must be accompanied by the necessary diagnostic information,

substantiating that the person does have a cancer, and where in the body the cancer is. From this information, patients are triaged to one of several oncologists with expertise in the type of cancer they have. Finally, an appointment is made and communicated to patients who come to their local regional cancer centre for an oncology consultation. So before a person crosses the threshold of a cancer centre there are decisions and aggregations made about which they have no idea (or control) but which very much affects who will do what with and for them when they arrive at the center. Where patients and their families actually become involved is when they receive their phone call for their first visit to the cancer center. Literally, the cancer system reaches into their homes and lives and organizes their time and activities to synchronize with the cancer system schedule. It is difficult to conceive how else this might be done, but this work of getting to the cancer centre is accomplished in this way and it has consequences. According to Foucault, cancer patients' existence has begun to be shaped and "brought into an increasingly dense and important network of medicalization" (Foucault, 1994, p. 134). Thus scheduled, people come to the cancer centre and continue their self-narrative as cancer patient. Here is a first visit account from a cancer patient, Margaret.

Going to the cancer clinic, that first experience, I think that's when I think because we knew what was wrong, we knew we'd entered a new world because there's people with no hair and they're young and they're old and they're all filling out forms and sort of like in the future walking through void spaces, some knowing where they're going and some not, you know it was a very unusual experience.

There is a sense of having been beamed into a science fiction scene with a disturbing mechanistic feel being described – a room full of aliens being processed. Margaret knows this is grave. Such purposive behaviour must be about something terribly important and terribly serious. Margaret speaks of fellow cancer patients as if they are very different, but she also notes that they are all here together filling out forms, so they are all in this space and activity the same. If

we reflect on this passage and think about Giddens' (1991) notion of the self-reflexive identity, Margaret has not arrived at a point where she can define herself in that moment or see herself moving ahead as a cancer patient. Her language belies her misgivings: "they" are in the future (not now, not with her) "walking through void spaces" – ill-defined and not calling forth a narrative to move her self forward. Small wonder Margaret closes this passage by saying it was a very unusual experience.

Contrast Margaret's description with another first visit account of a patient's wife Susie describing their entrance to the cancer system first through the surgical portal:

Ya, it's like little pods. I think the perfect to me example was when we went to the main part of (local hospital) for his pre admission, we walked to the desk, they said oh Mr. B, here are some pamphlets to tell you what's going to happen, read these over ... this is about the ... anaesthetic, this is about the operation, this is about the follow up, this is to fill out for your medication da da da and they had a little package for us. When you get to the cancer agency you go to the desk and they say, you're a new patient go to floor two, go there, go...

What Susie describes here has a similar feeling of Margaret's first visit description. Little pods, little packages, all ready in the making. Fill this out, go here, do this, go there, the da, da, da: all very much a feeling of being aggregated, being processed, being pushed forward in the cancer patient narrative, and being shaped. The process is efficient, and in terms of the cancer system objectives seems effective, but it was felt to be a depersonalizing experience by people becoming cancer patients and their family members.

Giddens (1990) would refer to this space described by Margaret and Susie as the "access point" for the lay person becoming cancer patient to the expert cancer system. According to Giddens, it is this crucial point of connection at which trust may be built up or otherwise destroyed. What binds lay actors into trust relationships with experts is what Giddens terms facework (1990), and is vital to lay persons' capacity to interact with the expert system. I have

reviewed facework in Chapter 3, so will here only point to the notion that it is what exists (or does not exist) at the interface of people becoming cancer patients and the cancer system and has consequences for how patients may or may not trust. Facework functions to reduce the concern that the human operators within the abstract system have the necessary knowledge and skills to deliver what the abstract system represents. In the cancer system, the operators are all front-line people involved in the system: oncologists, receptionists, nurses, and others. The abstract cancer system represents the knowledge and skills required to accomplish its mission: (a) to reduce the incidence of cancer, (b) to reduce the mortality rate of people with cancer, and (c) to improve the quality of life of people living with cancer (British Columbia Cancer Agency, 2009). For people becoming cancer patients the facework is concentrated on the second and third points. The aggregating and processing must factor in for patients and family members as necessary elements of delivering on these outcomes. Patients are moved through this first interface, and while aware of how odd it feels, they are willing to subject themselves to this. This is the price of admission to the expert system – their work of getting in synchrony with the system they are entering. It's sort of like leaping onto an ice skating rink with skaters all going in one direction and at a very good clip. There is a pushing off and a scurrying to join the flow, to get up to speed, to get with the story. It is like people becoming cancer patients know the enormity of information they have to take up, and they are doing it with as much alacrity as they can muster, adjusting their self-narrative just as quickly as they can.

Clinicians were also sensitive how trust is built up through the continuity of conversations with patients, whether those conversations started with themselves, or they were picking up threads of conversations started with a family physician. They were sensitive that this kind of dialogue with patients laid down foundations for patient-centred care and for fostering

trustworthiness, and as such I see this as a cardinal piece of facework some oncology clinicians were aware of. These conversations are also very much fabric from which people becoming cancer patients weave their emerging self-narrative. In the Gadamerian (1975) sense, these conversations are where meaning is made – clinician and patient each contributing to and building an understanding of the person's cancer patient narrative, weaving the going on of person in that story. Here Chris tries to sort out where these conversations and facework should begin.

I think it could be part of the cancer systems work, it could be part of the role of the GP, but I think it has to start so that there's ongoing discussion ... and I think that's especially um, with – with serious or with a chronic disease or a diagnosis like that I think that if patients sort of understand that yes, we're going to work towards um, you know, getting better and all that, but there are cases or there are situations that maybe it won't happen and those are things you might want to talk about with your family about what your thoughts are and how you want to be treated or you know, just start that conversation.

Chris is signalling to her patients that she wants to partner with her patients and that in doing so she is accessible and trustworthy. It is interesting to set this account from Chris's perspective alongside Mary's account reflecting a general health care system that Mary felt was inept. Certainly Chris does not seem aware of how people may come to see the general health care system as they become cancer patients, and that in fact her facework is not likely to be seen as a continuation of what might have started in the community, at least not from Mary's perspective. It is also important to note here that relationship building and ongoing conversations within the cancer clinic are not always consistent with institutional interests. First, there is no time afforded for conversations or relationship building in the context of a clinic visit. Each cancer patient visit is afforded thirty minutes with the oncologist, and this is not always the same oncologist. In this time frame, the oncologist will explain the biologic features of the disease, how it may be treated and what effects can be hoped to be gained – he tells the biologic

story. There is no time for difficult questions. There is little, if any time for the patient to contribute to the exchange in any other way than as a passive consumer of the oncologist-offered information. There is no time for patients to share their bodily story of their cancer experience, outside of what parameters of treatment response the oncologist plumbs. The reflexive self-narrative of these exchanges is that the medical narrative is paramount. This is neither accidental, nor without effect.

Another piece of facework designed to help patients and families in their becoming process is the “New Patient Orientation” the PCO offers at each of its regional cancer centers. This is a program offered to all new patients and is a group session. Here it is explained to people what cancer is, how it is treated through the cancer control system and what supports are available to cancer patients and their families. It is significant that these orientation offerings are made to groups of patients, rather than through a one-on-one approach. In one way, grouping is a way of making people anonymous, consistent with the aggregating and processing the PCO’s efforts have entailed. Foucault (1982) views this as a scientific and in this case administrative technique that ignores individuality in an effort to determine who the individual is as a reflection of an expert defined category, a technique consistent with the medical interest of cancer. In another way, however, this may be a way that helps patients to group with those in similar circumstances and to know that they are not alone in their unwelcome and frightening experience of becoming a cancer patient—in Cotter’s words, “one of us” (1999, p.6). Either way however, it is a technique arising from the cancer system that brings people becoming cancer patients into this first aggregation.

### **Orientation to the Expert System**

Once referred, cancer patients are triaged to an oncologist who through general training in oncology and specific training and experience in one or perhaps two types of cancer is positioned as expert in their type of cancer. Here is manifest the indelible cancer system structure. The types of cancer are associated with the tissue or body-part in which the cancer arises as this morphology tends to influence how a cancer behaves and to what treatments it may or may not respond. Accordingly, the cancer system itself is shaped around dealing with these different body areas, for example: lung cancer, breast cancer, colon cancer. Oncologists tend to focus their skills on one or two of these cancer types so that (a) they are knowledgeable about how to treat a particular type of cancer, and (b) so that they can further the research in a specific cancer type. It is noteworthy that in the discipline of oncology, very focused (disease specific and body-part limited) expertise is developed and is how this disciplinary arrangement gives shape to the omnipresent organization seen throughout cancer systems. Contrast this to the hodgepodge of general practitioner knowledge and expertise. Is there any wonder people having experienced the cancer system find their family physicians less competent by comparison? Patients and families are very much aware of these differences. This body-part organization of focused expertise is what people becoming cancer patients have to orientate themselves in order to align themselves with this expertise, and to understand what is happening in their clinical encounters, to story themselves forward as a particular type of cancer patient. This trust and faith placed with the expert cancer system serves to make the eventual abandonment into liminality even more striking for these people.

This body-part alignment exercise is essential to the next step of becoming a cancer patient. The person becomes not only a cancer patient but a lung cancer patient or a breast cancer patient

and with this alignment they join the many other cancer patients in their body part specific group, mostly because the cancer system organizes the oncologists, nurses and care team members around this way of seeing a patient. This alignment with like cancer patients is a more focused aggregation. Here people join with other selves who are also engaged in this creation of the self-as-body-part, I think because it is part of their emerging sense of self as cancer patient that is being shaped by the cancer system. This is cancer patient Tim's account of this alignment.

I was diagnosed with prostate cancer, I don't remember the name of it, but it was number 10, it was the worst and uh oh, I had tens for everything, my Gleason score, my everything and we were assigned an oncologist who we really like and it was pretty simple, the basic treatment for metastasized prostate cancer is hormone therapy which was Zolodex, was the trade name I guess, I don't know what the actual, but it suppresses the production of testosterone and testosterone is the gasoline that makes the prostate cancer grow and that was all explained to me. I was given my Zolodex injection and my PSA went from 700 down to 18 in the first three months and then down to zero and it stayed that way.

Note the language Tim has acquired in learning about his cancer and how it is treated. All very technical, very specialized terms about prostate cancer from a man who is a husband, father, golfer and architect in terms of some of the selves I glimpsed. Knowing a little bit about architects (my brother), I reflected on the work of organizing and engineering structures: the precision required and the need to control the process. Having another brother who is an artist, I wondered how an artist self might understand and express prostate cancer? I doubt that it would feel the same. So Tim joins with the expert cancer system's organizing efforts, adding his particular architect self to the reflexive project of his Tim-with-prostate-cancer self. Reflecting on Tim's language, if we recall how language is the way we construct meaning and is part of what shapes us as constituted selves, then we see in this account that this shaping is very much at play. But language also has been argued to involve nuances of privilege and power. Is Tim's adoption of language a way of aligning himself with the expertise and the power he senses of the

cancer system? Perhaps by aligning himself in this way, is Tim gaining some of that control for himself?

Cancer systems are rife with technical jargon. What is the effect this obscurity of language serves? One perspective is that it helps to codify a highly specialized area of health care. There are things in cancer treatment systems that are not in any other health care systems – they need special words, for example, brachytherapy. Another is that it makes this area of specialization virtually inaccessible, even to other health care practitioners, and most certainly to lay people who are becoming patients. A third effect is that this highly specialized language is one element in defining and unifying a discipline and the institutions around that discipline. In total, language clearly defines who is inside and who is outside with respect to the expert knowledge and the language used to express cancer and its treatment. Language segregates those who know from those who do not, the expert from the lay. Being an insider has benefits for new employees as they can identify themselves with this highly specialized type of health care, for example not just any nurse, but an oncology nurse. And finally, as I have argued, specialization is about the concentration of knowledge and hence power.

Giddens (1990) describes expert systems like the cancer system as a cardinal feature of modernity, and describes how this is played out in industries like the airlines and health care where people lacking the expertise of the operators within these systems are compelled to rely on both experts and the expert system. Giddens (1990) describes this reliance in terms of trust, and there are, he says, two ways of viewing trust. Trust of the first kind is the sort of trust between two people who know each other well, understand each other's credentials and are seen to each other as reliable. Collegueship between nurses would be a fine example of this sort of trust. Each knows that she or he is a nurse, understands what that means in terms of knowledge and

expertise, and can rely on this knowledge and expertise as bona fide. Trust of the second kind “does not presuppose any encounters at all with individuals or groups” (Giddens, 1990, p. 83). This second kind of trust Giddens states is a feature of what he calls disembedded institutions which exhibit faceless commitments (1990, p. 80). The PCO’s faceless commitment is (in part) to reduce the mortality of cancer, and it is for this specific commitment that people come to the cancer clinics. With virtually all cancer knowledge and expertise residing in this institution, it requires a significant investment in trust for people who have cancer and who have no other options for their treatment and care. According to Giddens (1990), providing form to this faceless commitment is accomplished by making expertise accessible through operators, and is the facework previously described that the oncology clinicians and PCO employees need to do to earn patient trust. Note however the greater weight in the asymmetry of knowledge and expertise is almost entirely within the expert oncology clinician. This asymmetry leads to greater power resting with this group, perhaps encouraging patients to search for ways to become more empowered as we saw with Tim’s language acquisition.

Giddens (1990) also observes that people who interact with expert systems are themselves influenced by early socialization concerning respect for technical knowledge. This socialization includes a sense that experts have special knowledge, but they can be quite obstinate about sharing it, and leads to an ambivalent attitude toward both technical knowledge and science. This can be seen in the social disdain people have for professionals, who are often portrayed as being “closed shop, having an insider’s terminology seemingly invented to baffle the lay person” (Giddens, 1990, p. 89). So the respect for the expert oncologist is tainted with ambivalence toward both the exclusiveness of the clinicians’ sequestering of this knowledge and the patient’s concomitant requirement to rely upon them and only them. At best, patients can be expected to

enter into a “tacit acceptance of circumstances in which alternatives are largely foreclosed”

(Giddens, 1990, p. 90). Tim’s next account shows a rather palpable sense of his ambivalence.

I guess I wonder at times how the system copes with the number of patients and people and I understand that the doctor comes into the room and has to think twice who the heck I am and you know, then he comes in and looks at my folder “cause he’s seen thirty other patients that day and uh or it’s a new doctor because your regular doctor is away ... but, I don’t know, they do the best they can and ... it would be nice if everybody knew everything about everybody but I think it’s probably physically impossible, or mentally impossible.

Tim comes to the centre time and again for the cancer expertise. He wants what his oncologist knows. His ambivalence is that he is also looking in these exchanges for something a little more personal. It is, after all, a relationship that has been maintained over time. Tim looks at the system with a sense of resignation that he is not likely to experience a personal touch with these encounters. He is a realist, but he stills hopes. And so Tim notes the incivility of the exchange and in the same breath, he excuses it because he still needs and wants that expertise. He can hope that someday he might be taken up as a person. The facework is almost absent: there is in fact no face, rather a multitude of anonymous faces. But Tim knows he is faceless too. He is the aggregated body-part-cancer-patient facing one of many body-part cancer experts. He struggles to maintain a self-narrative that combines his self-as-he-knows with the self-as-he-is-becoming, and realizes that the reflexive work in this project is his to do on his own with little or no guidance as he stories himself forward. Let us now look at what happens next for these narratives in the third aggregation in becoming a cancer patient.

### **Learning About Treatment**

Other orientation activities at PCO include a program offered to new cancer patients who are going to be receiving chemotherapy: Chemo Teach. Again, it is a grouped and general session about how chemotherapy works and what to expect from the experience, and is not

associated with any particular cancer. It is ironically at odds with the system's own body-part aggregation of patient types. Patients in the study found this lack of specificity unhelpful and, and in Jane's case, alarming.

I went to a general meeting that was for people who were going to have chemotherapy. I didn't find that very useful at all because there are so many different kinds of chemotherapy, so many different kinds of cancer that it just becomes very general and broad and it has to be vague, it can't be specific to what your kind of cancer is because there's twelve people there and they're all different... there were a lot of concerns that were brought up that didn't have anything to do with me that were really scary and, I can't even remember what those are right now but I can remember coming out of that meeting and just feeling ill informed and freaked out.

What was missing for Jane was that the program failed to speak to her as an individual – to her needs to know about her type of cancer and what was likely to happen to her – some aspect that would speak to her sense of self, that she could reflexively weave into the self-narrative of Jane. She has clearly now defined herself as a cancer patient with a body part specificity, but now the cancer system wants her to think of herself in another way and she is having trouble reconciling her self.

The Chemo Teach program is offered to explain the process of receiving chemotherapy: it is non-specific yet informative. It is a way of aggregating the information and the people so that there is a standard of information sharing, presumably understanding, and perhaps response shaping. But Jane has already been aggregated as a body-part patient, and was looking to hear something more specific along these lines. Here Jane was looking for a discourse of specificity and expertise about her kind of cancer that would inform her going on as a particular cancer patient. She was not at all satisfied with what she received and also was not, I would presume, shaped in the way the program intended.

What are the PCO's interests in these orientation programs? One interest is financial. By aggregating cancer patients for these activities, the institution is able to influence more patients

with the same space and personnel it would take to influence few or one. Another interest might be that the grouped patient will receive standardized information, the same patient-response-shaping at these sessions. Variation will be smoothed over and people learning to be cancer patients in these ways will consequently be more receptive to their treatment regimens – know what to do, why and when. They are being moulded to become good patient recipients of cancer treatment. It is what Foucault would refer to as an “economy of health” and an example of how the state “reaches in to the very grain of the individual, touches his body” (Dillon & Foucault, 1980). It is the very self of the person as cancer patient that is being moulded and restructured. Another perspective is that the PCO does this in this way to help patients know that they are not alone in their circumstances, and to perhaps gain some solidarity and comfort learning about treatment with others who are in the same space. Jane however does not get this impression; rather she feels that she has been inappropriately aggregated in ways that are not useful and somewhat frightening for her. Jane feels controlled and resists the manipulation.

Cotter (1999) reminds patients in treatment to stay the course, and that “this nightmare is a means to an end – an effort to ensure your future wellbeing” (p. 47). Thus aggregated, cancer patients receiving treatment stay the course as they have been oriented and shaped to do, but do they all do so willingly?

Discovering one has cancer and all that follows in engaging with the cancer treatment system is highly complex. Because there is only one system to engage, there is ambivalence about how this happens: patients and families are grateful for the expertise, but resisting its overshadowing medical dominance and the depersonalising that people feel to be happening as they become engaged with the system. This space of ambivalence could very much be seen as a neither here nor there and ill-defined space, which Giddens (1991) argues, and I concur, opens up

places of identity formation and self-realization, and can be glimpsed in the following observations of how people deal with dominance.

One way people seem to counter these feelings of discomfort is to adopt the language of the dominant system, becoming very much as Cotter (1999) describes “one of us.” Foucault (1970) describes this as a discursive formation, where language, actions and context create and maintain the structures which shape people’s thinking and speaking. And so people become a self that reflects the cancer system’s constitution of the cancer patient self and their sense of their personal place within that frame.

Another way people seem to deal with this dominance is to engage other systems of care: second opinions and alternative treatments which serve to undermine the monopoly on knowledge the cancer system has, and in doing so disrupt the balance of power. This conflict to becoming the shaped cancer patient is an area explored by Foucault as resistance “rather than analyzing power from the point of view of its internal rationality, it consists of analyzing power relations through the antagonism of strategies” (1982, p. 780). Foucault specifically cites the power of medicine over the population as one point of domination in our social structures. This resistance is not, according to Foucault simply an anti-authority struggle, but is more complex as I will explicate.

First, the target of these struggles is the *power effects*. Foucault states that people do not resist the medical profession because it is profit driven, but rather because “it exercises an uncontrolled power over people’s bodies, their health, and their life and death” (p. 780). Second, these struggles centre on the status of the individual. They are aimed at everything which ‘separates the individual, breaks his links with others, splits up community life, forces the individual back on him-self, and ties him to his own identity in a constraining way’ (Foucault,

1982, p. 780). In this way, these struggles are not exactly for or against the individual but rather they are struggles against the “government of individualization” (Foucault, 1982, p. 780). Third, these struggles are specifically opposed to the “effects of power which are linked with knowledge, competence, and qualification: they are struggles against the privileges of knowledge. But they are also an opposition against secrecy, deformation, and mystifying representations imposed on people” (Foucault, 1982, p. 780).

The first point helps us to understand the ambivalence that people express. Cancer patients are not angry or disappointed with their oncologists or nurses; they are more accurately disappointed at the behaviour their oncologist and nurses seem to exhibit because the system makes it so. People cannot afford to be angry with their immediate care providers in a system where there is little or no access to comparable expertise. Patient and family members holding both personal and impersonal conceptions makes comments like this from Susie, Tim’s wife, a little easier to understand:

...but god bless the nurses. You know, I just, the number of times, you know the way they helped you last week, in the last two weeks and where You know there have obviously been emergencies and I’m just out pacing the hall “cause I can’t stand waiting any longer and some nurse walked along and said to me one day, I’ve seen you pacing up and down this hall for forty minutes, could I help you know... just ... there are so many, many great things.

It is difficult to see what Susie is blessing in the nurses’ behaviours. The nurse in the narrative watched or ignored Susie’s pacing for forty minutes. But as this clinician is framed as an oncology nurse, with all the attendant expertise that Susie might need or want, can she afford to think of her in any other way?

The second of Foucault’s points is very much the concern held by the people I spoke with. The structure of the cancer system is designed (as all good systems are) to do exactly what it

does: aggregate patients in the name of effective and efficient care. But in this aggregation, people who are being aggregated struggle to express their individuality, like Tim conveys here:

One thing that I've always wondered is what are the statistics for someone in my condition? Nobody has ever told me that. And, and they're very reluctant to ... I guess well they don't know, but I'd like to know well, you know has anybody with my type of cancer and my metastases and my condition beaten it? Has anyone ever cured themselves or been healed or gotten healthy and well again and I've never, well maybe I've never asked the question. But they, they're not very forthcoming about what the next step is...

Amongst much hedging and excusing, Tim is asking to have his questions taken up in connection with who he is as a person, not just a nameless faceless statistic.

And finally, the third of Foucault's points goes to the core of the exercise of power in the cancer control system: the privilege of knowledge as it is experienced by people who are subjects of the system and most particularly when it is used as means of mystifying. Some of this is expected and tolerated as the privilege of expertise, but people who become cancer patients are also very aware of the power brokering that goes on about expert knowledge: Tim – “the more knowledge that you have or that that ... the more information you have available to, to get an insight into where you're at what might be possible or what's happening.” And it is disconcerting when it seems knowledge that is useful to them is being withheld as Tim's wife Susie recounts:

so I phoned and said is there some kind of a person or a like a place for caregivers or you know, who can I access ... telephone tag for, I don't know, two or three weeks and finally somebody said well we used to have that program but we don't have it anymore. And I found out you know at the beginning of March that that program is there and it's located on the 5th floor.

There is a sense that Susie's trust in the expert system has been eroded by this mystification.

To sum, engaging with the cancer system has consequences for patients and families. There is a discovery of the fallibility of the general health care system, the failure to recognize

the cancer, the inefficiency. There is the struggle to learn what one needs to do in the cancer system in ways that one can hold onto a sense of individuality in the experience and the subsequent shaping of the cancer patient self and narrative. There is the difficulty with engaging an expert system which is the only option – noting the incivilities, the banalities, but having to frame these experiences in ways that do not threaten to sever the relationship with the much needed cancer treatment system. People have sources of strength: their capacity to gain knowledge through the World Wide Web and through others who have experienced the system, as well as through their personal history and constituent selves who can be called upon. But there is an overall sense of the efficiency of the system exerting a shaping of the person becoming cancer patient – the aggregation techniques – the orientation, the scheduling, the group teaching models used. People becoming cancer patients are being shaped, and are shaping themselves to gain the greatest benefit that cancer treatment can offer. For the cancer system, efficiencies are at stake. For the person becoming a cancer patient, it is their life or death.

However, with all this deliberate shaping and being shaped, what happens when this effort comes to an end? How does the cancer patient narrative move on from the shaping experience, and how does the cancer system withdraw its shaping influence? These questions are explored in the next section concerning dis-aggregation.

### Chapter Five: Un-becoming a Cancer Patient – Dis-aggregation

In this second finding the accounts about being released from the cancer control system are explored from the perspectives of language, power effects and expert systems in a frame of modernity. As with becoming a cancer patient, this un-becoming experience is explored in terms of how people's cancer stories and selves are shaped using examples from the data, and this notion is also explored in the literature. Giddens (1991) states that "A person's identity is not to be found in behaviour, nor – important though this is – in the reactions of others, but in the capacity to keep a particular narrative going" (p. 54). When cancer patients are discharged from the cancer clinics there is what appears to be a breakdown in their cancer patient narrative and selves leading to either (a) their inability or incapacity to maintain the self that was aggregated into the cancer centre or (b) their attempting to re-connect with the cancer centre to re-weave their cancer patient self and narrative. As with the becoming accounts, it is interesting how oncology clinicians see the after-treatment space and the work they do with people and their families to "move them on" after treatment and as such, their accounts are woven into this explication.

As a caveat, it was clear that the clinicians who spoke with me about this work were very invested in this portion of their patients' care and further, these clinicians felt that this was not something institutionally well supported. I think this important to note, as I am going to relate "oncology clinician accounts" but think it more accurate to label them "accounts of oncology clinicians who are interested in how dying cancer patients are supported." This observation is epistemologically noteworthy. What I will explore is not *the* truth, but *accounts of truths*. But these are not just any accounts, they are situated accounts in that what clinicians say about things relates not only to how they see things, but also to their sense of how things ought to be. This

thought I quote after Ceci (2000) “when we make judgments about knowledge claims and appropriate ways to know something, we are concerned not only with epistemological questions, but also questions of value and power” (p. 60). Consequently, as I explore the clinician accounts, I am aware of the values and power with which the accounts frame issues, and how clinicians have privileged this particular account to speak to issues of the particular values and power they see within the institution.

### **Encountering/Ushering in a New Space and Self-Narrative**

Patients and families were asked to participate in this research for the specific purpose of exploring a transition *from* the cancer treatment centre. As discussed in the previous section, the interest they had was to begin their story from the beginning, their personal accounts of reflexively becoming a cancer patient. When patient and families came to this chapter of their story, they were similarly clear about this part of the story began and what it meant to them. Yet while the observations of how the first transition happened focused on a story of first this-then-that-then-this, the accounts for this second transition had more palpable elements concerning what did not happen, and what the experience of being in the after-treatment space meant to people. The accounts reflected back on the personal experience and feelings about their situation, their bodily and narrative cancer self. This was most plainly expressed by Hugh, the family member I spoke with whose wife had died.

Well, the treatment, the initial set of treatment went over about a year, with my wife and then as sort of the initial circumstances and all that was carried out then all of a sudden the clinic said okay now we need to have palliative care ... and at that point the palliative nurse started coming to the house and we had at that point had no further contact with the clinic so there was no uh follow up, no checks to see how things were doing, any checks we wanted to do we had to do with our family doctor.

The treatment is what is prized by Hugh with the after-treatment space being what they were told they now “need to have.” There is a sense of being abruptly hurried out of the cancer treatment centre. Note too that what hurries them out of the clinic is not a clinician or person; it is the clinic who “said” it was time to go – the faceless, nameless expert cancer system. This is significant. If this family’s oncologist turned them away, they would lose both the connection with the system and the relationship with the oncologist-operator. If it is just the system pushing them away, perhaps there is a chance that the oncologist will speak up and say it was a mistake, take them back, smooth it over. There is very much a sense of being dumped – no checks, no follow up. Rather like a lover ending a relationship by never calling, never writing, just disappearing. And any further care they required, they “had to do” with the family doctor. Note the palliative nurse coming to the house does not seem to be very worthwhile to them. Whatever she might have been doing was either not visible, not valued or both. Hugh’s account continues.

...and the palliative care nurse coming and checking and after some months when my wife was getting more and more in distress with the way things were processing, I said, well look, this isn’t right we need to get some more help and assistance from the people who are experts in cancer treatment.

Hugh highlights his dissatisfaction with the community care system as we suspected the cancer patient returning to community systems might. The palliative care nurse is doing something here which Hugh sees as “checking,” but she continues to merely check as things evidently unravel. Finally, when things get really bad and the nurse does not do what Hugh thinks ought to be done, it was time for Hugh to call back the experts.

Reflecting on the discovery accounts, it comes as no surprise that people are not confident about the general health care system. I suggest that confidence is not lost at this transitioning back place, but rather it was lost earlier as Mary and Sam described. This dissatisfaction is now rather predictably coming home to roost when Hugh and his wife need to rely again on this less

expert system. Contrast the orientation procedures for each system. With becoming a cancer patient, there are some very deliberate system generated and patient-identifiable activities that people participated in to get up to speed, to get with the program, and with this they shaped their sense of self and their self-narrative as cancer patients. With the reintroduction to the care of the GP and the new palliative home care nurse, Hugh describes no orientation activities whatsoever. The misgivings about community care, beginning with the discovery of cancer, are intensified by the experiences that cancer patients and their families have had with the expert cancer system. The discourse of cancer expertise has shaped patient and family expectations and participation with the discourse of general health care. Now, at least for Hugh, community systems can only be seen through a lens of omission and incompetence, and not a space where he can find a narrative to go forward with. What Hugh is doing is setting out reasons to return to the cancer clinic and take up the cancer patient self-narrative that his wife and he had formed and became adapted to.

It also strikes me in this first un-becoming account, how very difficult it must be to have all the activity that being tested and surveyed and treated entails when in cancer treatment come to an abrupt halt. I suspect that the engagement with the cancer system is so very intense it must be very difficult just to have one's calendar emptied of all this commotion. It was telling that when patients and families shared their leaving accounts with me, they stopped referring to their notes. In the way they had been accounting for things while in treatment there was in this after treatment space nothing note-worthy, no special language to acquire, no expertise to penetrate, and a comparable void of appointment and treatment activity. I believe that this sense of inactivity must be most especially unsettling when, after reluctantly subjecting oneself to all this attention, the cessation of the attention and activity is not a mutually agreed upon withdrawal of

interest. The expert cancer clinician casts or withdraws the clinical gaze. This again returns me to the notion of dominance. It is relevant that the decision about when this particular form of subjectivity ends is exercised by the clinicians and the cancer system, not the patient and their family. Hugh's self-narrative, encouraged and shaped when entering the cancer system, is now left for him to rework with the unwanted and intrusive feeling palliative nurse and family physician. Hugh will not move forward, he rejects the notion of reworking his narrative self in the manner left to him and clings to what he had become accustomed to – a cancer patient/family person being treated by the cancer clinic.

Clinicians interviewed were very sensitive about how patients experienced leaving the cancer clinic. In each clinician account there were reflections on how patients took up this leave-taking as abandonment reflecting the perceptions that cancer patients and family members had of this. Chris reflects on the theme of abandonment here.

I think lots of patients feel abandoned and that's probably a word used a lot and potentially overused in talking about this kind of scenario but I think there is a ... I can't tell you how many times I have patients say, when I'm here and I'm being treated I'm so well cared for, you know they're seen weekly by numbers of different care team members and they're so well attended to and taken care of and when care is over they're done. So I think there's, there is a feeling of being let go, being kicked out of the nest sort of thing and having to be responsible for navigating their way through the rest of their disease on their own when there was this really intense support around all that once they entered our doors and until they're deemed no longer treatable. So, I think there's a real feeling of probably loss there and abandonment.

Here, aligned with Hugh's account, Chris has captured the sense of how patients might take up this discharge as a sense of being abandoned. Chris, who used to work as a community palliative care clinical nurse specialist, reflects that there are two things happening at this time for patients: (a) they are being told they are untreatable and thus terminal, and (b) the one person who was once framed as their potential life saver is withdrawing from their life. And so it is like they are doubly bereft – of the hope of a cure and a forward moving narrative, and the support of

their expert clinician, perhaps at a time when they have the greatest need of them. Chris goes on to explain how she saw patients experiencing this from her work as a home care nurse.

Patients would tell me they just felt like they were dropped off, and the concern when they heard palliative care is that there was no more care for them...I felt it was like um, a cutting of an umbilical cord. ...as a home care nurse seeing patients, the same kind of story would come to me, is that they'd been told by their oncologist, their rad onc, that treatment, there was no more, no further treatment. And then I would get a referral to go in as far as a palliative care nurse and again they felt cut off from, from the doctor that had probably been seeing them over a period of time and where do they go then? And there was that, I think it's, you know, it's disappointing to hear the news that there's no more treatment, that this is terminal, this will probably take your life, but it's also that trusting relationship you had with your oncologist – you don't have that anymore, you don't have their input into your care anymore.

This abandonment resonates with what Hugh has described: the abrupt withdrawal, the push to move onto another system of care, to adapt to a new self as a dying person.

Chris also sees this abandonment taken up very personally “Dr. So and So doesn't want to see me anymore because they can't cure me. That's the perception I get from patients...I think for a lot of them it feels like rejection.” Hugh does not take this dismissal personally, as he knows he cannot afford to lose the relationship with the expert oncologist at this time, and so it is the *system's* fault. Chris is unaware of the power effects at play for Hugh, nor how Hugh resists the notion of reforming his narrative from cancer patient in treatment with the clinic to cancer patient when all treatment has failed.

Chris goes on to provide some insight about why this abrupt abandonment happens the way it does, and sees both the personal interest of the oncologist being served as well as those of the institution.

So within the cancer agency I think what happens is a lot of the oncologists, not all, are very quick to sort of, send them off, send them away from their service when they, when they realize this patient is no longer curative and again I don't know if that's a protective mechanism or if it's a time saver for them, maybe a bit of both.

Note that while there are institutional and disciplinary interests explored here, there are no patient interests. The biologic cancer story has come to a finish. Chris describes the discharging patients is an impersonal, technical matter, while being discharged is experienced by cancer patients is a clearly meaningful event, resonating with their bodily experience of being a person now not only with cancer, but who now must face dying of their disease alone.

Because of the one-sided nature of crafting this story ending, I explored with people if this transition came as a surprise to them: how prepared did they feel? Were the “continuing conversations” that the oncology clinicians valued (page 64) an important factor in helping people to feel prepared for this transition? Tim’s reflection on this sense of being prepared is interesting, especially if we compare it with Jane’s. Here first is Tim’s.

I think we’ve understood everything pretty well, haven’t we ... Oh, maybe it’s all in hindsight that I know it all clearly now, there were probably steps along the way that we weren’t perfectly clear, but I think I knew that from day one, you know I never really believed, that I’ve always thought I’m going to beat this, I’m going to win but, ah, I still don’t believe I’m going to die (laughing).

It is not entirely clear that there were “continuing conversations” or signposts, but Tim is allowing that they were probably were, or at least it seems that there might have been in his clarity of hindsight. Two things of note. One is this man’s sense of the lethality of his cancer. We heard this in the becoming accounts from Mary with her “trip.” Cancer patients seem to know from the beginning of their cancer discovery that they might or even will end up with a narrative of a dying patient, but they do everything they can to be the one who will not. According to Thorne, Hislop, Kuo and Armstrong’s (2006) study of cancer patients’ communication needs, something they found in each of their 200 accounts was the underlying lethality of cancer – they all felt at some level that they would die of their disease. If Tim could only carry on with his fight he may be able to keep his dread of dying at bay, which he had been

doing up until now with some success in his aggregated story of being a cancer patient. But now Tim feels that the aggregating forces are being withdrawn and he senses his narrative unwinding. Even when Tim admits that he is likely going to die of his cancer, he cannot believe it; he unwillingly considers that narrative, although he can read his own name on it. Here is a second very different feeling account of being prepared from Jane.

That was a, a really big bump too. There was a meeting when ... the results of the CAT scan and the CEA numbers were going up and so the oncologist said that there was a recurrence but I was asymptomatic and then after that I was symptomatic and that was the other shoe dropping. The minute that you are symptomatic uh, you're in you're not on that same path. You, you get sent home with a book from palliative care centre that has a DNR ..... which is hard to look at ... (crying)

Note first the tone – Tim laughed as he said he still did not believe he was going to die. Jane cries. Certainly Jane was in a very different space: a sad, bereft feeling space. Also, for Jane there are two distinct discourses. First, there is the biologic story, the medical discourse. Jane is told she has a recurrence of her cancer. The signs are there, the CT scan and the increased markers. But Jane's story is about her bodily attentiveness which tells her she is not getting worse, she does not feel different, she has no symptoms. Jane is aware that her body story does not fit with the medical one, and moreover that hers is not the prevailing one. Her bodily discourse has no relevance. It is the medical discourse that shapes the actions; it is this discourse which ends in Jane being sent home, discharged. All this happens for Jane in one meeting and then the intrusion of the palliative book and the DNR. There is no sense of continuing conversations here. There is only the unexpected and bodily irreconcilable dismissal.

When I explore what Jane's sadness and bereavement is about, I sense two things. One, Jane knows she is dying. But two, unlike Hugh, this rejection is personal for Jane. Jane knows that the cancer clinician not only rejects her because there is no further interest in her cancer, but the clinician is also signalling that he or she is not interested in her symptoms and in her

suffering, and ultimately is not interested in Jane anymore. Jane's biologic cancer story has ended and so to has the clinician's interest. Jane's death is not a personal event for the clinician. Her death is rather, as I have previously have reflected, "a technical matter, its assessment removed to the hands of the medical profession: what death is becomes a matter of deciding at what point a person should be treated as having died" (Giddens, 1991, p. 161). For Jane this is highly personal, and she cannot reconcile herself to the clinician's medical fact of her death and has no narrative to take her forward.

Clinicians also sensed that for patients and families this leave-taking was difficult. Here Kathleen describes how a patient's course of treatment and care leads up to this point and her astonishment when the time comes.

...basically she had ovarian cancer, she tried many different chemotherapy options you know, first line, second line, third line, I think she went to fifth line and, it had and then it had spread to her brain. She had a, you know she was having some emotional issues, just simply because of the physical aspect of having the cancer in the brain as well. But it was very hard for her when her doctor told her that there was nothing more that she could do, and those are the words that so many doctors say, oncologists. And, and so I'm going to send you off to see our wonderful people on the palliative care team and so for her that was like a real blow. You know you fought this hard for me and you're just going to drop me?

Contrasting this with Hugh's account of the system moving him and his wife along too soon, this person's story of being discharged is more personal. She is being dumped and she knows it and she is mad at the experts, not just the expert system. But she is still also tenaciously *in* the system saying these things to her oncology nurse, where Hugh and his wife seemed to only catch on to how very abandoned they felt after they were discharged. The language in this account is interesting. Kathleen recalls her patient saying she was told she was being *sent off* to see our wonderful people on the palliative care team." But the wonderful people are here in the cancer clinic. Kathleen's patient does not want new wonderful people; she wants her oncologist

who has “fought hard for her.” So while Kathleen is clearly articulating the medical story of lack of options and moving on from the cancer clinic, the patient counters with her personal story of abandonment and the pain of an unfinished relationship with her oncologist. For the oncologist, it is not personal, as this patient is taking it up; it is merely none of his business anymore. In terms of ending, it is not only a disciplinary disinterest being exercised; it is also the cancer clinic’s interest in moving on and out cancer patients for whom they have declared to have nothing to offer. For the patient, it is the abrupt withdrawal of interest and aggregating forces – they are left in a dis-aggregated and unstoried space.

### **Staying In the Biologic Story: Clinical Trials & Palliative Chemotherapy**

Yet, despite this dismissal from and by the clinic, or perhaps because of it, some people like Hugh felt it best to stay with the cancer clinic for as long as possible, as this was the place of cancer expertise. Clinicians at the cancer centre knew best how patients’ cancer had happened, how their cancer had responded to treatment and how their cancer continued to be for them. Another strategy of keeping in touch with the cancer clinic people as patients seemed to be aware of was to participate in clinical trials.

Tim: I think I’d like to stay in touch with them, because they’re the ones that have been there from day one and they know me and I know them and you, I’d much rather stay as part of them, especially since we’re down here now [moved from Whistler to Vancouver]. Oh and we had this wonderful nurse who looks after the clinical trial, the clinical trials nurse, she whenever we have anything now at all we just phone her ... it doesn’t matter what it is, just phone and she looks after it.

Tim did not view participating in a clinical trial as a means to cure his cancer, but rather a means to stay linked with the cancer clinic and its expertise, and to continue in his cancer patient self-narrative. It also seems that the clinical trials nurse is more than just a trials nurse. She is looking after everything Tim asks for and about. I wondered if this nurse knew how her work

was framed by this patient and family. Was she doing what she does as a clinical trials nurse and it was incidental that this patient saw this as doing everything? Or was there something she knew about being a pivotal support for Tim at this time that she was deliberately extending to him? Either way, her activities and way of being helps Tim remain in his cancer patient self-narrative, or stated otherwise, prevents Tim from needing to alter his self-narrative to that of a dying person.

Clinicians also spoke about clinical trials as they relate to transitioning cancer patients, but with a slightly different perspective. Sally, a counsellor, states that patients hear what they want to hear in relation to what they hope a clinical trial might do, not the technical factual information included in the consent process, and that this obfuscates where patients are in their disease process.

It's not always clear for the clinicians and it's certainly not clear for the patients and families and even with clinical trials, I think a lot of people, even though there's a large consent process and a lot that goes into informing people about what's involved with a clinical trial, I think people still have difficulty there. Again, based on who they are, what their perceptions are, what they see their roles are is what, how they have to deal with their disease. Um, also impacts how they hear the information about a clinical trial and the impact that could have too. So, most of those patients or many of those patients are in a palliative place um, and but see this as potentially hopeful, curative, even if it is just a clinical trial.

What is the truth of this situation? Is it the technical and factual information patients receive when being enrolled in a clinical trial? Is it the belief that patients express that the trial will provide a treatment that may yet result in a cure? Tim didn't really say anything about what he thought the clinical trial might do for him in relation to his disease. Clinical trials enrolment was to Tim just a mechanism he used to keep in touch with the cancer agency, and continue in his cancer patient narrative self. It may also be a way for Tim to avoid sliding or rather tumbling into a liminal space. Patients may be smarter than clinicians believe them to be. There is no

singular truth in these situations, there are only accounts layered upon accounts giving shape and context to these discourses.

Sally also thought that like clinical trials, palliative chemotherapy confuses things: “I think the transition becomes complicated by further [oncology] palliative treatment options as well, that muddy the waters for people around are they actually still getting active anti-cancer treatment or is this palliative pain and symptom management?” This dialogue about treatment intent is also related to the confusing array of terms that are used in discussions and decisions about cancer treatment. Chemotherapy is not just a blanket pharmaceutical approach to cancer treatment, but is the provision of specific treatments according to the expected outcome or intent. In the first instance, chemotherapy may be curative in its intent. In a second intent, adjuvant chemotherapy is chemotherapy given after successful primary curative treatment for the purpose of reducing the risk of developing metastatic disease. In a third intent, neoadjuvant chemotherapy is chemotherapy given prior to curative treatment (usually surgery) to reduce the size of the tumour and render the surgery less extensive. And fourth and finally, palliative chemotherapy is chemotherapy given with no intent to cure and all intent to mitigate symptoms (Watson, Lucas & Hoy, 2005). Note that only one of the four approaches relates to cure, and of this curative claim there are widely varying success rates. There are many cancer patient narrative lines to be found in medical oncology.

There is also a question of role conflation in medical oncology clinical trials. Oncology clinicians have reasons for giving treatments, both within a patient-treatment intent and a research one. And while it seems that the procedural aspects of informed consent are being attended to in Sally’s account, there is a sense that the understanding dimension of being informed is complicated for cancer patients: complicated by both the complexity of cancer

treatment options and peoples' own ways of wishing to understand those options and themselves. What makes matters more complicated is when we layer on the question of interests. Oncology clinician researchers are in a very delicate position of providing their patients with the best possible treatments as individuals, and at the same time recruiting subjects for clinical trials to add to the disciplinary knowledge about cancer treatments: treatments which are aimed not at the individual but at future cancer patients. And while this is all very clearly explained in the right and correct technical fashion, are people who are anxious to be cured of their disease able to make clear and unclouded decisions? And who, I wonder, benefits from this if, as it seems from these clinicians' accounts, these are not coherent decisions? In looking at the posture of patient with physician, Foucault (1989) describes the position of the cancer patient person in clinical trials as follows:

...he had asked for help of which he was the absolute subject, insofar as it had been conceived specifically for him; he was now required to be the object of the gaze, indeed, a relative object since what was being deciphered in him was also seen as contributing to a better knowledge of others (p. 101).

Clinical trials is a disciplinary concern, and complicated turf on which oncologist/researcher/clinicians stand, and they are all of them all three. Small wonder cancer patients and their families find this area confusing, yet perhaps narratively rich.

### **Learning About Prognosis**

A precursor to leaving the cancer agency was the visit where patients learned from their oncologist what the prognosis for their cancer was likely to be – the end note to their biologic story. This was a very significant conversation for the people interviewed and the accounts reflected several different experiences of this. I will compare four here to illustrate: Margaret's, Sam's, Steve's and Janet's. First Margaret:

My oncologist said, oh you've got a lottery ticket there, you're still buying lottery tickets? And I said, yes and I thought, hmmm is there a reason I shouldn't be? And then I said something about when I've got this beat and she turned around to me and she said, what have they actually told you? And I said, well they haven't actually told me anything.

Note the banality with which such critical information is delivered. Could it be that in order to say these difficult things so many times, that oncologists need to make these conversations feel ordinary and rather offhand? Kate, a nurse, offers some insight about how oncologists might be thinking in these situations.

Kate: I think they have to be to do their job that's what I think!

Ann: And so it's something that helps to protect them?

Kate: I think it probably is. I think a big part of it is protecting themselves because that's the business they're in, they're in the business of curing people of cancer.

An oncologist's work is to cure cancer, and certainly a lot of their efforts are about just that. But half the patients they see they know will not be cured, so what is their work with these cancer patients? Wallace, Daugherty and Hlubocky's (2006) study describes the emotional responses of oncologists when disclosing prognostic information as unhappy, unpleasant, frustrating, bothersome, difficult, hard, exhausting and draining. These conversations are very difficult for oncologists and are often associated with a sense of failure for them. In their large survey of medical oncologists, Cherny and Catane (2003) found that "Most [ESMO] oncologists recognize the importance of palliative care and supportive care for patients with advanced cancer. Despite this, many are prepared inadequately for these tasks, and actual participation levels commonly are suboptimal" (p. 2502). So it seems that dealing with the non-curable patient is work that oncologists recognize, they (a) do not like it, (b) do not feel prepared to do it and (c) often do not do it. There is only one biologic fact to convey – death from cancer proliferation, but for persons receiving this prognosis, they see this rendering of the story as the proverbial tip

of the iceberg, with all their complicated and important bodily experience of their now expectant cancer death left for them to deal with alone as they story themselves on.

A second account from Sam explores a conversation he had about his prognosis.

...he's [oncologist] coming back in September ... and now he indicated for whatever reason that he felt reasonably confident that he'll be able to see me in September and I could be in reasonable shape in September ... well that's nine months out and I was given a 50/50 chance of making it to nine months because he said the chemo does appear to be working and working well.

It is interesting how Sam makes meaning. Sam took every piece of data he could glean from the conversations he had with his oncologist and put together the picture he wanted to see: "I'll be here in September." This was not a difficult conversation for the oncologist; he was just setting the next appointment. The statistics and the chemo working well comments were from a previous conversation which I would hazard the oncologist was not placing in context with this current one, if in fact he was the oncologist in that previous conversation. But Sam put it all in context, and he made from this collage of conversations what he wanted to hear and storied himself forward to September, at least. He has enough time to take a trip to Australia to meet his new grandchild. Sam has discovered his continuing and rather liberating story in all this biologic and rather bureaucratic rendering. Again this represents yet another pair of non-intersecting discourses. The medical story of appointments and probabilities and the personal patient one of time and hope-giving facts about the disease and its treatment, finding how to story the self and the life to be lived with cancer.

Not all prognostic information came from the cancer center. Here is third account of how Steve, a family member, learned beyond doubt that his wife was dying.

... and then when CPP [Canada Pension Plan] phoned me about it they said oh by the way are you still working because there's whatever they call it, when you can have UI [Unemployment Insurance] thing if you need it for someone who's terminally ill. I knew,

but it was actually the CPP person on the phone asking me a couple questions about the forms saying you know maybe you should think about the compassionate benefits...

Steve knew, but this conversation validated his understanding in a way that made the fact his wife was dying unavoidable. There is an intrusiveness theme here and in some of these stories of un-becoming: Steve's call from the CPP person, Jane's palliative book with the DNR, and Hugh's palliative nurse "checking." None were sought out, none were wanted, and none were welcome. These intrusive features are surfacing as characteristics of the next system of care people are being moved on to, palliative care. Interesting to contrast that nobody from the cancer clinic went out after the departing cancer patient, intruding into this in-between space. Patients come to the clinic, not the other way around. Yet with the initial stages of the support for dying, the palliative care system seems to impose on cancer patients in ways that are very different. This contrast clearly has relevance for how un-becoming cancer patients and families may move between the two expert systems, or perhaps may not move at all.

Finally a fourth patient, Janet, was working to glean a bit more meaning than the bare prognosis provided to her by her oncologist. Janet was trying to find a place where knowing about her approaching death was more than just dreadful, and looking for ways that this prognostic information might be provided for a beneficent reason.

I can understand why they do it because it does make you put everything in order ... because the oncologist said that with my type of cancer um, maybe six years is what I should be looking at and uh, that was a shock. You know you go in there with positive ideas but on the other hand I did put everything in order because I was told that.

Janet's account reflects the tension between hoping for the best and planning for the worst, a term often used in oncology (Clayton, Butow, Arnold, & Tattersall, 2005). The time frame for this discussion is very different from the others, yet Janet still speaks to her surprise and the difficulty she experiences in understanding this information. Notice too that Janet is not in any

way angry or disappointed with the oncologist. In fact, Janet was working really hard to frame this conversation as that of a “good shepherd,” bringing her around to a right way of thinking for her own good, even though this squashed Janet’s positive ideas. But these oncology clinicians are the experts, and their discourse of knowing what’s best has authority from their preparation as clinicians and their having seen other patients go through this time and again. This is what Foucault would refer to as “the pastoral shape of power” with the oncologist keeping watch over each patient – in this case Janet – herding them in right ways to keep the entire flock safe (1980, p. 5). Janet has a going on narrative of putting things in order.

These four accounts (Margaret’s, Sam’s, Steve’s and Janet’s) about prognosis are rich illustrations of how complex communication can be, especially in these decisive and difficult situations – said and heard, not said and heard, said and not heard. The process that each of these four people used to gain an understanding of and a location of self-narrative with their prognosis involved not only an exchange of language with the oncology clinician but also what Gadamer (2006) describes as an “inner conversation of the soul with itself” (p. 14). For all four of these cancer patients the self-talk was far more important to the development of understanding than was the clinician-person communication. To move this thought a step forward, what each of these four people is doing is toiling to reconcile what they are learning with how they had previously seen their situation: bridging a narrative self who may be cured with a new narrative self who is probably dying. This is the self-interrogation underpinning the going on narrative (Giddens, 1991).

This work of taking up prognosis is especially difficult as the foreknowledge of death comes in conflict with our sense of continuity. Giddens is again helpful here. Giddens (1991) states that death poses a particular problem for the continuation of a narration of the self, because

we become unable to sustain our habitual forgetting of the inescapability of death. Death interrupts us. Death transforms our sense of self from one of a continuous living being, to a being experiencing a haphazard truncation of our potentiality-for-being. Again, the work people do that leads to meaning-making about prognosis is very much mediated by our constitution of person, which is itself not a static project (Cohen, 1994). But if patients are trying their best to maintain a sense and story of self-as-curable, it follows that anything which or anyone who claims otherwise must be perceived as intrusive. It certainly seems from these un-becoming accounts that palliative care is so framed by persons with cancer. This framing will be further investigated in the discussion about liminality, the space or margin between two expert systems, which is explored in the next chapter.

### **Living in Prognosis**

Learning about prognosis is a first step for a person with cancer and their families to begin to live in that prognostic part of their story. This learning may first begin as an oncologist-defined story, but how people understand and what people choose to do with this information is very much a person defined response – an individual’s bodily uptake of the biologic story. Sam’s response to learning his prognosis was “so I said I’m going for the brass ring! ... however long I don’t know.” The brass ring metaphor has its origin in a competitive game once played on a merry-go-round. For those on the outside ring of the ride, an arm would swing out holding a brass ring which riders would attempt to grasp as a prize to be redeemed for a second free ride. Nowadays, the expression “grab the brass ring” or “going for the brass ring” is used in relation to a symbolic prize most especially ones that are difficult to win (Quinion, 2009). So the metaphor Sam chooses is related to competition and winning that competition. Sam has a liberating/sporting story of his cancer which resonates with his hopeful and competitive self.

The cancer system has a “brass ring” and it is his work to try and find and grasp it. But the system is not going to make it easy, as Sam reveals how he learns about his treatment options.

... we don't do radiation and chemo at the same time, she [radiation oncologist] said. So uh, they radiated and it went fine and then I met with [medical oncologist]... and out of the blue, totally out of the blue, we're sitting down in the office and she said, so do you want to start chemo on Monday? ... and I said, what??? I had no idea chemo was even available, that you know what are the pro's and con's, what the hell changed, uh you know uh nobody mentioned when or a time frame or if I was going to do it or what, you know?! I was absolutely flabbergasted.

First, there is no brass ring. Radiation is framed as not curative and Sam is not eligible for chemotherapy, which he thinks is curative (there must be a brass ring somewhere). Then there is a brass ring. Chemotherapy is offered, and although the odds he was given were not great (50/50) he is going for it. His side effects are minimal “to his horrendous surprise” and he is told “if it turned out to be not as effective as they hoped for, they actually had another arrow in the quiver and there's another chemo agent that they could try” (there are more brass rings if you fail to grab this first one). The oncology experts contradicting one another are making it very difficult for Sam to know what to believe, but he believes in the brass ring, so whoever offers that gets Sam's vote – interesting facework. Sam's ardent belief that there must be something they can do very strongly frames what Sam feels is being offered and Sam's continued capacity to trust in the system whose experts are acting in such muddled ways.

When I asked Sam what it means to him to grab the brass ring, he is reflective:

I guess the total brass ring would be uh, you hit a home run and everything goes into remission and you find yourself still around and kicking two years later albeit with a sort of the sword of Damocles hanging over your head, but you know, you get a little bit of time to enjoy things.

There are two things I want to explore here. First, is what Seale (2001) identified in cancer languaging as sporting metaphors: winning the brass ring, hitting the home run. No battle or war metaphors and this man is a soldier. He chooses a sporting story, not as I might have expected.

Second, Sam is speaking to how he imagines he will live with this being-with-cancer. Sam has a sense that the disease is ever present. Cancer lurking in one's body is a powerful image for people with cancer, and the fears of recurrence have been shown to be as bad if not worse than that associated with the original diagnosis of cancer (Mahon & Casperson, 1997). Sam's self-narrative is a hopeful and tenuous one as he moves forward as boldly as he can on this vague ground.

Another response to living in prognosis was to "pit oneself against the disease," to take stock of personal strengths and measure up against the odds. Tim does this taking stock.

...maybe there's some way or maybe I'll be the exception and I'll have that, my immune system will kick in and start killing all the cancer cells and I'll be the one because I'm fit and strong and active and healthy and eat well and that I will be the one that will overcome it.

Tim's account is a bit like Sam's with both accounts looking for the ways to be the one who makes it through. I also think that Tim is looking for the fulfillment of all the cancer prevention promises – if you eat well, exercise, the fulfillment of all the efforts Tim has taken to take care of himself. Like Sam, Tim is looking to be the one who beats the odds; his story of cancer is one of battling successfully against the disease. Tim knows the numbers about his disease are not good but he knows that there has to be cases that land outside the bell curve, and with his good care of himself, he is hoping to win that position and be in that story.

A third response from Margaret was different again from both Tim and Sam.

I think I've coped with it well. Um, I'm one of those people, I'm fortunate I've done a lot in my life, I've done a lot of travelling, I've done a lot of things, probably more than a lot of people have done and I sort of feel well, you know I packed it all in a fewer number of years if you like! Uh, there's always room to do more but uh. No, I'm at peace.

Margaret is weaving this new bit of information into the fabric of a self-narrative of what she regards as a life well lived. Months after our interview her obituary reads "[Margaret] never

allowed her illness to subdue or diminish her; for her it was just another of life's challenges to be met head-on" (local newspaper, 2009, p. 5). Margaret did not feel the dis-aggregating and story rendering sense of un-becoming, partly I suspect because she had not experienced her self being aggregated as a cancer patient to the extent that most might. Margaret's self and story was a person-centred one, and the meanings she made and self-narratives she pursued were quite consistent with this.

Meaning about prognosis is made by self and with the self as Gadamer (2006) suggested. The "facts" of the situation are open to whatever interpretation people undertake, and each of these accounts shows how the self is resident in that activity. Hence the phrase in palliative care – "people die as they have lived," calling attention to the continued personhood of the dying patient and the un-severable connection between living and dying (Hallenback, 2003). Sam will continue to compete, Tim will continue to keep fit, and Margaret will take up her mortality as she does any and all of her life's challenges.

Clinicians said relatively little about living in prognosis, but spoke rather in terms of "the transitioning patient" which will be taken up in exploring the second research question that guides this work.

Here, we turn to the last and most ineffable space I discovered people storying themselves in, the liminal space. Liminality was not a space that people purposively worked towards, such as I have described in these passages, but rather a space that opened up before some people as they were grappling with an unwanted conclusion to their self-narrative as cancer patient and facing a new self-chapter as a dying person. There was not so much a "going on" but rather a sense of a "tumbling in" where people dying of their cancer felt themselves in free fall

towards some indescribable place in their narrative, which I have theorized as liminality, and that ineffable space as liminal.

### Chapter Six: Becoming Un-aggregated – Liminality

In this chapter I make meaning(s) from the accounts about the space between cancer treatments systems and the next potential abstract system, palliative care. This space I have termed as liminality, and here I explore what some cancer patients who came to this space say. Here again the findings are seen through the analytic lenses I have been using, looking at the effects of modernity and expert system shaping in terms of how participants continued their self-narrative, and how power effects are set out in the discourses. I then review the literature for instances of the use of the term liminality, so that I may demonstrate how my comprehension of liminality extends the understanding of the concept.

People were asked to reflect on what they thought was going to happen next after being discharged from the cancer system. Knowing that they had incurable cancer which was beyond treatment where did they feel themselves to be? This was the most difficult question I put to people, and one which for many it required I stop recording and give people some time to gather themselves. It was also, not insignificantly, one of the most difficult clinician-as-researcher experiences I had in this process as I wanted very much to dwell in this space with people, companioning them in their unwanted and fearful reflections. It is a place where as clinician I would ordinarily reach out, take someone's hand, signalling that I was bodily and empathetically there with and for them. It felt strangely detached to ask questions and wait for responses, but it also felt like this was the researcher's posture I ought to be taking. I felt at odds with myself, yet at the same time knew that being both the reflexive palliative care clinician *and* researcher I could feel and encounter this sense of selves together and opposed to one another. Again, as with Hugh's recounting of my previous intervention in his story of his wife's cancer journey, I felt myself to be in the story and storying the story at the same time.

Responding to my exploration of what this space felt like, Jane reflected most movingly on the liminal space she found/lost herself in.

...and I have been spending quite a bit of time figuring out what the aim is and what my aim is at this point and I find myself um, I find myself finding that difficult finding what that goal is. Um because when you're healing that's a thing to look forward to and it moves you forward to your future. Um, but if um, you're not moving that way, you're not moving towards a future that um, is being without illness, I don't know how you can say what direction that is? I'm not sure I have the vocabulary for it. It's ah, sort of stalled, sort of static.

Linguistically, this passage brings to mind a term *atopon* which Gadamer uses to help describe coming up against that which is strange to us. He writes “based on a polarity of familiarity and strangeness [the tension] is in the play between the traditional text's strangeness and familiarity to us – “The true locus of hermeneutics is this in-between” (Gadamer, as cited in Hryshko, 2003, p. 108.). Familiar to Jane is the healing place, something to move forward and story herself toward. Unfamiliar to Jane is the place where there is no healing, the place of not being without illness. She cannot say death. This is a place for which Jane has no words and she does not know how she will move forward in this space of utter strangeness. This space is also framed as an in-between space flanked by two poles. The proximal pole is what is known – the here and now of being a person with cancer that may be healed. The distal pole is not clear at all, and where the stepping off place is what Jane calls a “stalled and static place.” It is the dying and death place, but Jane has not yet found these words, she cannot story herself forward in this space.

Goalless, with the experience of losing a healing direction, Jane cannot see what to look forward to. The future Jane is moving towards is obscure and she is rendered aimless.

Directionless, if Jane is not healing she is not moving into a future without cancer. But Jane cannot bring her vision around to her future with cancer, the incurable and progressing disease

she now knows she has. Motionless, within this space Jane tells us she is stalled and static. This space escapes her linguistic horizon and she consequently has no words to speak herself forward into some direction. She has lost her story, biomedically *and* bodily, and in terms of Giddens' (1991) conception of self-narrative, cannot go on. She is neither here nor there, she feels that she is living and somehow not living in a way she has ever encountered before.

Simultaneously, her husband John is in what I would describe as an adjacent liminal space which I more fully explore in the next section on relationships and liminality. He is not with Jane in her liminal space as he cannot bring himself (or allow anybody else) to be there with her, as he tells me that he feels this is admission to her being a dying person. John stands on the periphery of Jane's space – calling on Jane to continue to fight until she wins so that she might be back to being Jane in the ways he feels she ought to be, and he needs or wants her to be. For himself, John tells me he is searching for his own supports as Jane's caregiver: he has been to meetings and is looking for online groups that would support what he feels to be his specific need as the husband of a woman with *colon* cancer, and has found very little. He has been shaped by Jane's experience of being a colon cancer patient and cannot find the corollary support group for the care-giver of a person with colon cancer. John is in his own neither here nor there space which has features of Jane's liminal space but is at the same time different.

Do all cancer patients and their family members experience a liminal space as Jane and John do? Participants' accounts would suggest that they do not, and here I would like to contrast Jane and John's experience of their liminal space with that of Mary and Fred, and then Tim's. This comparison illustrates that not all people may experience liminality the same, and some people may not experience liminality at all. First we will contrast Jane and John with Mary and Fred.

Mary: You see how things just change, how it becomes ... I honestly have had more growth in me and I've grown more as a person because of this.

Fred: And I have changed worrying about her to caring for her. That's a big difference... and I love it, I love caring for her, I do. Our relationship has been closer than it's ever been.

Mary is aware that she is going to die, and so is Fred. They are living in a not-treatment space, and are comfortable that this is "how it becomes." Similarly, they are not speaking about engagement with the next expert palliative care system, because they are not engaged with this next system although they are aware of it being there. They are comfortably finding their rhythms together as a couple in this space, and are using this opportunity to deepen their relationship. They refer to this time as "a gift."

A third account from Tim describes a liminal space so constricted that it features more as a margin that he crosses without dwelling overly long in the mental or linguistic space of uncertainty and stasis that Jane described.

Tim: ...when I first heard it [palliative care] I was horrified and then I thought, man we've all been on palliative care from the day we're born. We're all going to die and we're all doing the best to make our lives as healthy and positive we can and that's what I'm thinking of it is, a way of extending my life and making it as happy and comfortable and healthy as we can. Right now I guess, I don't know, it's going to be drugs and somebody helping me bathe and empty my waste I suppose, but I'm hoping I can manage to you know, stay home and do most of it here and keep active and as long as I can still move I'm going to keep trying...

Ann: And have you connected with anybody in the palliative care group in your community?

Tim: Yes, yes we are hooked up with the...people here on the [name of community] and they got me in with a local doctor who is the palliative care doctor at [the local hospital] and we've seen her a couple of times.

Tim does not settle into or dwell in the liminal space that Jane and John or Mary and Fred do, rather he has moved over and through this potential space into the next expert system of care.

He has a fairly cogent picture of what this next expert system will provide in terms of symptom

relief and personal care, and is quite okay with that. He would be viewed as having successfully transitioned by both his oncology clinicians, and I would suggest his new palliative caregivers.

It seems that one feature of a liminal space is that it can be somewhat elastic – a space of neither/nor for Jane and Mary and a mere margin for Tim. But Jane and Mary did not experience liminality in the same way either. I think how liminality is experienced and subsequently traversed is related to the self (or couples' selves) finding/losing themselves in it. Jane and John bring to their space what I think is a well-disciplined orientation and response to the expert cancer system. Jane cannot find what to do next, how to be, and in fact who to be now that she has been discharged from the cancer system and released from the expert medical gaze. And so this sense of self is heavily mediated by connection with (or abandonment by) expertise. Jane truly feels abandoned and is at a loss in this abandonment – she is betwixt and between and cannot seem to find herself.

Parallel to Jane's experience, John is still seeking the "right" support group to guide him through this ambiguous space, but one which he feels must align perfectly to the aggregating forces of his wife's experiences with the cancer treatment system. There is a structureless feeling to Jane's sense of self-narrative with nowhere to go on to. In contrast, John seems to cling to the defining structures of his wife's cancer story to find self-defining toeholds with which to go on. These are responses shaped by the expert system unfolding in a place bereft of expertise and Jane and John do not know how to go on – ensconced as they were and continue to be in the biologic story of Jane's cancer, they have lost their own story line.

Mary and Fred, on the other hand, seem to have a wider repertoire they draw on, and in their liminality, emptied of expertise, they are drawn to each other and the wisdom they have as a couple and a family who have experienced loss and grief. They make meaning through

companioning each other and their reflection on who they are as they go on in their situation. They know there is a biologic story, but they do not depend upon it for their narrative. They have a story line they can follow and live in within the midst of their liminal experience.

Tim comes to a potential liminal space with yet another self and shaped expectation. As a man whose work involves design and engineering, he is positioned to seek out the next plan, the new design, the blueprint for action and does so, smoothly stepping over the liminal margin and ensconcing himself in the expertise and structure of the next expert system, palliative care: he not only has a toehold in his going on, he speaks as if he has a shining path. Each of these three people and/or couples has very different stories, experiences of being in the after treatment and before palliative care space, and consequently I will argue have very different requirements for support, where the notion of finding a self-narrative and staying or going on is what is at stake.

The liminal space that cancer patients experience, in the truly betwixt and between sense of this term, is the space after the prognosis is given, curative attempts are abandoned, and the clinic has moved them on (or at least attempted to do so), but before the person becomes taken into the next system of care, the next expertly defined narrative chapter, if indeed they ever are. It is also important to note that this liminal space was not as clearly marked out for all patient and family participants as it was for Jane. For some, the space was marked only as a margin, and did not take on the features of “being stalled and static” as Jane’s did. But for all there was a clear point of transition whether that was identified as space or margin. This in-between space is described by Pattison (as cited in Riley, 1983) who explores this as the interval of “living-dying.” This interval Pattison states characteristically comes after the crisis undergone by the self after learning the prognosis, be that the predicted hours, weeks, months, or years. Pattison (1983) calls attention to the requirements for dealing with the living-dying interval and for skilling the

self to deal with such fears as loneliness, loss of others, and loss of identity. In advocating for support systems for the dying person, Pattison says that the crucial task is “to retain self-esteem and respect for the self until death” (as cited in Riley, 1983, p. 194).

I see this work as people needing to story themselves forward from a person who may be cured of cancer to one who will likely die of the disease. It is as if these people cannot reweave an unwinding narrative of themselves, once the biologic story line is abandoned, hence the notion of being non-aggregated and then consequently un-aggregated. The feeling is that people cannot muster whatever they require to take up their self-narrative, consistent with Giddens’ (1991) observations about how people facing death come to a narrative stop. As noted, not all people experienced this place in complete solitude, and it was interesting to note the history and consequential interaction of couples seemed to shape how they coped with this space.

### **Relationships in Liminality**

Watching people drift into liminal spaces was difficult for family members interviewed. People who are cancer patients enter the liminal space: family and friends sometimes did, and sometimes did not. In this section I will contrast two couples’ accounts of how relationships become in the liminal space – first, Jane and John and then Mary and Fred.

After interviewing Jane, I learned that her primary care giver was her husband John. The day after interviewing Jane, I received a very angry email from John reprimanding me as a “student researcher” for “bringing conversations about death into the house.” John’s sense was that the only way for them to fight his wife’s cancer was to keep optimism and hope, and that the “death talk” I pursued with Jane robbed them of both. John wanted Jane to keep faith with a battling story of cancer; Jane told me her sad, lost and liminal story of being a person with cancer who will not likely be cured.

What was disconcerting about this couple's situation was that Jane was sharing her profound sense of losing self and being lost yet there was no room in the home to express the feelings she so obviously had. Jane was isolated in her liminality, as it seemed she and John had some collusion of silence about what was happening with her. It also seems that John had his own sense of isolation, as he can neither stop nor follow his wife Jane from going where she is narratively bound. My vision was of John standing on the shore watching Jane floating away and sinking in the waves as she did, with John being shore-bound and utterly unable to do anything to change this. I wondered if it is difficult to learn to become a dying person and to story that life, what it must be like for the not-dying family members who are compelled to witness this as they continue forward alone in their self-narrative.

A second very different couple account is Fred and Mary's story about how they related to each other in this liminal dying space.

Fred: Our relationship has been closer than it's ever been.

Mary: Well yes, for the first 40 or so years of our marriage you were a workaholic. So then I raised the kids and we did everything in between but it has been. It's been ... if I had died of a heart attack a year ago we would not have gotten to where we are. I mean we go to bed early, we talk to each other, we say things that we didn't talk about before.

Fred: And we enjoy it immensely.

Mary: We do.

Fred: We just lie on the top of the bed and talk for hours and we never did that.

Mary: No, never.

Mary and Fred sat side by side, holding hands and grinning at each other. There was a very different and open feeling about this exchange: nothing hidden away, nothing not spoken about. In fact more than ever Fred and Mary were finding places of connecting with each other. They were in their liminal space together, comforting each other and finding a mutually meaningful narrative that they could both story onward with. What was different for these two couples? Mary and Fred had a long and instructive history with losing and loss. They had raised a

chronically ill child, and they had buried their son after a tragic accident. They knew this space of loss and grief and had learned how precious their time was in it. Mary had also indicated that as soon as she knew she had cancer she was aware of its lethality. Therefore Mary and Fred not only drew upon a personal repertoire of selves in their baskets, they also departed from the cancer system expectantly and without rancour: that expert shaping had lost force in their going forward narrative. In contrast, Jane and John did not claim much experience with loss of this magnitude and were consequently building their expectations and behaviours on *terra incognita* and doing the best that they could. Jane with her liminal story and John with his battling story just could not find common narrative ground. Having no significant experience to draw on, they did not have the same repertoire of behaviours, the same capacity to knit together a story. As well, Jane and John were both clinging to the hope that somehow a cure would appear for Jane – together they held onto this hope and with it the cancer system that they felt could deliver on this hope. The issue is, in terms of the basket of selves people might have, most people are unlikely to have Mary and Fred's vast experience and framework around losing and loss. Additionally, many people feel that they cannot let go of their relationship with the cancer clinic as it represents the narrative of a continuing self, without which they may become a discontinued self (Giddens, 1991). As a result many people in liminal spaces may have no identifiable self supports, and no way to see themselves moving away from the possibly cured cancer patient narrative.

The in-between space of neither cancer systems nor palliative care is vaguely identified and not associated with either care system. It is also a space where people losing their biologic story of fighting their cancer are left to recraft their bodily experience and story to one of dying of cancer for which some experienced a sort of narrative suspension. This is the liminal space to

which I will now turn to explore in terms of its conceptual underpinnings so that we might better understand this space and narrative parenthesis.

### **Exploring the Historicity of Liminality**

Liminality was explored from its nascence in anthropology, where the term is used to describe the rites of passage a person may undertake when moving from one group to another – for example adolescence to adulthood, or one social situation to another—for example single and celibate to wedded (van Gennep, 1960, p. 11). This work leads to the conception of a liminal person as vaguely constituted and ambiguous, operating in a betwixt and between space (Turner, 1969). Meyers (2008) uses the concept of liminality to explore Sartre’s and Merleau-Ponty’s existential conceptualization of being and nothingness. This philosophic work was specifically examined as it particularly highlights the “betwixt and between” notion of both the person and the space and brings this layer of meaning found in the opening passage from Jane into an interesting and instructive light. Two selected sociology papers which explore the concept of liminality were examined in terms of their capacity to extend the ambiguity of liminality and its social functions. The migration and perturbation of the concept to health care literature was then followed, with specific attention to the use of the term in describing the experience of a person with cancer. This exploration also touched on the cancer and palliative care health literature about *transitioning* patients. The conception I brought forward is one that resonates with these constructions of liminality, yet is not satisfactorily explained by any one of them, with this study adding a theorization of liminality that extends how it is has generally been taken up in literature, and specifically been taken up in health care. Therefore, this section theoretically anchors liminal space and participants’ experiences drawn from the data, connecting the experiences I have discovered in the after-treatment space to the meanings that may be made of this.

**Anthropology and liminality.**

Liminality is a term attributed to anthropologist van Gennep and later developed by Turner to describe experiences of transition, ambiguity, and being “betwixt and between” (1969). Van Gennep’s (1960) anthropological studies explore the ceremonies that attend a person’s transitions from group to group which he framed as rites of passage and for which he states the “underlying arrangements” are in many ways similar to each other whatever the transition is (p. 191). Van Gennep examines ceremonies and rituals concerning events over the lifetime – pregnancy and childbirth, initiation into adulthood, betrothal and marriage and death and funerary rites. The goal of transitions according to van Gennep is to “pass from one defined position to another which is equally well defined” (p. 3, 1960). Transitions are comprised of three stages: pre-liminal stages, liminal stages, and post-liminal or new world stages, with accompanying rites at each stage. Van Gennep’s work has been used as a framework across diverse disciplines including medical anthropology (Scott, Prior, Wood & Gray, 2005; Thompson, 2007), sociology, (Walker, 2005; Wozniak, 2009) feminist studies (Heilbrun, 1999) health research (Cayless, Forbat, Illingworth, Hubbard & Kearney, 2010; ), and nursing (Harrow, Wells, Barbour & Cable 2008). Much of this research attends to transitional experiences using the stages outlined by van Gennep, while others look more closely at what constitutes the ambiguous and vague in-between and liminal places (Bruce, et al, in press; Molzahn, Bruce, & Sheilds, 2008).

According to van Gennep (1960) the middle liminal phase is characterized as ambiguous (both the phase and the individual) as the transitioning person traverses a cultural realm which has few of the features of either the past or future states. This ambiguity creates necessary spaces for the individual to take up requisite new constructions of the self, to ready the self for the new post-liminal space. We see this ambiguity of space and self clearly with Jane’s narrative:

she feels directionless and she is yet unable to articulate her new construction of self or story, she cannot narratively go on. Coming from a highly structured and informed experience of being a cancer patient, this new space altogether lacks the accoutrements of the expert system to which she has become accustomed. There is no referral to the liminal space. There is no orientation to the liminal space. There is no schedule, goal or pathway or story associated with the liminal space. Comparably speaking the liminal space is featureless and void. Ineffably situated, it is small wonder that Jane lacks the capacity to describe it, to story herself on. Turner (1969) points out the feature of the speechlessness in the liminal space as requisite to a new post-liminal wisdom which he describes as an “aggregation of words and sentences” (p. 103), and distinctly connects to Giddens’ (1991) notion of storying the person forward. And similar to Giddens’ (1991) this preparation is not merely about communication but relates to the ontological refashioning of the personhood of the traversing liminal being. But Jane does not wish to be refashioned. The future state she does not want to associate with is to become a dying person in need of palliative care which she characterizes in terms of the intrusive features of the “blue book” and “the DNR.” This is not a story line she wishes to take up. In fact, Jane feels the story line of being a dying person and this next expert system intruding into her experience, threatening the continuity of her self-narrative as cancer patient and sought for story line of being a person who will heal. We do not see Jane seeming to engage in a readying of the self for Turner’s post-liminal world.

In contrast, Mary and Fred come to their liminal space and its ambiguity with foreknowledge. They have been there before with their son’s death and can enter into this space with the wisdom of what they learned through that experience. They are less reliant on the withdrawn wisdom of the expert cancer system. They have and can story themselves forward in

their liminality – they know that Mary will die, but rather than pushing this conception out of their minds, they work with this knowledge that Mary is dying by intensifying their living with each other. They can conceive of a post-liminal space of Mary’s active dying and they grasp the reality and the experience of this eventuality – a very different sort of living/dying than Jane’s and John’s.

Fred:            So life goes on and it’s what you make it ...taking advantage of the new friends that show up, the more compassionate people you meet that weren’t in your lives before, suddenly you meet those people and you develop relationships with them because they get it, they understand the meaning of life if you like you know. So you end up surrounding yourself with people who care more and understand life and mortality. We don’t do that in the normal course of our life.

The question of temporality is relevant here. Do people who seem to dwell in a liminal space do so only momentarily? Turner describes the temporal feature of liminality as being a “moment in and out of time” (1969, p. 96). Could people be in and out of time, shifting their sense of being liminal with their mood, or perhaps on reflection of a revised sense of self-narrative? For example, while Jane speaks of the “here and now” I wonder how Jane might reflect on her sense of self in this space at another time – a week later, or perhaps in telling her story to another person. Did perhaps the conversation Jane and I had shape Jane’s impressions about dying and change the meaning she was making of her liminality? Gadamer (1989, 2000) suggests that it would, as meaning is made through conversation which changes both persons perceptions who are involved. Does Tim always feel so secure about what is happening and where he is going, or does he experience moments of doubt, days of bleakness? Does he forget the new design that he tells me about in relation to palliative care in a moment that he pauses on the step, looks out the window, loses his place in his distracting book? Would he have confided something different about his feelings if his wife Susie were not there? Does he tell someone else – his son, his close friend – something different about what he is experiencing? I suspect

very much that he might. Tim was not only speaking with me, but with his wife in the room, he was playing to an audience, and when Susie mentions what she will do to help change the system for others when Tim is gone, Tim says “Let’s not go there,” placing the public discussion of his non-existence at the margin of the discourse shaping our encounter (Foucault, 1982). I suspect that experiences of liminality are not fixed once and for all, but rather come and go, wax and wane as people reflect on their mortal nature with self and other, forgetting and remembering that they are going to die from one moment to the next.

Giddens (1991) connects the self with the life events that shape the self and states “the life course is seen as a series of “passages” which in modernity are neither institutionalized nor attended by formalized rituals” (p. 79). In this conception, liminality can be seen as one of Giddens’ passages especially if this statement is aligned with the anthropological views of liminality I explored. It is noteworthy to me that Giddens thinks of these passages as “neither institutionalized nor attended by formalized rituals” potentially placing the notion of liminality beyond the cancer system and before palliative care as institutions, and calling to question the notion of ritual in his conception. Giddens did not write his reflection on self-shaping to specifically explain the liminal space, but I wish to point out how the anthropological conception of liminality focusing on rites of passage resonates with Giddens’ thinking and how it does not.

Giddens thinks we move through passages, but he also argues that we have lost our traditional rituals. Looking at passages and rituals, both van Gennep and Turner suggest that the rituals are derived to accompany rites of passage through the middle liminal phase. Giddens goes on to say that modernity has changed how these rites happen, removing them from tradition and sequestering them in expert institutions (1990). Is the rite of passage from cancer treatment and being a cancer patient to palliative care and being a dying person ensconced in the palliative

care referral? The nature and location of these potential rites of passage will be explored in the next chapter where people's liminal experiences happen and should be supported, thus exploring the second research question.

Here I would like to recall that Giddens (1991) states that death poses a particular problem for the continuation of a narration of the self because we become unable to sustain our habitual forgetting of the inescapability of death. Again, I think that Giddens' thoughts draw forward the function of self-storying I have been exploring. Death is not something that we keep in the forefront of our thoughts even though there are few things in life that are comparably as certain to happen. How does this come to be? What personal and social forces are at play here? Zimmerman (2004) suggests western society avoids death, and says of this avoidance that it is "death-denying to a point of which this [avoidance] has become social fact" (p. 1777). Giddens suggests that our capacity to keep death at our cognitive periphery is what allows us to continue our narration of self, the self-story. The self is interrupted and brought up short by death and we see this in participants' accounts. Jane's self is both interrupted and brought up narratively short in her liminal space. Mary's self is interrupted but narratively finds a way to continue. Is it the variety and depth of the self-repertoire Jane and Mary have that influences how they become what Turner (1969) calls the liminal person? Both Giddens' and Turner's ideas layer meaning and depth to the concept of the liminal space and how this contributes to my sense of what happens to the ongoing self-narrative of the dying person. Let us look a little more closely at the liminal person and see how these meanings are made clear.

### **Liminal personae.**

Building on van Gennep's work, Turner (1969) elaborates what he calls "liminal personae" or "threshold people":

The attributes of liminality or of a liminal person are necessarily ambiguous, since this condition and these persons elude or slip through with a network of classifications that normally locate states and positions in cultural space. Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial. (p. 95)

Turner describes liminal persons as people who possess nothing (1969, p. 95). This notion of possessing nothing aligns with Jane's sense that she has lost her sense of self and possesses no words, she cannot find her words to story herself forward in her liminal space. She has a clear vocabulary and sense of what healing is – her pre-liminal space. She cannot express what the post-liminal space is – it is in her words a place of non-healing, but other than the opposite or negation of her pre-liminal space, she cannot find descriptors, nor can she for that matter find her own story line for this next space she senses is looming before her. So it seems that the liminal person is a vaguely constituted self, as reflected in Jane's passage: "Um, but if um, you're not moving that way, you're not moving towards a future that um, is being without illness, I don't know how you can say what direction that is?"

It is also interesting how Turner (1969) looks to the ceremonial to assist the ambiguous liminal person. What might be considered ceremonial of the spaces that Mary or Jane find themselves in? In a modern technology-driven world, we have, according to Giddens (1991) changed the nature of the rituals or ceremonies which guide and support us "modernity breaks down the protective framework of the smaller community and of tradition, replacing these with larger impersonal organizations" (p. 33). This has implications for how people might be guided in these liminal spaces. Traditionally, those rituals might have involved a sense of religion, and perhaps righting oneself with one's world or simply reconnecting with significant others as a means of leave-taking. Giddens (1991) goes on to say that one distinctive feature of modernity is its persistent orientation towards the future, focusing people to reflexively plan and structure

their selves and their futures. This orientation and reflexive planning is mediated “through contact with expert knowledge” (Giddens, 1991, p. 5). This separates out the “social life” from its “original” (personal, localized and traditionally shaped) position to one of “lifestyles” where the self-identification and the reflexively-organized life planning is accomplished by assessing risks and through contact with expert knowledge (Giddens, 1991, p. 5). Giddens (1991) concludes that in taking this modernist approach to life, people lose “direct contact with events and situations which link the individual lifespan to broad issues of mortality and finitude” (p. 8). We see in Jane’s passage her sense of loss of direction when she feels no longer to be a person of interest to the cancer agency. We witnessed Hugh’s clear anxiety to reconnect with the cancer agency when he felt that he and his wife had been let go to drift. And we heard Tim’s struggle in his exchanges with the cancer system to be taken as a person, not merely as a contributor to a statistical probability. If these people cannot sustain trust in their own self-integrity, or lose their capacity to “keep a particular narrative going” they come to their own liminal space where human control and indeed existence reaches what Giddens’ refers to as their “outer limits” (1991, p. 162)

Mellor and Shilling (1993) similarly argue that the organization and experience of death as we now experience it in society is a feature of high modernity (after Giddens). They see that the “existential contradiction of being aware of the inevitability of death while being unable to have certain knowledge of what death will entail” is a powerful threat to a person’s ontological security (1993, p. 421). In this threatened state, dying people are often removed from their “homes and the public arena” and left with suffering in loneliness. This counters what Berger (1967) noted in premodernism, that the construction of meaning concerning death is a crucially social and communal phenomenon. This modernist orientation to death has resulted from a) the

increased identification of the self with the individual and physical body as opposed to the social body (Elias, 1985); and b) the erosion of the sacred (Berger & Luckmann, 1967). The result of this reorientation has left individuals “alone to construct and maintain values to guide them through life and death” (Mellor & Shilling, 1993, p. 429). If we do not socially embrace dying as part of our human condition, we problematize people’s experiences of dying – they become merely medically documented experiences of sickness and individually lived through loss of narrative. I think that the “other agencies and impersonal organizations’ that take the place of the sacred in this study are palliative care systems that embody technical expertise as this relates to dying: prognostication, functional status measurement, and other technical devices such as clinical pathways and advanced directives. Outside of, and perhaps in spite of these technical and impersonal approaches to dying, people in modern times are left to re-story themselves in their living and dying by themselves as they are ensconced in their self-narrative histories and diminishing social networks. I now turn from anthropology to the philosophical writings of Sartre and Merleau-Ponty to help further explore the features of liminality as these two thinkers wrestle with the notion of being and nothingness, a dialogue which I think informs my conception of liminality.

### **Existential philosophical reflections on liminality.**

Sartre and Merleau-Ponty both grappled with the problem of being in the world, Sartre arguing about the ontological dichotomy of being and nothingness, and Merleau-Ponty exploring a more flexible relationship in the perceptual dualism of visibility and invisibility (Meyers, 2008). I was struck by this work as it seemed to add depth and dimension to the being/not being sense of liminality I discovered in the accounts. Meyers’ essay explores how both philosophers approached their question of being in the world through the lens of liminality. Sartre uses a

viscosity image to explore the interrelationship of being and nothingness with the notion of sliminess being between solidity (being-in-itself) and liquidity (being-for-itself). Sartre describes this slimy space as an essentially ambiguous something-nothing space (Meyers, 2008). Merleau-Ponty extends Sartre by exploring being in the world perceptually, and in doing so attempts to overcome the dualism of Sartre's notions, and the negativity of the in-between places. This he does by exploring the interdependence of what Sartre conceives as mutually exclusive ontologies of being and not being, arguing that one cannot *be* without the notion of *not being*, and by doing so drawing attention to the being/not-being space between the two as essential to either conception. Further, Merleau-Ponty places the notion of being and non-being in the framework of perception of body in the world-with sensation being the unity of body and world (Meyers, 2008). Meyers (2008) draws attention to the liminal region of being that together Sartre's and Merleau-Ponty's writing explicate and argues for the intra-polar ontological space of liminality.

These philosophical renderings of liminality explore the feature of being in between in terms of an ambiguous something-nothing space, as well as the feature of intra-polarity, both of which resonate with findings in this study. The ambiguity of the space I have described is both linguistically and ontologically parenthetic, as clearly rendered by Jane in her solitude as well as Mary and Fred finding themselves in their lacuna of heightened togetherness. If one thinks about liminality as a lacunal space that opens up after cancer treatment and before a new uptake into palliative systems, these polar extremes might be considered the two expert systems of cancer treatment and palliative care and/or the states of living and dying. It is noteworthy that Tim did not experience the middle tension of this polarity, and so did not declare himself in a liminal space. Tim merely continued his narrative self on into the next expert system. Mary and Fred found new

language and meaning. Jane did not. She finds herself unexpectedly and dejectedly outside of the first expert system, and very clearly resisting the overtures of the next as we see in this passage:

That was a, a really big bump too. There was a meeting when ... the results of the cat scan and the CEA numbers were going up and so the oncologist said that there was a recurrence but I was asymptomatic and then after that I was symptomatic and that was the other shoe dropping. The minute that you are symptomatic you're in you're not on that same path. You, you get sent home with a book from palliative care centre that has a DNR ... which is hard to look at ... *crying* ... the binder, the blue binder on palliative care.

Belonging to neither expert system, Jane is clearly in a liminal space. Viewing liminality through this philosophical perspective exposes layers of the notion of being/not being which leads to questions of polarity and in-betweenness that add depth to this concept. So that I might explore yet another layer of meaning to the conception of liminality, I will now turn to selected sociological renderings of the concept.

### **Sociological reflections on liminality.**

Two sociologists have explored liminality in some depth: Fanetti (2005) and Walker (2005). Fanetti explores the concept of acculturation with liminality representing the “cultural chasm between Eva Hoffman’s Polish past and her American present” (2005, p. 405), which Hoffman explores in her seminal work on experiencing the intercultural world in her 1989 book *Lost in Translation: Life in a New Language*. In her book Hoffman chronicles first her postwar childhood in Poland where she felt her history and context as an emerging human being and which she calls *paradise*. In the next chapter of her life Hoffman narrates the 1959 transition of herself and her Polish-Jewish family to Vancouver and eventually the United States. Eva experiences this transition, the subsequent struggle to establish her self, and the disorienting impact this displacement had on her self and entitles this space *exile* and as both unwanted and resisted. She no longer knows who she is in this utterly new place, and subsequently “can say

nothing” (Fanetti, p.418). Fanetti explores how Hoffman experiences this chasm through language, not in its understanding, but rather through its “essencelessness,” yielding an ability to connect with but not fit into both and any culture Hoffman encounters. Hoffman chooses to dwell liminally between both her Polishness and her Americaness and their “rigid constructions of culture and identity” (2005, p. 418). Here I see Fanetti (2005) construing liminality as yet another inter-polar space, similar yet different to Sartre and Merleau-Ponty, exploring concepts of self through language and acculturation. Becoming a cancer patient was described earlier in the work as a process of acculturation of the person to the new and unwelcome identity of cancer patient. Similarly palliative care with its disciplinary terminology can be conceived as yet another acculturation for cancer patients after unsuccessful cancer treatment. Between expert systems lies the potential space where language and identity may remain grounded and flexible as Fred and Mary explained, or diffuse and lost as Jane describes. We are also reminded of Giddens’ (1991) notion of the self-narrative and the “going on” the continuation of this narrative furnishes, or in the case of Jane, does not. Mary and Fred know where and what the polar regions of their experiences are and like Hoffman they choose to connect with, but not fit into both – to be liminal. This is how they find themselves able to go on narratively (Giddens, 1991).

In her reflective essay, Walker (2005) explores the notion of porches in terms of their liminal features. Her thesis is what was originally constructed to “close us in ended up connecting us” and she explores how and why this happens (p.18). Walker explores porches as “opening up” transitional spaces between private and public life (p. 18). Liminal porches are places between two polar places of which a porch is neither – it is a betwixt and between place. Walker also describes porches as places of transitions, assuming movement between polar places. Here we see reflected the anthropological notion of liminality as a stage in ritual which is to be

traversed and the philosophical reflections of in-betweenness in relation to defined inter-polar spaces. This rendering of liminality does not appear to extend the concept in any novel way; rather Walker applies the anthropological and philosophical features of liminality to her interest and concern of exploring private and public life. Finally, I will turn to how liminality is applied in the health literature, both generally and as this relates specifically to cancer.

### **Reflections on liminality in health care literature.**

Frankenberg (1986) examines the use of root metaphors in the performance of sickness roles and used the term liminal to describe episodes of life disruption by any illness where structure and custom are abandoned. Drawing on Susan Sontag, Erving Goffman, Anselm Strauss and Victor Turner, Frankenberg argues that for chronic illness “the theme of movement through space and over time is ubiquitous” (1986, p. 624). This conception of liminality resonates with the findings of this study – Tim’s story captures the notion of movement through time and space, Mary and Fred see themselves moving through space and time that is dwindling. Also Frankenberg’s conception of liminality implies, as the findings in this study suggest, that the liminal space has bounds: it is an episode or space, not a state.

The term liminality has been most extensively used to describe patients’ experience of cancer. This may be so as it is the trajectories of cancer that are so very well mapped out, and as such transitions inclusive of a liminal aspect are more readily discernable (Hallenback, 2003). Little, Jordens, Paul, Montgomery and Philipson (2006) in their study of the subjective experience of colon cancer patients, proposed that liminality is a *process* which starts with the discovery of a malignancy and in this first manifestation is “acute.” After a period of stabilization all existence is charged with an enduring sense of liminality, departing from what they term as van Gennep’s (1960) “tripartite process.” This conception of liminality focuses on the breadth of

life lived after cancer whether or not one's cancer is curable, and so describes a state of perpetual, albeit variable limbo for all cancer patients (Little et al., 1998, p. 1490). In contrast, the way liminality is conceptualized in this current study is more narrowly applied to the cancer patient having learned that they will die of their disease and their consequent loss of self-narrative and ontological bearings when receiving this news. What my conception adds is that the liminal space is co-constructed by the individual and the health care system: the individual doing so with loss or faltering of their narrative line and the health care system by presuming on the simultaneous declaration of a liminal space and its remedy in the term transition.

Similarly, Navon and Morag (2004) in their study of prostate cancer patients receiving hormonal therapy write that patients lost a "sense of continuity, excitement, hopes and coping capabilities" and that the alterations engendered by hormonal therapy led these patients to a liminal state, described as an "inability to classify themselves culturally and socially" (p. 2337). This study also draws on the anthropological understanding of liminality rendered by van Gennep and Turner, but like Little et al., emphasises the persistence of the changes wrought by hormonal therapy leaving these cancer patients "permanently unclassifiable" and in life-long liminality (Navon & Morag, 2004, p. 2338). I feel that this sense of permanence is not clear in my conception of liminality, rather that there is a sense of flowing into and out of liminality, as we saw so clearly with Tim's ability to see himself as dying in some moments but clearly identifying himself as a healthy and robust person at others.

Bruce, et al. (in press) explored liminality expressed as the experience of living in-between a promise of treatment, prolonged life, or cure and the threat of recurrence or progression of disease with cancer, end-stage renal and HIV/AIDS patients. The theme of liminality emerged from the research team as the narratives they were studying drew attention to

their participants capacities to move “between and among their stories” to capture waiting, living with inconsistencies, and being storied and storying themselves (p. 10). Accounts which captured the sense of liminality in these themes in terms of their “messiness, open-endedness, and (in)consistency” but also the participants’ dwelling in these spaces not feeling compelled to move on and through them (p. 16). This finding suggests that the anthropological notions of pre-liminality, liminality and post-liminality may be too constricting for some people leaving cancer treatment centres. Indeed, in this study, a year after I interviewed her, Jane died in liminality as John watched on wondering what had gone so terribly wrong. Tim too died in a liminal space, brought into an acute inpatient area for “rescue measures” as his clinical trial drugs failed to arrest his cancer and his body finally and irrevocably unravelled. So liminality may well persist to a person’s life end, and yet we cannot know from this work that this is the only way the self-story ends.

Palliative care language has taken up the symbolism of thresholds with imagery of doorways in logos and literature, and has described this space and the traversing patient as being in need of supporting rituals through which patients can experience growth and self-actualization (Froggatt, 1997). What strikes me as problematic with this framing is that in modernity we are, as I have argued, bereft of traditional religion and community support to be or to pass through this space (Giddens, 1991). One might reason that our modern attention to spirituality and the natural order in our world functions as a substitute for what may have been lost with the recession of organized religion and more tight knit community. This notion resonates with Walter’s (1994) neo-modern approach that he states Western society has taken towards death. Walter’s neo-modern notion of death is described as an individuated and situated response to death which is private and self-directed. It would seem that this modern or neo-

modern approach to death requires each person to define them self in relation to their spirituality, weaving this reflection of self into their narrative: there is no one size fits all.

In their study of dying patients and family experiences, Chekryn-Reimer and Davies (1991) observed that patients and families see the transition and work associated with adjusting to dying as unwelcome, which they actively resist yet unwillingly adapt to over time. Is the resistance related to the vagaries of the liminal self and situation, or perhaps to the movement towards death, or perhaps the need to interact with yet another expert-dominated system as represented by palliative care? Is Jane only in the liminal space until she reaches Tim's apparent comfort level with the new and next expert system? Devry and Ronaldson (2001) describe how patients spoke of their fear when facing a transition from curative care and their concomitant resistance to the inevitability of death. Can cancer patients' transitions to palliative care be similarly taken up, that is with great resistance to the unknowable future that dying represents? I think this resistance is reflected in the accounts I have gathered, and that this either/and feature of liminality renders this space rather difficult to pin down. On the other hand is the liminal space something that can be shrunk to a line one crosses to comfortably slip under the surveillance and control of yet another expert system? Tim's account suggests that it can be. Perhaps liminality is different for cancer patients? Perhaps liminality is different for each person with cancer?

More specifically, describing dying in the cancer treatment setting, Shou (1993) states,

The definitional context in which the awareness of terminal illness initially begins for the cancer patient is in the treatment situation. There is no facile boundary between the end of the mainstream "treatment" and the beginning of "dying" in many instances: dying will begin in the larger context of an illness calendar already in existence, often in treatment centres the public mandate of which is "cure." (p. 246).

Shou identifies, as did I, is that cancer patients are faced with this turn in self-narrative in the cancer treatment centre, and that this narrative turn is poorly defined, again as I learned with

Tim's sense of what clinical trial therapy represented and what clinicians expressed about the conflation of treatment aimed at cure and treatment aimed at palliation. What Shou also seems to be saying here is that it is difficult for people to make this cognitive or perhaps linguistic transition from curing to dying when surrounded by the same people, space and general experience of the treatment centre that they have so closely identified with their struggle to overcome the disease. Yet great consternation was expressed by all patient and family participants when the idea of separating from the cancer treatment centre was explored. How might the liminal patient be supported in an unwanted departure from the treatment centre and an unwilling approach of either palliative care experts or death itself? This question will be explored in the next chapter inquiring into the nature and location of liminal care.

The accounts of patients and clinicians indicated that people often found this transition to be a surprise, that while they might have suspected or feared that their situation may become one of having incurable cancer, they were still not somehow prepared to take this up as their own story. If in fact the transition of a cancer patient to dying patient requires a cognitive or perhaps linguistic threshold of acceptance and a liminal pause or parenthesis as described, does the cancer treatment centre have the culture to form this imagery and existential space? Can a person with incurable cancer story themselves into being a dying person when still in the treatment centre? Clinician accounts indicate that they might, but that most times people they cared for do not. The treatment centers' mandate to treat and research cancer left little time in the clinical schedule and the organizational discourse for this type of person-centred, person-sensitive transitional care. This possibility of the PCO supporting people as they exit the system will be explored in the next chapter looking at care in the liminal space.

To sum, the data reveals that people who have been told that their cancer can no longer be treated and that they will likely die of it may find themselves in what I have described as a liminal space. In this section I have explored what the various accounts gathered explained about liminality, and how this concept has been explored and developed across a range of disciplines. The perspective I wish to advance here is one that resonates with some constructions of liminality, yet is not satisfactorily explained by any of them. Anthropology speaks to the notions of stages, which helps to define liminality as a “place-to-be-moved-through,” but implies the directionality of the “mover.” Phenomenology adds the conception of being/not being which resonates with the sense of living/dying in parenthetical spaces we heard in the data. Sociology helps in reflecting on the language of liminality, or rather the lack of clear and agreed upon meaning which gives support to the aporia Jane experienced when she could no longer story herself on. Findings from this study suggest liminality is elastic and can be taken up as a space in which a person may dwell, and at another time merely a margin which another may simply step over. It is a self-shaped and expertise-mediated space that pertains to people’s capacity and willingness to re-story themselves as they “go on” from being a person of cancer to being a person who will die of their cancer (Giddens, 1991). It arises as problematic, as people lose their narrative threads and are concomitantly bereft of social structures to support or explain this living/dying space. Thus, this portion of the work explores and provides an answer to the first research question: How does the transitional patient organize a self that engages with the liminal space between cancer treatment and palliative care?

This section also touched on the literature about transitioning patients and what might be done to assist them, setting the stage to explore the second research question: Where ought this liminal space (between cancer treatment and palliative care) to be located – inside or outside the

cancer treatment centre? It is interesting and significant that the transitional literature has forestructured this part of a cancer patient's experience as one of movement. Transitioning is very different from dwelling in liminality, and it is this omission in the literature that has left the gap in understandings that findings from this study begins to fill. In the next section, I explore the support that might be offered to a liminal person, and from this understanding I launch into an exploration of where this support might take place, and who might best provide it.

### Chapter Seven: Care in the Liminal Space

In the preceding section I explored the concept of liminal space that some cancer patients can find or lose themselves in, comparing and contrasting my emerging conception with some notions from anthropology, philosophy, and social health literature that addresses liminality, as well as the literature that deals slightly differently with the notion of transitions of people between cancer treatment and palliative care. It is noteworthy that this final body of literature presumes upon the *liminal* space as *transitional* space. In this sleight of language the notion of a liminal space has been shaped as purposive and directional, denying Jane's description of liminality for example, the essence of which was exactly the opposite of this purposive and directional languaging. It is also curious to note that the purpose and direction of transition in the literature is also presumed to be *ipso facto* palliative care, a topic and space Jane found both intrusive and unwelcome. This chapter will explore the tensions concerning this directional construction of the concept of liminality and how it positions people I interviewed who were living through becoming a dying person. Here I will exploring approaches that *seem* to be taken up, and others which *might* be taken up to *support* liminal persons as they dwell in or traverse a liminal space and live in their stories of being betwixt and between, or threshold persons.

To begin I wish to state that it is my belief that palliative care is a good and necessary health care service for patients with a life limiting illness such as cancer. In fact, I spent much of my life doing this work and advocating for better support of palliative care systems. Here, it is my intent to decentre the correctness of this assumption and problematize what interests might be served by how palliative care is currently conceived as a health care option for cancer patients. Earlier in this dissertation, I have argued that cancer treatment systems factor as an example of Giddens' (1990) abstract expert systems, and that this has meaning for how the cancer patient

self is co-constructed. I have also argued that there are interests that shape how a cancer patient is co-constructed. Similarly I will argue here that the palliative care system is yet another abstract system that supports interests which serve to co-construct the now dying-of-cancer patient. Next I will explore and critique the health system solutions that have been introduced which appear positioned to assist the liminal person. Finally I will propose what might support a liminal person and their self-story as they dwell in or otherwise traverse their liminal space, and then propose where this support may occur and who might best furnish it.

### **Palliative care: The next expert system?**

Syme and Bruce (2009) chronicled the development of palliative care in Canada. In this development, it was the hospice movement that aimed to augment the disinterested expert medical system which was focused on curing and correcting. Over time the hospice movement has evolved towards the expert medicalization of dying with palliative care being mainstreamed into health systems, and the care of the dying person becoming more gathered under the expert medical gaze (Foucault, 1989). Researcher Margaret O’Conner (2007) explores the effect of the evolution of palliative care into an expert medical field:

Perhaps the historical discourse about dying could be viewed...as a discontinuous discourse: once a shared communal family activity and regarded as part of human beginnings and endings, it is now not only separate and hidden from the community gaze and family, but has become a medical event in the hands of those who have made care of the dying their specialty, with its own particular language (p. 236).

What O’Conner seems to be saying is that the personal and human bodily story of life, and here death, has been supplanted by a medical or biologic story, just as I found that the personal and bodily story of cancer receded in the overcast of the medical biologic voice. If indeed palliative care has become or is becoming like cancer control in terms of being an expert medical system, what can be seen and understood about the features of this positioning? I will explore

here that like cancer control, these features include but are not limited to language, the evidence of increasing elaboration in technology and the disciplinary expertise that is becoming more and more sequestered, again through the theoretical lenses of both Giddens and Foucault.

The language of cancer control, peppered with acronyms and arcane scientific terms is almost unintelligible to the lay person, and whereas palliative care language is less difficult, there is growing technical vocabulary and acronymic taxonomy that is becoming attached to this area of care. I will consider three examples of this technical development in terms of the palliative care unit (PCU), the do not resuscitate (DNR) order, and the Palliative Performance Scale (PPS).

The PCU is a tertiary care area in an acute hospital where patients who cannot otherwise have their suffering controlled are treated and cared for. PCUs are the intensive care unit of palliative care with a high ratio of specialized medical and nursing staff to patients as well as access to all the services and staff available in the acute care hospital. Patients who are referred here must have needs which outstrip the capacities of their family and community care providers, and any other sector of the health care system. It is a place of last medical resort for the dying patient, and the first portion of specialization in the field I attend to.

From the perspective of system elaboration and streamlining, PCUs are not very different from the cancer control system. There is a referral process. Patients are aggregated. Clinicians are specially trained, often credentialed and highly expert. The clinical space is clearly defined and purposive: it is for people who are highly symptomatic and/or actively dying. There are criteria for who is admitted which must be satisfied: patients must have signed a DNR, and generally accept that their care will not be cure-focused. There are tertiary symptom management techniques that are employed: for example neuroablative techniques for pain control. There are medication regimes that require expert titration and surveillance: for example

methadone induction. It is in the PCU that the concerns of dying and death become a medical interest, and where the bodily experience and story of dying is seen through and shaped by this lens. It is here that the penultimate science of palliative care is manifest, upholding “an image of reliable knowledge” which draws forth lay persons’ attitudes of respect towards “technical specialism” (Giddens, 1990, p. 89). Through Giddens’ (1990) lens, PCU’s are not dissimilar from cancer control systems. Also like cancer control systems there is facework required of experts, particularly at access points where trustworthiness and integrity of the expert and the abstract system is established (Giddens, 1990, p.85). I turn now to explore how a patient accesses the PCU.

In order to access this specialized area of care, it is a ubiquitous requirement for people to have agreed to and signed a DNR, ironically surrendering all hope for medical salvage yet entering into the most medically specialized area of this type of care. A DNR order is a specific type of advanced directive, differing from all other physician orders in that it is a directive that compels a non-action. It is particularly interesting to consider this requirement in terms of Giddens’ notions of facework, as what we see here is a highly coercive notion of commanding surrender to expert trustworthiness. Certainly Tim sensed a rather wresting notion of consent in being required to sign such a document, hardly encouraging trustworthiness in either the expert or the abstract system to which he was trying to gain access.

... she [palliative care doctor] said oh you have to sign this do not resuscitate form. I haven't signed it, I didn't know anything about it, I didn't know it was a requirement or anything but, that sort of put the kernel in me, when do you stop treating someone and this do not resuscitate I guess is the perfect example. You know, he's old, he's got cancer, if he stops breathing he's got a tag around his neck that says do not resuscitate. So that put the sort of the spark in my brain that well, maybe I'm ... *laughter* ... at the point where I'm on the scrap heap and too much of a drain on the system and when do you draw the line and obviously they're not going to go to extraordinary measures to save me if I stop breathing ...

Physicians Elwell and Fainsinger (2000) state that for patients who have high expectations of medical capabilities, the withholding of cardio-pulmonary resuscitation is “not so much an avoidance of useless treatment as an abandonment of the hope of ‘cure.’ It is an acknowledgment of the fallibility of treatment and is regarded as ‘a difficult pill to swallow’ for the patient, the family” (p. 54). I would like to point out that the term used here “a difficult pill to swallow” is a very interesting and perhaps revealing choice of metaphor. Even the withholding of an intervention is expressed as a pharmaceutical intercession. I believe that the use of these kinds of expressions underscores the potency of medical dominance in a way that has somewhat unwittingly permeated our language. Perhaps more disturbing, this languaging is something that as a society we take as normal and “everyday” yet we sense its lurking hegemony. Tim’s account clearly signalled his sense of this – the request that he sign a DNR was the beginning of having this offering/not offering completely out of his control, and seen as the first step on a slippery slope ending in being offered/not offered any care whatsoever *whether or not he wanted this*.

Perhaps not surprisingly, there is a great deal of consternation in the palliative care community about the use of the DNR as criteria for access to palliative care services. On the one hand, the requirement for a DNR has been seen as a catalyst to physician-patient conversations about goals of care, exploring patient hopes, wishes and needs and mapping these out along the likely clinical course of their disease. As noted in the clinician accounts these are difficult and time consuming conversations, but important as a foundation to clear and shared communication with patients. But interestingly, a signed DNR is also requisite for access to all PCU’s in BC, and up until quite recently, a few home-based palliative care services. On the other hand, people needing these services are most likely to need this conversation about goals of care, and the experts who might engage them in this exchange are on the other side of having signed the form

and as such denied to them. The irony is that the people who would have the knowledge and experience to help with these critical decisions are the ones who people can only access *after the critical DNR decision is made*. It is a situation in the care of dying people that argues against not only the notion of expertise, but the particular sequestering of that expertise within the abstract and expert PCU. What is needed is for people to be able to decide/not decide/redecide, in other words *flux about things* and not in any way having to make the irreversible decision of DNR requisite criteria to access these services.

The last technical palliative care term I will explore is the Palliative Performance Scale (PPS). The PPS is a validated tool which helps the expert palliative care clinician to determine what point a patient may be in terms of their functional capacity, from a start-point of fully and independently active to an endpoint of dead. Functional capacity relates to a person's ability to work and undertake their normal activities, ambulate, provide self-care, take in food, and maintain consciousness. On the one hand the PPS is a useful measure of a clinician's view of what a patient is capable of doing for themselves and what patients may need assistance with, and as such can be and is used to communicate a patient's functional capacity between care providers. It is in this way this instrument is used in the transitioning of patients between providers and systems. On the other hand the PPS is a technology whose power effects determine differential service levels – what care people are entitled to. How this happens is in the Provincial Palliative Care Benefits Plan, where the physician must determine and declare the patient to be less than half way on the scale, or to put it rather crudely, half-way dead before they can be placed on the Plan. If a person is, in the eyes of their physician, not sufficiently close to death, they will be denied the support in terms of medication and supplies the Plan would otherwise provide them. What is highly significant in the application of the PPS is that in neither

clinical use nor service determining respects are patients and families ever aware of the PPS's use, even though the readings this tool renders are highly significant to patients' sense of their prognosis and to their likelihood of obtaining supportive care. Like the DNR, the PPS functions as another rather interesting way of approaching facework. With the DNR, trustworthiness is commanded; with the PPS the expertise is so highly sequestered that the lay person is afforded no sense of the trustworthiness of the operator or the abstract system the operator represents in any way: things are being done *about* him or her, not *with* him or her. As such, the PPS is what Foucault (1989) would call a technology of surveillance—a tool designed to aggregate and control, about which patients and their families have little or no knowledge.

Finally, evidence can be found for elaboration of other technologies and consequential expert terminology consistent with abstract expert systems in the palliative care field. Intrathecal pain pumps are implantable pumps that supply medication to the intrathecal space (behind the blood-brain barrier) to address intractable pain syndromes. Pleurex catheters are systems of drainage that allow for effective and efficient drainage of body spaces (pleural and abdominal) which tend to fill to excess, and associated discomfort, with cancer-caused fluids. Botulism toxin injections are an offshoot of cosmetic interventions aimed at reducing wrinkles, and in palliative care used to mitigate myofascial pain induced by trigeminal nerve involvement, which is excruciating pain that people experience in their jaw and cheeks. None of these technologies are without important benefits to patients who are suffering, it is simply noteworthy that these technologies were not featured earlier in the development of palliative care, and are now part of what is understood to be a full-service palliative care program – highly technical, specialized and necessarily expert, and increasingly abstracting away from the hospice movements' founding notions of gentling death (Syme & Bruce, 2009). Similarly, it has been noted that while “high

tech” is often an impetus for specialization, palliative care has been previously characterized as “high talk” as it focused on skilled communication: this migration from high talk to tech has been argued by Periyakoil and von Gunten to compromise the “kernel of inner energy that led the original movement” (2007, p. 41). As a highly specialized abstract expert system, palliative care is coming of age.

Concomitantly and perhaps consequential to more highly specialized interventions, there has been an interesting evolution towards more medicalized specialization of the discipline of palliative care. Medical sociologist Clarke (2002) questions whether the discipline has indeed ever achieved its original objective to encourage and support a “gentler acceptance of death” (p. 905). His contention is that in the face of this ostensible gentling, medicine has persisted with an adherence to “resisting, postponing or avoiding” death, and that inescapable medicalization of health care is clearly evident within palliative care (p. 905). Here as with cancer control systems we see the increasing specialization and sequestering of that specialist within an increasingly abstract expert system (Giddens, 1990). With the movement towards specialized dying places (PCU) and specialized interventions for symptom control, the need for specialized training and enhanced recognition and funding is, as one would expect, being pursued.

The Canadian Society of Palliative Care Physicians has lobbied for specialist status for palliative care physicians over the past decade. Their mission states they aim to “Promote and implement certification of physicians with special competence in palliative medicine,” and their goals include the following:

1. Establish Palliative Medicine as a formalized academic discipline within each Canadian Faculty of Medicine;
2. Establishment of a recognized certification process as a clinical discipline, and

3. Recognition of palliative medicine as a formalized field for study, support and practice. (Canadian Society of Palliative Care Physicians, 2010)

Clearly this section of medicine views the practice of palliative care as specialized and requiring expert status as compared with other areas of medicine.

Similarly, nurses have sought disciplinary specialization through certification in hospice palliative care as determined and recognized by the Canadian Nurses' Association (CNA). The CNA says about certification "Certification helps you stay current by testing your specialized knowledge and skills, and having a trademarked credential after your name to designate certification validates your competency in your area of nursing practice" (Canadian Nurses; Association, 2010), specifying the claim to both disciplinary knowledge and concomitant validation of status. Specialization is about knowledge and power, or power through the sequestering of knowledge, and is very much becoming a feature of those clinicians who wish to be identified as palliative care experts, which is very similar to what was observed in cancer control systems.

With these energies invested towards palliative care being and becoming an expert system, how does one see any perceptible difference between cancer treatment and palliative care as exemplars of expert systems? Both have expressly trained experts who differentiate their disciplinary skills with specialized language and the provision of discipline specific interventions. Both practice in specialized places for which there are specific access criteria. Where difference may exist (and this would be important to lay persons accessing these systems) is in the public apprehension of the expertise. Reflect on the public exposure to either expert system. For cancer there is the much publicized *Run for the Cure*; for palliative care there is the little heard of *Hike for Hospice*. For cancer advocacy there is a much advertised national cancer effort, the

*Canadian Partnership Against Cancer Corporation*. For palliative care advocacy there was the erstwhile *Palliative Care Secretariat* within Health Canada which was terminated by withdrawal of funding a few years ago after enduring an anaemic lifetime of five years. For cancer there is the very well organized volunteer society Canadian Cancer Society which is national in breadth and provincially chaptered and visible to all through their well-publicized annual *Daffodil Days*. For palliative care there are locally championed, resourced and otherwise supported hospice societies, with no flower or other icon-identified days. People hear, learn about and actively support the cancer system—it has cachet. People often hear and learn about the palliative care system only when they have to. While palliative care seems to aspire to being a recognized and creditable expert system, it lacks the sophisticated and well developed public relations machinery of the cancer expert system. I would note that the cardinal criteria and access points to the palliative care system (DNR and PPS), here critiqued as obfuscated and/or coercive, do not help lay people to either recognize or trust the palliative care experts or the expert palliative care system.

Learning about and comparing this next expert system, cancer patients have been conditioned to the well-oiled, efficient and esteemed cancer system. It is small wonder, despite palliative care's public messaging and disciplinary efforts towards expert status, cancer patients leaving the cancer system are either vaguely aware or utterly unaware of the next expert system, and in encountering it find palliative care comparably disappointing. Remember Hugh's account:

You see you know 'cause I'm sure there's a significant variation in how people react and how things progress from point a to b and so on and so my wife, all she was having was the palliative care nurse coming and checking and after some months when my wife was getting you know more and more in distress with the way things were processing, uh I said, well look, this isn't right we need to, we need to uh, get some more help and assistance from the people who are experts in cancer treatment.

But they also often found palliative care, in its increasingly expert system form, intrusive; for persons like Jane it was not a space they were ready to take up, and they preferred to linger in liminality.

The minute that you are symptomatic uh, you're in you're not on that same path. You, you get sent home with a book from palliative care centre that has a DNR ... which is hard to look at ... *crying* ... the binder, the blue binder on palliative care.

A seminal review article by oncologist Neil MacDonald (1998) refers to palliative care and oncology as “two solitudes” and calls for the integration of palliative care into oncology.

Following MacDonald’s work, many in the field of both cancer treatment and palliative care have called for better integration of these two abstract systems, either as palliative care becoming a component of cancer control, or in the better transitioning of patients and families between the two expert systems. Palliative care, as a component of cancer control was available to all the patients and families interviewed for this project through the PSMPC teams and clinics at the PCO. In fact, Tim and Hugh’s wife were seen by these teams and in these clinics, but they did not identify this care as special or different, nor did they subsequently express any different attitude towards palliative care as an expert service. In the accounts I gathered the separate system of palliative care was identified by all participants, and found to be unhelpful by Hugh, intrusive by Jane and Martin, irrelevant by Margaret, and only potentially useful by Tim albeit with grave reservations about its access criteria. Transitioning, if it was done, was not clearly successful, except perhaps for a cautious and conflicted Tim. One wonders if the integration or linking of these systems is a) possible, or perhaps more important, b) beneficial to people dying from cancer or their families?

It is here that I now turn to examine health system efforts which can be seen to link these two systems, again using Giddens (1990) and Foucault (1989) as my analytic lens. What will be explored is whether these efforts are likely to be ones that dying cancer persons and their

families value. What exists that may be thought of as shaping the support, care or processes of persons like Jane being in a liminal space? And finally, do these efforts and existing processes help persons dying of cancer story themselves forward?

### **Bridging between expert systems**

Participants found themselves in a between-systems middle, flanked by unequal but, as I have argued, not dissimilar expert systems. For all patients there was a hopeful adherence to the safe and competent cancer system, and a vastly differing appraisal of the next expert system which seemed to contribute to a difficulty in moving forward. Recall Hugh's comparison of the "checking" palliative nurse to the expertise of the cancer system—the nurse seemed to be doing something, but Hugh neither recognized nor valued this, and was convinced that only the cancer treatment system could offer his wife anything of value. Examining this neither-here-nor-there space there appeared to be no in-between expert system. But it appears that there is system-identification and recognition of the in-between problem, and there are system-generated solutions proposed to it. Here I will explore three areas – patient navigators, clinical pathways and instructional advanced directives, as in-between solutions that are system-proposed to support in-between people, critiquing whether these solutions would work for people who find or lose themselves in a liminal space.

#### **Patient Navigators.**

Over the past two decades the concept of cancer patient navigators has developed, starting first in the United States (Darnell, 2007). Patient navigators were originally envisioned as providing access to the cancer system, most particularly in underserved populations. This original vision has latterly developed to one of overall navigation for all cancer patients

(Canadian Partnership Against Cancer, 2009). What has been criticized of this gradually accelerating movement is that the conception that a health care system which needs to be navigated speaks to a larger issue than mere way-finding. In Giddens' (1990) terms, the navigator is a role that embodies facework and access – the expert operator in the abstract system which is so rarefied that an additional facework expert is required. As such, the concern has been posed that a new and externally located position (with regards to the cancer control system) will not likely solve the issues patient navigation aspires to solve (Thorne & Truant, 2010).

I find it interesting to reflect that the solution of navigators is very much a cancer system-generated solution mirroring the inherent characteristics of patient management used by the expert cancer control system: the silo-ed aggregation of patient types. This time the aggregated group is not a tumour type, and lacking this depiction has become the directionless and lost, or as I have described, people who might find/lose themselves in a liminal space between expert systems. In the cancer control system, aggregation was used for efficiency – to smooth over differences and shape patient expectations and behaviours to their treatment regimen. Feeling this exertion to regularize their responses and behaviours, cancer patients most often found this unhelpful. This unhelpfulness was experienced while being fully under the influence of the cancer control system in their cancer treatment regimens. Imagine how helpful aggregation might feel once the cancer control objectives of treatment response variability had been removed. There is no longer any compelling reason for people having un-become cancer patients to respond to this shaping. In fact, I would argue, there are more reasons than ever to resist the interference and influence of a cancer control system that has dismissed them.

Certainly patients and clinicians in this study spoke to the need for greater guidance and clearer mapping of probabilities throughout engagement with the cancer system. Susie articulates what support this would have provided:

... if there was some way to set people up, I don't know, with a volunteer or somebody who could just pull things together for you...someone to advocate for you ... just a chance to know what possible treatments, what options you have, you know what are your rights as a patient, you know who do you go to?

But others, finding themselves in a liminal space as Jane did, were not clamouring for an expert guide. In fact Jane outrightly rejected the grouping she experienced from the cancer control system. Jane never once asked me what to do, where to go or how to be, even though she knew that in speaking with me she was talking to “someone in and of the system.” Jane was in a personal struggle coming to terms with her diminishing and eventually ending sense of self for which she could find no guidance beyond the life-learned expertise of the self. Jane had lost her own story threads and was looking how to re-story herself, to go on. Susie, on the other hand, was looking for ways to navigate *the system* – not her own or her dying husband's story line. I think this difference is highly significant, and wonder if navigation may perhaps serve one rather more instrumental need and not the other more personal one.

That is to say, if people come into a liminal space as Jane did it would seem that they do not need to be told what to do or where to go as an *a priori* intervention, but rather they may need something different that supports their silence in losing their voice and story or their exploration of how voice and story may be regained in the face of a truncated self-narrative. I am cued to this position by my own clinician response that I had listening to Jane. In my nursing practice ethic, I wished to *palpably* accompany her – to be clearly there with her in her sorrow and confusion, but only this *thereness*, uncluttered by a need to soothe or to direct. On the other hand, I think that directional guides might perhaps be better suited to those like Susie, and

husband Tim, who would step over a liminal margin. But as Tim merely seems to need to step over a margin, does Tim even need a guide? I think not. But it does seem that the cancer system wants to provide a guide in the addition of a navigator to their staff, *whether or not any or all cancer patients may value this*. The difficulty is that navigation is a system-generated solution which is highly predisposed towards the interests underscoring cancer control, which we learned from the aggregated accounts is about grouping and smoothing over differences. Navigators as currently proposed may address inter-system difficulties, but unless accompanied by the clinical posture I describe, would not support and help to support and perhaps re-story people in liminal spaces. It is a system-generated solution underpinned by system interests. I now turn from the health system solution of navigators to the second system-solution of “pathways” the health system identifies need to be navigated.

### **Clinical Pathways.**

Clinical pathways are developed to support clinicians to provide consistent and measurable standards of care. Generally, care pathways include guidelines, protocols, evidence-based practice recommendations, expert opinion and research and development. Clinical pathways are a system-generated solution to patient movement and care. The most prominent tool in the palliative care transitional literature is the Liverpool Care Pathway (LCP). This tool was developed in the United Kingdom originally as a basis for end-of-life education for care providers, and more recently has been used as a template to standardize how patients and their families are cared for at the end-of-life, including how they experience transitions between expert agencies (Ellershaw & Murphy, 2005). It specifies who does what when, how things are recorded and when things are discontinued. In a multi-centre study of the effects of applying the LCP, outcomes of improved symptom burden and documentation have been shown (Veerbeek, et

al., 2008). It seems to me that the application of the LCP is similar to the PPS and the DNR, as it is a tool that very much shapes how a person may be treated, and what they might be eligible offered without them even knowing its use. As such, it seems that this tool also represents an extension of the evidence-based, structured approach to patient care that the expert cancer system has been shown to provide. If this is so, like many tools of the expert system, there are pros and cons to this shaping care. Sally, the counselor, thinks clinical pathways are what the cancer system needs:

A true clinical pathway that says at this point and time these kinds of conversations take place, it's just part of our process and integrate it as just part of good, clinical care. That doesn't mean that every patient is going to change how they make that transition but I think we have a responsibility to help them do that and to integrate as best we can and rather than leaving it to their own devices to manage until they get to a point where we need to have a conversation because there's no more treatment options.

Not surprisingly, Sally takes a very situated and particular view of clinical pathways as they are concerned with conversations. This attention to communication may in fact be helpful in terms of the continuous conversation concerns clinicians had, as well as to the fractured sense of care that cancer patients experienced with too many different clinicians not knowing who did what and who left off where, as Tim so clearly identified:

...the doctor comes into the room and has to think twice who the heck I am and you know, then he comes in and looks at my folder 'cause he's seen thirty other patients that day and or it's a new doctor because your regular doctor is away...

But there is also a part of me that is concerned about how packaged this approach may feel to people and families, as perhaps a technology of "moving them through." We felt Susie and Margaret's concern about being processed *into* the cancer system (pp. 60-63), would this being processed *out of* the cancer system feel any different? Would Susie find the "da, da, da" of the handling and handing over familiar? Is a clinical pathway merely an expert technology serving abstract system needs and interests? In one sense I think it is as clinical pathways attend to the

aggregation and movement of patients through the arcane health care system. Certainly this type of organization of care might suit Tim, but would it suit either Jane or Mary? I suspect that Jane may need multiple connections and conversations, where she can explore and try on approaches and stories about being a dying person in a safe, uncontrolled and unhurried space. Mary, on the other hand, seemed to be having her conversations with her beloved husband. Perhaps a clinical pathway could be proposed which includes these liminal lacunae – places of being with, bearing witness and co-creating meaning. But it remains that a clinical pathway is a system-generated solution, and as such is prone to appropriate the shaping of a person's sense of who they are in their own story into the clinician's expert hands.

Giddens would place clinical pathways in the realm of processes aimed at connections between individual experience and abstract systems where “abstract systems become centrally involved not only in the institutional order of modernity *but also in the formation and continuity of the self*” (1991, p. 33, emphasis added). This does not make a clinical pathway ineffective; it is just that this positioning has an effect of reification and routinization which Foucault would suggest should be carefully noted, as this is one way of objectifying the sick individual into the “endlessly reducible pathological fact to be found in all patients suffering in the same way” (Foucault, 1989, p. 119). It is the dislocation of the individual from the caring behaviours directed towards him or her – efficient, perhaps, but not without consequence.

With this examination of two system-generated solutions to the in-between of oncology treatment and palliative care, I will now turn to a third and final tool designed to be a patient-centered solution to care in the in-between places where liminality happens.

**Instructional Advanced Directives.**

Instructional advanced directives (IAD) are designed to enable an individual to reflect on, make choices and specify what interventions they wish to have under what conditions, and who they may wish to have represent their interests if they are no longer able to do so themselves (LoBuono, 2000). IADs have been described as a blueprint as they allow clinicians to provide treatment and care that reflects patients' articulated wishes. Literature concerning IADs focuses on their utility, legislative, legal, cultural and ethical concerns, and reasons for their use (facilitating and obstructing factors).

IADs can be thought of as a technology which links the dying person's sense of being a burden to family caregivers to their thinking about and making choices concerning life-extending medical care. Wilson, Curran and McPherson (2005) interviewed 69 patients with advanced cancer and found that 77.1% of patients experienced being a source of burden to their family caregivers, with 38% of these patients experiencing this burden as moderate to extreme. In another study of elderly patients, Zweibel and Cassel (1989) found that burdening others was ranked among the top reasons (93%) patients did not want life-extending medical treatment. I will focus on the use of IADs as they relate to cancer patients' perspectives of burden as both a facilitating and obstructing factor for them as they transition to dying.

Is this concern about burden a factor that might be at play in terms of why patients more willingly move from curative cancer treatment to palliative care using an instrument such as an IAD? This question brings to mind Tim:

...we've all been on palliative care from the day we're born. We're all going to die and we're all doing the best to make our lives as healthy and positive we can and that's what I'm thinking of it is, a way of extending my life and making it as happy and comfortable and healthy as we can. Right now I guess, I don't know, it's going to be drugs and somebody helping me bathe and empty my waste

Tim is anticipating his symptom and physical needs and perhaps spelling this out in an IAD, making sure all T's are crossed and I's are dotted – perhaps to make sure his family is not unduly burdened, but also perhaps to spell out his own sense of worth in a system he fears may all too soon abandon him as worthless.

In a social context that values productivity and independence, being a burden on others is not merely a personal concern, it has become a societal one. Like many pre-modern acts and behaviours that were part of the traditional social networks and supports for people and families, the notion of caring for another at end of life, and correlatively taking up burden on a loved one's behalf has gradually become a state interest, not merely a private family exchange and concern. Giddens (1991) notes that “with the maturation of modernity, abstract systems play an increasingly pervasive role in coordinating the various context of day-to-day life” (p. 149). IADs are one piece of the abstract system's support which shapes and directs this burden-relieving work. Other pieces which are state-oriented as I am suggesting are the Provincial Palliative Care Benefits Program and the Federal Compassionate Leave Program, one supporting the cost of medications and supplies for dying patients in their home, and the other supporting a limited paid leave of absence from employment for a federally-defined family care giver to care and keep a family member at home. Through these structures, a part of the burden of caring is being shaped and taken up by the state, to the point of deciding who will give the care. In one way, this burden reduction can be seen as enabling a family-care-giver-supported death in the home, perhaps like it was in pre-modern times. In another way, this burden reduction can be seen as a means whereby the state has entered in and removed the gift-giving capacity of the family care giver, and the gift-receiving opportunity for the dying person, and in doing so limiting this gift in terms of place of death, choice of care provider and the provision of state-involved resources. This

perspective on IADs is what Foucault would refer to as an “economy of health” and an example of how the state “reaches in to the very grain of the individual, touches his body” (Foucault & Dillon, 1980). It is the very relationship between dying person and care-giver that is being moulded and restructured according to the interests of the state, and not necessarily those of the individual. These health system supports are also shaping the choice the dying patient might make to wish about where they die. All state generated palliative care initiatives are focused on the less costly home death supported by less costly family care givers. This is not accidental, nor without effect.

This perspective notwithstanding, one clinician, Chris, felt that advance directives were exactly what the cancer agency needed to support in order for patients to feel more prepared to transition out of the treatment centre.

Chris: I think we could do a better job of it [transitioning patients].

Ann: When you say a better job of that, what are the things that you’re reflecting on as things that would be useful and helpful?

Chris: Well, I think I’m all excited about advanced directives. I think that advanced directives should be discussed throughout the whole process if you have a diagnosis like cancer, um you know, even though you know you’re in that treatment phase and maybe there’ll be good results, um some of those discussions or that process of discussion should – I think it would be healthy if it was started.

Here Chris is not referring to an advanced directive in the ways that the research has taken this up: not a decision-making guide, not an assignment of proxy, but as a technology to stimulate conversations, discussions and a process of discussions – a way of engaging patients in making decisions and becoming more involved in their care. Again, I think this a tool that might work for people like Tim, but would perhaps thrust discussions and decisions on Jane, or work against the person-generated liminal adjustments Mary is making with Fred, if these peoples’ situated perspectives were overlooked. In sum, I do see merit in the cancer person-exploration-of-goals discussions and the emphasis on iterative conversations about what might be needed or

wanted by people and their families, but caution the exploration of the underlying state and health system interests that may be being served if and when tools like IADs are employed.

To take stock, these three tools have been explored and critiqued as ways which current initiatives in cancer control may assist a person finding/losing themselves in a liminal space. Each has each been shown to have some merit, but all fall short of supporting the person in the liminal space as they are tools and ways of thinking that extend institutional concerns and interests by shaping the liminal experience, and co-shaping the liminal person. I believe that care for people in a liminal space is different than the requirement for tools and pathways. What is thematic in the critique of these three tools is that the being-with and conversational co-creation of meaning may be subordinated to system interests of efficiency and control. I believe that care in the liminal space requires the extension of support and concern in a person-centered way from either or both oncology and palliative care clinicians and begins with first appreciating the person encountered in this space, and the meaning they are making of being so situated. How might this care be thought about, taught perhaps and supported? This final section will explore these questions and propose some new ideas.

### **Caring in the liminal space – Being-in-practice**

The preceding section reviewed system-generated solutions to bridge the gap between cancer treatment systems and palliative care. These solutions are not focused on what I have described as the liminal space that some people like Jane experience, they are rather concerned with issues of system alignment and efficiencies. If these solutions in any way address the needs of people like Jane, they are not designed for this. It is my position, therefore, that for those who might come to liminality like Jane, spaces must be made to support their needs. Further, I believe that it is only when this collective and comprehensive self is appreciated and honoured

that a space for support is created, and that this care would need to be provided with a highly empathetic but light hand. What I refer to is clinician capacity and organizational space – perhaps liminal lacunae as I have described. Kate helps to clarify the liminal space she sees her patients in, showing that she clearly has the capacity to recognize liminal needs:

...so then they come to a place of feeling disappointed and I think it's, I think at that point I think that's probably the hardest phase for them is when they sort of start to see that things have moved on, it's scary, they don't know how fast it's going, they don't know what it means, they don't know what it's going to look like...

And here Kate demonstrates the skill she uses to delicately explore and support patients she finds in this space:

...I have to try to put myself in their shoes, I have to try to understand what's happening for them and why they can't accept it [a terminal diagnosis] and go with it. I mean, I don't try to drill anything into anybody's head.

This is a way of caring in the liminal space. Kate does not need to guide people towards an acceptance that they are dying; rather she accepts that they cannot acknowledge this and goes with their sense of how things are for them. Rather than guide, Kate follows her patients – Kate listens to and learns from her patients.

To truly appreciate what people experience moving out of cancer treatment, this care must be tailored to who people are and how they come to this space in terms of their own self-narrative, and it is in the tailoring that Kate's skill and capacity lies. For Tim, and cancer patients like him, there could be support gained from a clinical pathway or other journey supporting tool – something that bridges him in a tangible way from one care system to another. He is prepared to make this transition, and signals that what he needs is this type of guidance.

On the other hand, Mary is storying her own way with her own supports and care: she and Fred would likely find a pathway intrusive, or at least not very relevant. Mary knows where she is going, and is comfortable and comforted in her liminal space. Mary and Fred seemed to want

to share what they were doing and being with me, not for any expertise on my part, but more so as a way to speak their story out loud and reflect upon it. My “nursing” in this space was to actively listen, show interest and explore with them.

But for Jane, her care needs are about dwelling in the liminal space, and being lost in herself as she does seem to be. What Jane might benefit from is from being accompanied, listened to, having her interests and concerns attended to and supported. Jane needs time and space to explore the loss of her story and, if she wishes, to begin to story her way forward in her life. The skill required for liminal care is Kate’s person-centred interest and posture, manifest in her way of being-in-practice and contributing to the meaning her patients are making through careful thoughtful conversations. What is called forth in Kate is the *utmost* in facework. She needs not only to demonstrate that she has the expertise to gain her patient’s trust, she must also reveal her wisdom in engaging with people lost in liminal spaces. So too the language of liminal care must be simple and accessible, and absent when required. Giddens states that the demeanour of expert is used to reduce the impact of human fallibility (1990, p. 86). Here the concern is the *ultimate* fallibility of humanness – the unravelling story of a dying person. The liminal exchange actually strikes me as a definitive exemplar of a hermeneutic fusion of horizons, where the two people are engaged, learn from each other and create a horizon as they learn about each other’s stories and their ways of speaking the horizon – both willing to enter into the conversation and be changed by it (Gadamer, 1989, 2000). Specifically, Kate will enter into this liminal space again and again with patients she cares for. Each time she will face with them their liminality and their positioning in this space of being living/dying persons. To be here in this way, Kate must each time face her own potentiality for living/dying, and each time find a way of

being in this space. So perhaps Kate's expertise is the work she does in her own self to face and embrace her mortal humanness and so enabling her self to face and embrace others'.

So unlike either the three cardinal features of abstract expert systems found in system-generated solutions, liminal care is characterized by (a) language accessibility not obscurity, (b) absence of technology rather than an increasing elaboration of technology, (c) expertise that is manifest as shared and co-created wisdom, not sequestered and arcane disciplinary domination.

Therefore, is Kate's way of being in this conversation not merely another expression of expertise, and demonstrating yet another way or perhaps demeanour of being an expert? Yes, I think this is expertise, but it is the expertise of the person, not merely the science or the abstract system. It is expertise centered on a deep appreciation of the person and the personal experience of a life story. It is expertise that calls forth the expert, not from a place of knowledge and technique, but from a place of wisdom, authenticity and personal reflexivity. It calls for a way of being-in-practice that places the nurse in the closest possible proximity of other, sharing in the liminal space in a way that changes the self-narrative and going on of both. And it is neither safe nor is it predictable where the story may carry either or both.

Finally, as cancer systems have been shown to be the efficient and process-driven organizations that they are, how does this kind of person-oriented practice flourish or even exist within such a space? No nurses other than the PSMPC nurses or APN's were interviewed, so there is no narrative to narrative comparison that I can make over all nurses who work at the PCO. Kathleen did however refer to how her work differs from her colleagues, and it appears that the skill and space to practice in a person-oriented way is not available to all her colleagues.

Kathleen: I think we need to deploy our nurses completely different, because I think front line nurses can do the similar work that I do.

Ann: And the reason they don't is?

Kathleen: Good question, good question! I don't know if it's fear of patients, you know!? I don't know if, I think it might be a cultural shift that needs to happen. I think and I've thought about this ...I've thought about trying to encourage nurses to step into some of the same things that I do and then come and talk about how is it that they were in that room with the patient and the doctor and what symptoms were they assessing and how do they think the patient's doing and then what might their plan be. But the system doesn't help us to practice. I don't know, but I know it's big!

Kathleen thinks the nurses she works with *can* do similar work to hers, which clearly suggests that they *don't* practice like she does. When Kathleen explores this she finds two reasons their practice differs. One, nurses are afraid of engaging with patients in this way. I would argue are likely afraid in the same ways that Kate and Kathleen are, but unlike Kate and Kathleen have not worked with that fear to understand what it is and how to live with it. This work would be the skilling portion of what this care entails, focusing on confronting mortality, and listening to and foregrounding others' fears. But Kathleen is also suggesting that the system does not encourage nurses to work in this way and this, she says, is big. The kind of person-centred care liminal care is based upon needs not only skill, but space and time to accomplish. I think that there in the cancer control system is a perfect balance between fear and fetter – nurses fear to go into these spaces with patients and the system rescues them from this work by fettering their capacity to do so with schedules, space allocation, and oncology nurse-as-self-shaping.

This fear and fettering I am suggesting does not seem to be at play with the nurses interviewed for this research. Two reasons explain this. One, as I noted in the methods chapter, the oncology clinician participants who spoke with me were those whose interests align with a different sort of patient care. They were either part of the PSMPC staff, or staunch supporters of this program and this person-centred approach to care. They were different from mainstream oncology clinicians and so reported on the different work they do and how it fits or does not fit

with work other oncology clinicians do. Two, in my work as a leader in the cancer system for a PSMPC program, I am very aware of how poorly this different sort of care fits within, and is consequently supported by cancer treatment systems. The reflections on this care and program from colleagues in my work range from this program being thought of as elitist and poorly integrated within the centres to the opposite conception of being a model for care for all cancer patients that they wish the organization might embrace. Both reflections can be taken as accurate, and are in their polarity one impetus I why have had to take up this research. This concern is an example of how I have used of Reason's (1996) writing in this work to look at how knowledge I uncover might disrupt and change the patterns of power in cancer care systems, and how this disruption might make spaces in cancer systems for person centred liminal care.

If this is work that has meaning for patients as Kathleen and others suggest, and the cancer treatment systems seem ill-suited to the support of this work, the question is where might what I have called liminal care be best placed, and how might this be accomplished?

### **Locating Liminal Care – Who does what where?**

If liminal care is not a set of abstract expert skills, but rather relates to an expertise in terms of understanding who a person is when approaching their death, the question is not so much who should do liminal care or where this might happen, but how this might, and I would argue must be done. It is not likely helpful to sequester this expertise and work to a newly introduced person whose role is the guide for those who are betwixt and between, or other navigation-like roles, but rather to embed this approach in the work of clinicians in their everyday practices: to learn how to recognize a people in liminal spaces, their needs and concerns, and to take steps towards supporting them. But if what I state is so, which clinicians might do this work, and where? What might this look like? What would it take to excavate this

knowledge, to research and understand this knowledge, and to be explicit about its use in clinical practice – and its limits?

### **Locating Liminal Care – Who?**

Much research and writing has been done to outline the disciplinary accountabilities in supporting transitioning patients. I will examine here what physicians view as their role, how specifically oncologists take this up, how nurses frame this work and how the interprofessional team factors in this work.

It is the physician's sole disciplinary responsibility to prognosticate, and with this responsibility comes the burden of accuracy which their patients seek from them as experts. Despite its importance to both clinicians and patients, prognostication has been undervalued as a clinical skill in medicine: "physicians are not taught to prognosticate" and consequently do not do this very accurately (Glare, 2005, p. 331). So the key information about a patient's expected length of life and timing of death is unclear, and I daresay a source of discomfort for the expert physician. This has implications in two ways. First, cancer patients are expectant of expertise from the cancer system – how do they reconcile their expectation with this inaccuracy in one of the key areas of concern a person with cancer is likely to have? Accounts gathered in this research from patients and families indicated that they were highly tolerant of this inaccuracy, perhaps as they needed so very much to feel that their expert clinicians were not so tainted with uncertainty, were truly "in control" of the situation. In this way patients' expectations collude with physicians' expert diagnostic stance, even though the evidence for either is lacking.

Sam: [A radiologist] decided to radiate the hip and she was not very hopeful ... you've got maybe two chances out of three that it might be slightly better and one chance in three that you'll go through the side effects of the chemo and have no improvement what so ever... then [another doctor] filled in for her ... and out of the blue, totally out of the blue, she said, so do you want to start chemo on Monday?

Participants aimed any and all disgruntlement at the system, consistent with Giddens' (1990) observations about how operators in expert systems are seen as separate from the system itself as lay consumers find it necessary to uphold their trust in the expert system.

Tim: I guess I wonder at times how the system copes with the number of patients and people and I understand that the doctor comes into the room and has to think twice who the heck I am and then he comes in and looks at my folder because he's seen thirty other patients that day and or it's a new doctor because your regular doctor is away ... but, I don't know, they do the best they can and it would be nice if everybody knew everything about everybody but I think it's probably physically impossible, or mentally impossible.

Flesh and blood operators may be wrong, yet the expert system continues its claim to expertise despite being demonstrated to be quite frequently wrong. The second question I have is how this inaccuracy might influence how patients approach a transition from cure to palliation: the prognostic threshold itself is not very clear, as Margaret's narrative about learning the futility of buying lottery tickets laid bare. If patients cannot get a clear picture of the imminence of their death, how do they story themselves forward?

Maguire (1985) was one of the first physicians to identify how medicine takes up care of transitioning cancer patients, and stated that physicians used distancing as a means to "avoid personal emotional overload and/or the 'strong unleashing of patient emotions'"(p. 1711). This distancing was very well articulated in Paul's account where he speaks about knowing that he and his colleagues use the limits to the clinical visit as a means to avoid difficult conversations: "my clinics get as busy as anybody else and I'm susceptible to the, I just don't have time for this discussion today."

This stance, Maguire also stated, was testament to the physician's poor preparation in communication about terminal illness and issues. I think that the capacity to cope with these difficult conversations also relates to the engagement with and personal interest a physician

invests in the person who comes to the clinic as their patient, as we see with Edward's careful and person-centred exploration:

In the transition or discussing the transition, for me there are several things, one is patients maintaining hope and that means discussing what hope is and can be...giving reassurance that there are people who can take care of the major problems. Um, so maintaining hope and reassuring patients that they will not be alone and that they will not have to suffer.

Following Maguire's concerns, much medical literature addresses the timing and content of transitional communication (Baile, et al., 2000; Faulkner, Maguire & Regnard, 1994). It would seem that if medicine wishes to claim this area of patient care, it is incumbent on them (according to their peers) to do this well. We are reminded why this might not be so by Kate.

I think any cancer diagnosis comes with the fear of death. I think that the oncologists tend to err on the side of optimistic sometimes. They'll tell patients that they're going to try and cure this when it's something very unlikely to cure and so they give patients sort of a unrealistic hope for cure, and in that case I think it slows down the patients' process of acceptance. I think they have to be [optimistic] to do their job. I think a big part of it is protecting themselves because that's the business they're in, they're in the business of curing people of cancer. And so for them to sort of give up right at the beginning probably feels to them like they're failing.

So Kate thinks, like Maguire (1985), that oncologists optimistically augment these discussions to avoid feeling themselves that they have failed – the medical discourse about hope is arguably one of self-protection.

Looking more specifically at medical communication in cancer treatment, oncologists Baile and Aaron (2005) describe the gaps in communication that occur between what patients need and what oncologists provide at the transition to palliative care: "physicians miss opportunities to respond empathetically to their [patients'] concerns and ignore patient wishes to discuss health related quality of life issues" (p. 332). They go on to say that "communication is the cornerstone" of comprehensive cancer care, and oncologists who learn this aspect of patient care can expand their supportive role (p. 331). On the one hand, communicating well about prognosis would seem a necessary and desirable skill for oncologists as it relates to their

relationships with patients. On the other hand, expansion suggests appropriation, from whom one wonders?

Baile and Aaron (2005) do not in any way refer to their interdisciplinary team as having any part to play in this work. Yet I would argue that nurses and others have much to say about health related quality of life of cancer patients, and do so in a highly empathetic frame as was specifically demonstrated in the clinician accounts by counsellor Sally and nurse Kate. Thus, nurses and other clinicians may be disenfranchised if physicians expand what they see as their supportive role. Or on the other hand, are Kate and Sally clinicians who might in their own right become expansionist in what seems to be uncontested territory from oncology medicine's point of view? The notion of disciplinary turf seems worth a second look.

Arnold (2000), an oncologist, describes his role in helping cancer patients plan for death as a "medical interest." He states that "ambiguity, ambivalence, and uncertainty...dominates the discussion with patients and their families" (2000, p. 17). This, Arnold (2000) relates to four interrelated factors: (a) physicians are unable to exactly predict when a patient will die, (b) medical media promises longer, better lives with soon to be released drugs and treatments, (c) people are inherently action oriented – doing something is better than doing nothing, and (d) technology now has the ability to alter illness and elongate the dying process. Here again is evidence of the interplay of patients' expectations, medical expertise and social and political forces, together expressed as the oncologists' expected hegemony of medicine and science over sickness and death – expected by the patient, amplified by the media and in Arnold's work, employed as the gaze through which oncologists rightfully view their patients' behaviours. The interplay is expressed by Arnold as medical discourse (Foucault, 1989).

Clarke and Everest (2006) further link the cancer experience with people's compulsion to turn to medicine. "Medical dominance is reinforced and its importance underscored by an emphasis on individual fear. Medicine is assumed to be the appropriate and benign solution to the problem of cancer" (2006, p. 2598). Again, the power of the expert oncology system is vested in the medical expert, and would seem to be reinforced by peoples' fear of the disease.

Other works looking at the complexity of transitional support for cancer patients were co-authored by physicians and nurses, exploring how this professional pairing might better support the needs of patients (Dunlop & Hockley, 1998; Kirk, Kirk, & Kristjanson, 2004; Thompson, McClement & Daeninck, 2006). This literature begins to combine the disciplinary difficulty of these discussions with the context and experience of the patient. Schofield, Carey, Love, Nehill and Wein's (2006) synthesis of transitional literature indicates that the majority of relevant literature consisted of "descriptive or qualitative studies" and as such were lacking the "rigorous design" they felt was required (p. 397). Yet it would seem that the descriptive and qualitative are just the approaches necessary to capture the meanings that this complex space exemplifies for both clinician and patient. These meanings should be paid specific attention to, and for which reasons these are the methods I have, I think, appropriately chosen and have consequently profiled a different perspective.

One interprofessional study specifically addressed the who, how and when of discussions about end of life issues with terminally ill patients (Clayton, Butow & Tattersall, 2005). Patients and health professionals held disparate views about by whom and when discussion should be started and identified four possible options: (a) patient raises the topic, (b) all patients to be offered the opportunity to discuss by their health practitioners, (c) health care practitioners raise the topic when they believe the patient needs to know, and (d) health care practitioners raise the

discussion when the patient and family seems ready (Clayton, Butow & Tattersall, 2005). This fourth option was described as doctors and/or nurses using “their intuition, common sense, or judgment to gauge when the person is ready – for example by being sensitive and responsive to verbal or non-verbal cues from the patient” and as such resonates with my conception of being-in-practice (Clayton, Butow & Tattersall, 2005, p. 137). Option one seems open but leaves the patient, who may not know what questions they ought to ask, to wander. Option two seems the most open *and* inviting, perhaps stimulating discussion with and engaging the patient, and yet has the ubiquitous institutional framing to it. Option three is plainly patronizing. Option four presents a challenge to the clinician to know what the cues are that a “ready” patient would offer. Clinicians may not themselves have experienced a liminal space – but they have at least had opportunities to witness people’s passage into it time and again. It is this wisdom gained from this repeated exposure that I argue is key to recognizing and supporting people in liminal spaces.

And finally, literature indicates that nurses are often with patients when decisions are made to stop treatment or change goals of treatment from curative care to palliative care. Thompson, McClement and Daeninck (2006) state that it is at these transitions that patients are in need of careful support and anticipatory care. This care they believe is best provided by nurses who employ a wide variety of strategies, although I would be cautious about any strategy that would be forestructured here, as it resonates with system structures such as navigators and clinical pathways that have been argued to shape and process individuals according to interests other than their own. Chekryn-Reimer and Davies (1991) describe the nurse’s role as pivotal in helping families live through the experience of a member’s fading away. Accounts from Jane’s, and to a lesser extent, Mary’s husbands certainly indicated that as observers losing their partners, these spouses needed support.

Continuing to focus on the nurse's role, McSteen and Peden-McAlpine (2006) describe nurse-guides in transitional cancer care as not taking over decision-making for patients, rather nurses "assisted in obtaining and clarifying the information needed for patients to make decisions" neither leading the way nor prodding from behind (p. 263). Nurse guides, according to Gadaw, "explain the objective clinical information that complements the subjective personal information that only the patient could provide" combining the biologic with the bodily story of cancer (1989, p. 100). Here is how Kate exemplifies this expertise in liminal care as she carefully follows patients in the liminal space

Well to be honest, I sort of have to come to a place of acceptance myself with that. I'm a really practical person. I look at my own personal self and I'm a very practical person, if I was in those shoes I would be completely ready and accepted and organized for everything that's to come. But not everyone is like that and so, personally, from my personal, how I deal with it is I have to try to put myself in their shoes, I have to try to understand what's happening for them and why they can't accept it and go with it. I mean, I don't try to drill anything into anybody's head. The most important thing is that they're doing this with full understanding and if they don't understand it, and they're not accepting because they don't understand it, that's a different thing entirely and there's a gap there that we need to fill.

Kate is a nurse who works on one of the Pain and Symptom Management/Palliative Care teams at the Maple clinic. Kate is also someone whose basket of selves contains a survivor of childhood cancer. Kate has her own cancer self-narrative that allows her to connect with patients and help them weave theirs, or alternatively understand when their stories falter and do not seem to go on.

Gadow's (1989) conception of this nursing care combined with Kate's reflections on her nursing care remind us that the way we build our understanding of what is new and strange to us is through conversation (Gadamer, 1989). Perhaps through exchange of information as conversation, patients and nurses may co-create a familiar and safe place in what is experienced as a strange and unfamiliar liminal space. Gadamer (2000) believes that it is in encountering

others that we experience ourselves, and that this encounter simultaneously shapes those we encounter in their self-reflection. That is, I cannot enter into a conversation, experience the exchange and not in some way feel altered by the exchange. Simultaneously, I am in exchange with someone who too cannot converse with me and not in some way feel themselves changed by the encounter. I see this very clearly with Kate's self-reflection on how she and patient come together "how I deal with it is I have to try to put myself in their shoes, I have to try to understand what's happening for them." Kate's placing of herself in the patient's shoes is how she prepares herself to follow their story line, rather than asserting her own. Gadamer states that the only way one can "experience (their) own limitation is through the encounter with the other" (2000, p. 285). The patient presentation of self and the particular and situated nursing interpretation of clinician are thus interdependent, and so too are both patient and nurse open to understandings and misunderstandings of one another and the situation they are in. It is here that meaning is made, understanding approached and stories perhaps re-ravelled.

Finally, Rushton (1995) adds that experienced nurses do not perform their guiding function according to laws or institutional rules, but have through their experience, developed a moral imagination and sensitivity that upholds the patient's perspective which in turn cultivates a relationship between patient and nurse that creates ways to furnish meaning to the experience: it is person centered care. We see this imagination and sensitivity in Kate's accounts of how she supports her patients. However, this statement, while it supports the Gadamerian co-creation of understanding through conversation, is I think a little bit naïve as it suggests that nurses somehow are participants in, but held aloof from, the institutional context in which they work, which the clinicians very clearly indicated in their accounts they were not. In fact their intentional work in the area of liminal support was very much fettered by the institution:

schedules, lack of interprofessional patient support work, and limits placed on those other than specialized teams and advanced practice nurses to do this work. This observation resonates with Purkis' critique of nursing practice she studied in health promotion where she stated "within a society defined by conditions of late modernity, that is, practices deeply embedded with modes of surveillance and discipline, conduct in the clinic cannot be divorced from the conduct and accounts available from managers and funding agencies" (1993, p. 283). The nurses' being-in-practice discourse is fettered at best and at worst literally obfuscated by the institutional discourse. As Kathleen clarified, the space for this work is organizationally limited and the nurses who might do this work must do so in the face of this institutional fetter and their own fears to so engage their patients.

To sum, the nursing literature portrays transitional support as the territory of the nurse, matching well with the medical literature that calls physicians to account for their inability to accurately prognosticate and for not handling the transitional experiences of patients well. Clearly there needs to be sensitivity to how patients are being told that their treatment will not save them from a cancer death, and this telling is the oncologist's purview in their disciplinary claim to prognostication. But literature points to nurses taking up other conversations after this learning. How this work might happen in the cancer centre or outside the cancer centre is what I will next explore.

### **Locating Liminal Care – Where?**

In the cancer center, nurses or other cancer care clinicians might take up this work. To do so, they require skill and time to express interest in who their patients are as people in their own stories and how they are with the family who accompanies them. Patient accounts revealed that this is accomplished by clinicians' having familiarity with the patient's self-narrative, not merely

their biologic/cellular story. Yet clinicians interested in this type of supportive relationship with their patients indicated that this was not furthered, but rather fettered by the clinic schedule and organization of oncologists. If continuity of personhood cannot be accomplished through oncologist consults within the rigid clinic schedule system, perhaps this important aspect of supporting patients might be taken up by other members of the cancer care team, perhaps by the nurses. But this would take skill, time and clinic space for nurses to meet with people who are cancer patients that Kathleen tells us nurses are not currently afforded.

But is it merely a matter of clinic schedules, nurse deployment and space? If these are reasons for lack of support, then support for patients in this liminal space would proliferate with the resolution of these barriers. If alternatively these barriers are merely excuses not to engage with patients and their families in certain ways because it is uncomfortable work, all the scheduled time, interprofessional goodwill and organizational space would not change the cancer patient's personal experience one iota. I would argue that it is a bit of both, as Paul's account reminds us:

Paul: Well, I think primarily it's the health care providers (fault). They will know whether they personally will feel uncomfortable with that and they're probably extrapolating from the patient that the patient and family are going to feel uncomfortable with this ... I'm a little behind in clinic so let's not talk about it ... and let's just kind of ...

What we might conclude is that what is required is organizational will to alter the barriers, along with a cultural shift in clinicians' *raison d'être* from cancer treatment to cancer persons' and family care – not undoable, but certainly acting on more levers than just time and space. We have learned that there is an overall organizational disposition towards efficiency through aggregation – liminal care would seem at odds with this.

What if a cancer system situated solution was pursued? What could liminal care look like in the cancer centre? We know from the accounts that the time of liminality sets in just shortly

after a person with cancer learns that their cancer is incurable and curative cancer treatments have been exhausted. We also know that this understanding is gained in an oncologist appointment which like any other follow-up appointment is thirty minutes long with the pressure of a waiting room full of other follow-up and new patients needing attention. Assuming that oncologists are aware that these upcoming appointments are a final and devastating meeting, could this specific appointment be scheduled as one that took a bit more time for the patient to explore how they take up their news, and how they move on with themselves? This solution would require organizational change, oncologist skill, and human resource investment. Organizational change would need to align with organizational interests, and so recognition of liminality and its relationship to cancer control would be necessary. This is not impossible, but a significant shift in orientation. Oncologists could be taught skills in supporting people who become lost in liminal spaces, but this thinking and skilling may be poorly aligned with the disciplinary expertise in cancer treatment. And finally, oncologists are manifestly the most expensive clinician on the cancer treatment team. It is not likely embraceable, feasible, nor affordable to change cancer control systems to accommodate oncologist-led liminal care. I also wonder if patients can hear this news from one person and do this very different type of work with the same person. What about liminal work being done by other than oncologists?

What if, again assuming the final visit can be anticipated, the patient had scheduled time with an oncology nurse occurring directly after their medical consult? This time would be space in which patients like Tim might receive information about palliative care and ask questions about who, and what next. Alternatively, this time could be about being with, accompanying and supporting a person like Jane, after they learn they are dying and sense their personal stories being suspended or coming to an end. And alternatively still, this time could be just offered and

known to be available at some time according to the peoples' needs and wishes: scheduled adjacent to the oncology consult, but used merely to be available. Again, this type of service would require organizational endorsement, clinic space and oncology nurse skill and time. Organizational endorsement would require a cultural shift in thinking about what cancer patients need after treatment comes to an unsuccessful end, and what the cancer system's part in that after care ought to be. This is policy change of a significant magnitude, and one at which this research is aimed. Skilling of nurses not currently involved in providing liminal care would be required. This could be accomplished using nurses currently doing this work as guides and mentors. And although liminal care may take time oncology nurses do not currently have, if the organizational policy was to shift towards support of this work, time and space could and would need to be made. And finally, employing oncology nurses in this work would also create a very different conversation than the one that patients would have just had with the oncologist, helping to shift the meaning-making from oncologist-led to nurse and patient shared. However, it very well could be that people who find/lose themselves in their liminal space might need to step away from the clinic for a time before they are ready for any engagement about where they are, no matter who that engagement is with. Or people in this space may need to step entirely away from the cancer clinic and their cancer-clinic-situated experiences of battling and loss, and have their liminal needs and perhaps re-storying of themselves supported elsewhere.

What would care in a liminal space look and feel like if it were external to, but perhaps adjacent to the cancer system? We know that we cannot merely factor in palliative care here – many patients and families have a need for something in between these expert systems. What if home care nurses were made aware that cancer patients were having this very difficult conversation with their oncologists? Could a home care visit be offered to people coming to

these conversations for that day or next to position the home care nurse in the in-between situation as Kate did, listening empathetically and honouring the person wholly. Home care nurses could make one visit or, if required by the person and the nature of peoples' needs, a few visits. These visits would need to be made explicit and apparent to people in their in-between space else they might find themselves taking up a perception like Hugh's where he could only see his home care nurses' skills as lacking the expertise he is looking for from the expert cancer system. Again this is policy-driven system change and home care nurse resource-intensive, but not ideologically contradictory from what home care nurses are in place to provide. Purkis' study of nursing spaces shows "how the spaces operating between nurses and patients are not empty voids but are *social* spaces though which particular meanings about nursing can be conveyed" (1995, p.101). Part of the nurses' work of being-in-practice is to make this palpable to the patient. The other part is to accommodate the patient as person and in this exchange constitute between-nurse-and-patient understanding and going on. (Gadamer, 1976).

Finally, what if palliative care clinicians were to leave their usual place of expertise in person and place, and approach people who might be in a liminal space without a requirement to "move over" patients and their families to their system of care? Could palliative care clinicians bring their skills into another arena and practice outside of their sequestered disciplinary settings? I think they could. It is, in fact, care I have participated in and have witnessed in my clinical career. As a clinical nurse specialist in an interagency program I was able to meet with cancer patients where they were, in their sense of their position in their cancer story and in whatever physical location they were in. In our meeting, I held both skill in and knowledge of oncology and palliative care, but exercised my capacity to appreciate who these people were by reflecting on how I recognized them: as someone's mother, father, sibling, child of, or partner with. Each

of them had a place in my head and heart as reflections of my mother, father, sibling, child of, partner with and I allowed their person to unfold in my conception of what that meant to be that self for them. Like Kate, this is facework of a very different kind. The question is, can this be considered *expertise* and as such subject to the modernist sequestering of such facility into the abstract expert systems? I think it can be considered expertise, yet may exist in lacunae within or outside of system structures. Having expertise can be different from being an expert. The former can be a way of expressing embodied knowledge, while the latter is more caught up with the concern about attachment to and sequestering of expertise in abstract expert systems. Liminal care is possible within abstract expert systems, but only if policy exists to support the space and time caring in the liminal space requires. Liminal care entails a way of being-in-practice, in fact demands a being-in-practice which nurses focusing on people's lived experiences and expressions of self-narrative could and must attune themselves to, as Kate clearly calls upon herself to do:

I listen to where they're at in their life and what their roles in life are ... are they a parent, are they um, or are they are grandparent, so, I think personally, they have a lot of difficulty depending on age, roles, responsibilities ... based on who they are, what their perceptions are, how they have to deal with their disease.

Kate did and does this practice in this way as she is afforded time and space for this work within the PSMPC program, even though the cancer control system around this program is differently conceived and articulated. Without the cancer system's organizational shift towards this care being part and parcel of cancer control, liminal care cannot occur outside of these protected spaces. Without recognition of the needs of people in liminal spaces, this work will not occur either within the cancer system or elsewhere in the health care system. That recognition and call to action is what this work has been designed to foster.

To sum, some dying cancer persons may well make a smooth transition to the expert system of palliative care, and the cancer control and palliative care systems seem somewhat tooled towards this stepping over type of transitional story. But some patients may not be helped with this moving-on approach, and to know what needs a person might have, one must know the person who is the patient, to learn their story. All patients leaving the cancer control system would benefit from a leave-taking appointment with nurses, where needs and corresponding approaches during the in-between period might be explored and matched. This time could be supported and resourced within the cancer control center, but has resource and ideological implications if so situated. Major policy shifts are required. Resources are at question, as this is not currently routine care for oncology nurses, and adding this work would likely require more time and/or more nurses. Similarly ideology is at question as it seems unlikely that an organization that has up until now not factored post-discharge care into their processes might not take up this type of care as either their interest or accountability.

This leave-taking appointment could alternatively be located in the home and community care system, and would have similar resource requirements, but I daresay less ideological incompatibility as home care nurses are often situated to care for people “after:” after discharge from hospital (as in maternal care), after surgery (as in post-hysterectomy), after trauma (as in post-fall), and after a new diagnosis of a life-altering disease (as in diabetes). The concern with the home care visit is that in some way it needs to be explicit and not therefore lost in the “after-expert-cancer-centre” mishmash of services. And finally, this in-between space could be supported by connecting people with cancer with palliative care clinicians who bring with them their person-centered skills but leave their expert location behind them. Care in the liminal spaces is related to expertise, but need not necessarily become caught up and sequestered within

an abstract expert system, but rather unfold in a lacuna of trust and space co-created by nurse and patient.

So, while our expert systems busy themselves with the shaping of patient-persons and wrestling with system issues of treating and processing cancer patients or dying persons, people breathe and live and story themselves in liminal spaces. Cancer, home care or palliative care nurses can meet with liminal persons if, and only if, they are able to leave behind their organizational sequestering of expertise and power, and co-create and tread lightly, wisely and carefully in these person-sacred spaces and stories. In the words of D.H. Lawrence from his poem *All Soul's Day* "Be careful then, and be gentle about death. For it is hard to die, it is difficult to go through the door, even when it opens" (1994, p. 607). Nurses are well positioned to be that careful gentle person.

The following concluding chapter will review the education and health policy questions that positioning nurses in this work raises; revisit and review the answers to the research questions and what is learned from this work according to the opening reasons for human enquiry Reason (1996) posed; and posit what remains unknown about liminality and nursing care and how these questions might be taken forward in the discipline of nursing.

### **Chapter Eight: Conclusions and Going On**

This eighth and final chapter reflects on what this study reveals and how it contributes meaning(s) about peoples' experiences in the liminal space after cancer treatment is ended. This area of concern reflects and poses an answer to the first research question problematizing the in-between liminal space – *how does the transitional patient organize a self that engages with the liminal space between cancer treatment and palliative care?* Next, as this work is a *nursing* dissertation, the practice of nursing in this space is taken up and the requisite education to support this practice. Finally, requirements for health policy commensurate with nursing for people in liminal spaces are reviewed, revisiting the notion of *where* raised in the second research question – *if question one can be understood, then where ought this transitional space (between cancer treatment and palliative care) to be located – inside or outside the cancer treatment centre?* To close this chapter and this work, the aims of the introduction are revisited in terms of Reason's (1996) reflections of the purposes of human inquiry: (a) the actualization of my self-capacity through this project, (b) the contribution to knowledge in terms of changing people's experiences working from their needs as this relates to being a person in a liminal space, and (c) disrupting/interrupting patterns of power in knowledge acquisition and dissemination as a research project in itself, and as this knowledge factors as a policy lever to disrupt and transform cancer care systems.

#### **Problematizing the In-Between Liminal Space**

This study has illustrated that people becoming cancer patients co-participate in some very purposive shaping of self and story, or as this study has conceptualized, the effect of *aggregation* when engaging with the abstract expert cancer system. Using the lenses of Giddens

(1984, 1990, 1991) and Foucault (1988, 1989), I found this shaping effect is strongly experienced through engagement with and treatment through the cancer control system, privileging the medical story of the cancer narrative over other more person-centered narratives. After much shaping work has been done and experienced, I discovered that cancer patients' understanding of being told that there is no further treatment catalyzes a *dis-aggregation* of their sense of self with regards to their cancer patient self-narrative, and a feeling of abandonment by the expert cancer system. I then learned that for some cancer patients, this dis-aggregation flowed into a feeling of *un-aggregation* where the self-narrative unsupported by the dominant medical discourse unravelled, with the person in this space feeling to be living/dying, being/nothingness—*liminal*. Liminality was explored across disciplines and throughout the literature of health care and while some work was found to support this study's conception of the term, no similar application to cancer patients' experience combined with my theoretical framing was found. Thus, the liminal space between the expert systems of cancer control and palliative care described by this study extends and adds to the literary understanding of the concept as it is framed in terms of Giddens' (1984, 1990, 1991) rendering of modernity and Foucault's discourse analysis (1988, 1989).

Palliative care was critiqued as an ascendant expert system after Syme and Bruce (2009), paralleling this service with the features that were identified in cancer control as exemplars of Giddens' abstract expert systems (1990). Patients' and families' resistance to yet another expert system was explored as both resistance to being shaped into the dying person and narrating a dying story, as well as the reluctance to abandon the connection with what they saw as the superior expert cancer control system. This resistance was forecasted as it echoes the sense of fallibility some patients found in the general health system when becoming cancer patients.

System-generated bridges focusing on system interests of *transitioning* effectively and efficiently were examined and found unhelpful to the needs of persons lost in liminal spaces, but perhaps of some limited utility to those for whom the space factored as a mere margin, or whose needs were instrumental in nature rather than personally reflective. And as system-generated solutions there was clear evidence of the language obscurity, increasing elaboration of technology and sequestering of expertise Giddens' (1990) associates with abstract expert systems.

### **Locating Liminal Care**

After coming to understand liminality in this situated manner, I explored the support of cancer patients tumbling into this space and losing their narrative threads. Medicine was found ill-prepared and ill-suited to this work, while nursing was clearly geared towards this relational and thoughtful care. Care was framed as being-in-practice and the medium of practice as conversation, in terms of Gadamerian conception (2000). Capacity for this work was found in the data with the nurses who were interviewed, but institutional fetters and personal fears prevented other nurses to engage in this work. The question this raised was whether this capacity factors as expertise, placing this concern and care in yet another expert system and/or silo, or whether nursing practice embodies this capacity as a way of being-in-practice whether new to practice or experienced. In Giddens' (1990) terms this nursing work was considered the utmost of facework, placing the capacity in the *person* engaging in reflexive practice and a person-concerned approach to exploration and care of other. It was argued that this is personal depth, reflexivity and wisdom, yes expertise, but dissimilar from Giddens' (1990) sense of disciplinary sequestering and the concomitant necessity to place this expertise within abstract expert systems.

### **Enabling Liminal Care and Space**

This conclusion raises the question of both nursing education and health care policy supporting this kind of practice. Nursing education is all too often focused on providing becoming-nurses with the technical and knowledge skills necessary to nurse patients in observable and tangible ways. Disciplinary concerns have, as I stated earlier, been all too focused on this positivist framing of nursing practice. Communication I have argued is key to liminal connection and caring. Cheek (2007) suggests, and I concur, that a critical perspective be taken on communication between nurses with clients focussing on “developing better understandings of the way in which communication itself affects understandings of health” (p. 27). In this way becoming-nurses can learn to recognize the limiting and shaping power relations that pervade health care encounters and create spaces for being-in-practice that are safe and supporting to persons lost and unravelling in liminality. Nurses can reflexively find the silence or words that meet their patients’ expressions and concerns and *co-create meanings with their patients* when all meaning seems lost. Learning this posture requires that becoming-nurses are acquainted with the critical lenses that provoke nurses to think about how best to recognize and serve people they encounter in their practice who are in a liminal space. But, similar to the becoming-nursing aims outlined, this study does not only aim to provoke individual practitioners to change their practices, but also to invite the discipline to reflect on the nature of nursing knowledge that differs from and augments orthodox science by exploring knowledge that is situated, provisional and embraces heterodoxy as a way of being (Reason, 1996).

Finally, requirement for health policy commensurate with nursing people in liminal spaces is important else all positioning and education in the world will founder. Expert systems have interests which reflect on their system concerns first, and subsequently the patients’ interests they

serve often incidentally. Liminal nursing care will only flourish in systems where this is an interest or value. Cancer control systems were found least likely to support this type of nursing care because of the clear interests in normative aggregation and depersonalization. Palliative care systems were found to be becoming more like cancer control in terms of their emerging disciplinary concerns with expertise and abstraction with language and tools, and are therefore less amenable to what I have framed as interests of people in liminal spaces. Home care was found to be best suited ideologically to support care of people in liminal spaces as home care nurses' practice was both centered in personal spaces, and was often framed as aftercare. This aftercare would now be after-unsuccessful-cancer-control. But here too caution must be exercised as critical ethnographer Purkis warns that practices in home health are shaped by home care nurses and managers who "together work to exclude the local knowledge of patients and nurses regarding experiences of living with chronic disease" (2001, p.141). What is required to keep open spaces of caring for people who are lost in liminal spaces is an autonomy of practice that acknowledges the nurse's wisdom in investing time and self in these critical exchanges.

### **Research – Going On in the Questions**

As these three health care systems were examined, I have done so in a dispassionate manner, failing to take into the exploration the needs and interest of *persons* in liminal spaces. This study found that patients were inordinately attached to cancer control systems, suspiciously imposed upon by palliative care systems, and unaware or unimpressed by home care systems. This preference factor is one which requires further study, where nurses from each of these three sectors are provided first some opportunity to reflexively examine liminality and liminal care, and thus are prepared to take up the personal and situated care of a cancer patient who is lost and narratively unravelling in a liminal space. This inquiry calls for yet another nursing study to

compare and contrast how patients experience liminal care provided by cancer, palliative care and home care nurses.

To close this chapter and this work, I revisit the aims of the project in terms of Reason's three reflections on the purposes of human inquiry. First, I had in my reflection on this work as a nursing dissertation indicated that I was newly aligning myself with a postmodern turn the discipline seems in part to be taking, giving attention to different kinds of knowledge which focuses on how meaning is constructed. This way of questioning or problematizing was new to me, and as with most new learning, I was painfully conscious of my lack of competence. What has emerged for me is a new way to situate knowing that will never be ignorant of interests and power effects. This was the purposive aim of the actualization of my self-capacity through this project. I am a ruined positivist.

Reason's second reflection relates to human inquiry making contributions to knowledge. In this project knowledge was gained using the lenses of Giddens and Foucault as I examined cancer patients' experiences and needs as they lost themselves and their narratives in a liminal space. The knowledge contribution this work makes is (a) that cancer patients may lose themselves narratively after intensive and purposive shaping forces are withdrawn, (b) being so lost, needs in the liminal space are supportive rather than directive, (c) current tools aimed at *transitioning* may help those who pass over liminal spaces who have instrumental needs, but are not helpful to those who may need to dwell in and lose themselves in liminal spaces, (d) the discipline best suited to supporting people in liminal spaces is nursing, (e) the capacities required by nurses caring for people in liminal spaces can be acquired in terms of expertise but need not be associated with the language obscurity, the elaboration of technology and the disciplinary sequestering associated with yet another abstract expert system, and (f) liminal care seems best

situated in home care systems where autonomous nursing practice is encouraged. If this knowledge is applied to care of cancer patients leaving treatment to create a new and unwelcome dying narrative, these lost folks may feel less alone and less abandoned, and instead more supported and better understood.

Reason's third reflection indicates that the project itself must disrupt/interrupt patterns of power in relation to knowledge acquisition and dissemination, and in this project, by doing so factor as a policy lever to disrupt and transform cancer care systems. While doing this work I referred to the project as "career limiting," as I was wary that the unmasking of interests in the cancer control system would not be tolerated by those enmeshed in this system. At the same time, and on the other hand, I was hopeful that being within the cancer control system I might be influential in policy reform aimed at better supporting people who lose themselves in liminal spaces. I was a little bit right and a little bit wrong.

In terms of the career limitation – my work with the cancer control system that I was doing at the start of this project is ended. I will have no "insider influence" to disrupt and/or transform this system. But then, I am clear now that what I thought of as insider influence was fallacy, another bit of self-actualization I experienced. A system like cancer control does not shift policy because of intermediate or even high-level leader influence. Cancer control will only shift its way of being through modification of its interests. However, this I have learned – "interests are never exchanged or surrendered" (Purkis, 2001, p. 144). Interests are only ever modified to align with a structure of behaviours with which peers identify. Oncology will attend to their sequestered interests, and cancer systems will enmesh these interests in well-established and lucrative funding structures. People with cancer will surrender themselves and co-construct their cancer patient narratives with oncology clinicians so situated and interested, because they

believe they have no other treatment choices. Resistance will continue to flourish in consumer interests in complementary medicines and self-education, but these flashes of opposition will not erode what is so very firmly established in cancer systems. Therefore, this work will not transform cancer control systems, but rather it will contribute a critical perspective to that resistive effort.

In terms of now being “an outsider” I am oddly freed to operate outside of the interests and influence of the cancer control system, and work with home care and palliative care systems which I have assessed as more likely to shift and accommodate the interests and needs of people who are narratively lost in liminal spaces. Work can be based on this report that would help palliative care or home care nurses skill and situate themselves for the co-creation of meaning a liminal exchange would entail.

As a scholar my work adds voice to the needs of people who narratively lost arguably cannot raise their own. Well-known researcher in dignity at end-of-life, Chochinov’s testimony to the Senate of Canada's Special Committee on Euthanasia and Assisted-Suicide in 2000 is as follows: “Unfortunately, in end-of-life care, we do not have a vocal constituency: The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak.”

I add to Chochinov’s list those lost in liminality, who losing themselves narratively, are too bemused to speak. Thus, I find myself only beginning.

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### **Appendix A: Patient Flyer**

The University of Victoria  
School of Nursing



University  
of Victoria

Organizing transitions in palliative care: Being outside/inside cancer treatment systems

**Are you a patient whose treatment at the BC Cancer Agency is concluding?**

If so, you may be interested in participating in this PhD nursing study.

**What is the purpose of this study?**

The proposed study examines how the transitioning patient experiences the move from cancer treatment into palliative care. The proposed study will help you and me to understand the in-between space which is may be described as neither cancer treatment nor palliative care.

**Who can participate?**

You may be eligible to participate if you no longer have treatments at the BC Cancer agency and have not yet enrolled in a palliative care program

**What would you need to do?**

Your participation would involve;

- Providing informed consent
- Participating in a 45 - 60 minute interview at a location that is convenient for you

**How would you benefit from this study?**

If you participate in this study you will;

- Explore and talk about what you experience as you leave the cancer treatment centre;
- Learn about what options are open to you for support and care after your treatment ends;
- Help care providers understand what patients go through when they leave their treatment team and centre.

**Study Funding**

Canadian Institute of Health Research (CIHR) Communication and Cross-cultural Palliative Care New Emerging Teams (NET)

**Will my privacy be protected?**

All personal information will remain confidential.

**Contact me**

**I would greatly benefit from your input. To participate in this study, please contact me:**

**Ann Syme, RN, PhD©**  
BCCA – UVIC  
Pain & Symptom Management  
2410 Lee Ave,  
Victoria, B.C. V8R 6V5  
Tel: (250) 519-5608  
Ann.Syme@bccancer.bc.ca

## Appendix B: Clinician Flyer

The University of Victoria  
School of Nursing



University  
of Victoria

Organizing transitions in palliative care: Being outside/inside cancer treatment systems

### Are you an oncology clinician who cares for patients whose treatment at the BC Cancer agency is concluding?

If so, you may be interested in participating in this PhD nursing study.

### What is the purpose of this study?

The proposed study examines how the transitioning patient experiences the move from cancer treatment into palliative care. The proposed study will help you and me to understand the in-between space which is may be described as neither cancer treatment nor palliative care.

### Who can participate?

You may be eligible to participate if care for patients who are transitioning from cancer treatments to palliative care.

### What would you need to do?

Your participation would involve;

- Providing informed consent
- Participating in a 45 - 60 minute interview at a location that is convenient for you

### For more information, please turn over→

### How would you benefit from this study?

If you participate in this study you will;

- Discuss your understanding of what patients go through when they leave their treatment team and centre.

### Study Funding

Canadian Institute of Health Research (CIHR) Communication and Cross-cultural Palliative Care New Emerging Teams (NET)

### Will my privacy be protected?

All personal information will remain confidential.

**Contact me**

**I would greatly benefit from your input. To participate in this study, please contact me:**

**Ann Syme, RN, PhD©**

BCCA – Uvic

Pain & Symptom Management

2410 Lee Ave,

Victoria, B.C. V8R 6V5

Tel: (250) 519-5608

[Ann.Syme@bccancer.bc.ca](mailto:Ann.Syme@bccancer.bc.ca)

If you are a member of the Pain and Symptom Management Team, please contact my proxy  
Maxine Alford [Malford@bccancer.bc.ca](mailto:Malford@bccancer.bc.ca) or 250 519 5607

## Appendix C: Patient Letter of Invite

UNIVERSITY OF VICTORIA

Phone: (250) 721-6369

Facsimile: (250) 721-6499

Web: <http://www.coag.uvic.ca/eolcare>

### An Invitation to Participate in a Palliative Care Research Study

Ann Syme, a doctoral candidate at the University of Victoria School of Nursing and employee of the BC Cancer Agency, is conducting a research project to help understand how patients and families experience leaving the cancer treatment centre and move into palliative care. Transitioning from cancer treatment towards palliative care often involves an enormous adjustment for patients and their families, and yet has not been very closely looked at. I believe a better understanding of how patients and families experience this transition will help us to develop health services that can best support patients and their family members at this time. This research will involve approximately 6 patients along with their family member who are leaving the cancer centre knowing that the cancer has not been cured. A further 6 clinician participants will be recruited to ask them what they believe patients and families need at this time. Participants will be drawn from the cancer centres in Victoria and Vancouver.

This letter is an invitation to you as a cancer patient concluding treatment to participate in this research. My objective is to learn from you about how you experience this transition, and how you cope at this time. Participation is strictly voluntary and requires your informed consent. Your acceptance or refusal to participate in this study will in no way affect the care that you or your family receives from the health care system.

Participation in this study includes 2 parts. In the first part, you will be interviewed by me for approximately one hour. This will take place at the cancer clinic or your home, according to your preference. The second part will involve me re-contacting you after I have reviewed your interview and clarifying areas that may be unclear or where I need to check my interpretation of what I have heard you say. This second contact if necessary will take 15 minutes to ½ hour and will be by telephone.

If you agree to participate you should be at least 18 years old, English speaking and be moving out of curative cancer treatment at one of the two regional cancer centres.

If you are interested, please tell the nurse or oncologist or any other care provider at the cancer clinic and they will give your contact information to myself or my Research Assistant, Jodi Graham.

Thank you for considering my request. Your participation will be an important contribution to helping us better understand what patients and their families need as they transition out of cancer treatment.

Sincerely,

Ann Syme, R.N., M.S.N., PhD©  
Provincial Leader Pain & Symptom Management  
BC Cancer Agency – Vancouver Island

**Appendix D: Clinician Letter of Invite**

UNIVERSITY OF VICTORIA

Phone: (250) 721-6369

Facsimile: (250) 721-6499

Web: <http://www.coag.uvic.ca/eolcare>**An Invitation to Participate in a Palliative Care Research Study**

Ann Syme, a doctoral candidate at the University of Victoria School of Nursing and employee of the BC Cancer Agency, is conducting a research project to help understand how patients and families experience leaving the cancer treatment centre and move into palliative care. Transitioning from cancer treatment towards palliative care often involves an enormous adjustment for patients and their families, and yet has not been very closely looked at. I believe a better understanding of how patients and families experience this transition will help us to develop health services that can best support patients and their family members at this time. This research will involve approximately 6 patients along with their family member who are leaving the cancer centre knowing that the cancer has not been cured. A further 6 clinician participants will be recruited to ask them what they believe patients and families need at this time. Participants will be drawn from the cancer centres in Victoria and Vancouver.

This letter is an invitation to you as an oncology clinician to participate in this research. My objective is to learn from you how you think patients and families experience this transition, and what you think might be helpful to them from you as a care giver to help them cope with this time. Participation is strictly voluntary and requires informed consent. Your acceptance or refusal to participate in this study will in no way affect your employment at the BC Cancer Agency.

Participation in this study includes 2 parts. In the first part, you will be interviewed by me for approximately one hour. This will take place at the cancer clinic where you work. The second part will involve me recontacting you after I have reviewed your interview and clarifying areas that may be unclear, or where I or where I need to check my interpretation of what I have heard you say. This second contact if necessary will take 15 minutes to ½ hour and will be by telephone.

If you are interested, please contact myself or my Research Assistant, Jodi Graham. If you are a member of the Pain and Symptom Management Program, please contact Maxine Alford at 250 519 5607 who will act as my proxy.

Thank you for considering my request. Your participation will be an important contribution to helping us better understand what patients and their families need as they transition out of cancer treatment towards palliative care.

Sincerely,

Ann Syme, R.N., M.S.N., PhD©  
Provincial Leader Pain & Symptom Management  
BC Cancer Agency – Vancouver Island

## Appendix E: Patient Consent

### ***Participant Consent Form – Patients***

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You are invited to participate in a study entitled *Organizing transitions in palliative care: Being outside/inside cancer treatment systems* that is being conducted by Ann Syme.

Ann Syme is a PhD Student in the School of Nursing at the University of Victoria and you may contact her if you have further questions by calling 250 519 5608 or emailing [Ann.Syme@bccancer.bc.ca](mailto:Ann.Syme@bccancer.bc.ca)

Consent for this research is being sought by the researcher, who will answer questions you have about the research now, or later in the researcher process. Ann can be contacted at 250 519 5608 and emailed at [Ann.Syme@bccancer.bc.ca](mailto:Ann.Syme@bccancer.bc.ca)

As a graduate student, I am required to conduct research as part of the requirements for completion of a doctoral degree in Nursing, and as such the document (known as a dissertation) that will be produced from this research will be available to the public. The research is being conducted under the supervision of Dr. Mary Ellen Purkis. You may contact the supervisor at telephone # 250 721 8050 or email address [HSDDean@uvic.ca](mailto:HSDDean@uvic.ca)

This research is being partly funded by the Canadian Institute for Health Research under a New Emerging Team for Palliative Care.

#### **Purpose and Objectives**

The researcher is interested in the experiences of patients and their family members when they transition from active cancer treatment to palliative care and how they perceive this transition period and the different environments to which they are exposed when such a transition occurs within the health care system. The researcher plans to better understand this transition period by talking with patients and their families about what it is like for them as they complete their treatment with their oncology team. The researcher is also interested in talking with patients and their families about what sorts of health concerns they have when their cancer treatment is over and who they have spoken to about those concerns.

#### **Importance of this Research**

Results from the proposed research will assist in several ways. Results may provide some understanding about what cancer patients and their families experience and need as they conclude their treatment and are perhaps moving into palliative care. Understanding this will lead to shaping our cancer treatment system and our relationships with palliative care community partners to better support patients and families at this time.

#### **Participants Selection**

You have been identified as a person who is eligible for this study and you are being asked to participate because you have finished treatment and may be moving towards palliative care, and thus are in a position to reflect on what it means to you to move through this transition. Participation in this study is completely voluntary, and you may choose to participate or not. If you choose not to participate, you will continue to be offered the best care available.

**What is involved**

If you voluntarily agree to participate in this research, your participation will include an interview with the researcher which will be taped and transcribed into a written document. The interview is expected to take  $\frac{3}{4}$  to one hour, and can be conducted at the cancer clinic or your home. If you need to be contacted subsequently to clarify or better understand the transcribed document, someone will call you first to ask for your consent by telephone to proceed

**Inconvenience**

Participation in this study may cause some inconvenience to you, such as finding time to participate in the interview, or choosing to travel back to the clinic to do so. Expenses associated with travel will be supported by the researcher. Otherwise, there is no plan to pay you for participating.

**Risks**

Talking about moving out of treatment is likely to make you think of what is going to happen next. This may make you anxious or sad or both. Talking about this will not bring this on, it will only unearth this for you, and the researcher's skill is in understanding what this means for people, and she will offer to refer you to someone to help you with this.

**Benefits**

The potential benefits of your participation in this research is that you might be better able to understand what you are experiencing as you move from treatment to palliative care, and perhaps better able to talk about and clarify for yourself what might help you with this transition

Your participation in this research may help others who go through this experience in future and may benefit those responsible for planning such health care services.

The experiences you describe will contribute to the general state of knowledge on this topic and help others who read about these experiences in other provinces or countries.

**Voluntary Participation**

Your participation in this research must be completely voluntary. If you do decide to participate now, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study you will be offered an opportunity to withdraw yourself and your data, or yourself alone, and this option will be made clear to you. If you decide to withdraw, your family member may decide to withdraw with you or stay within the study. Any concerns about your decisions to withdraw can be discussed with the researcher at any time.

**Researcher's Relationship with Participants**

The researcher will not know you the patient, except through the referral she receives from the oncology team.

**On-going Consent**

To make sure that you continue to wish to consent to participate in this research, the researcher will be using what is termed process consent, where you will be asked to verbally re-consent with her to continue with the research if you are contacted subsequent to the interview

**Anonymity**

The interview tapes will be given to a research assistant who will transcribe and erase the tapes. Your association with your answers will be known only to the research assistant and to the

researcher. Your anonymity is assured and your name or any identifiers that may connect you with the research will be protected when the research is published.

### **Confidentiality**

Your identity will be kept strictly confidential. All documents will be identified only by code number and kept in a locked filing cabinet. Subjects will not be identified by name in any reports of the completed study. Data stored on computers will be password protected. Your privacy is protected by legislation that requires the researchers to ensure that access to the records is protected.

### **Dissemination of Results**

It is anticipated that the results of this study will be shared with others in the following ways: to yourselves; within the BC Cancer Agency; at conference presentations; in published articles; in dissertation class presentations; and at scholarly meetings.

### **Disposal of Data**

Data from this study will be disposed of by erasing tapes, and shredding paper copies.

### **Contacts**

Individuals that may be contacted regarding this study include Jodi Graham, Research Assistant (250 519 5573, [jgraham@bccancer.bc.ca](mailto:jgraham@bccancer.bc.ca)).

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545) or [ethics@uvic.ca](mailto:ethics@uvic.ca) as well as the Research Subject Information Line in the UBC Office of Research Services at (604-822-8598) or if long distance e-mail to [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

*Name of Participant*

*Signature*

*Date*

\_\_\_\_\_

*A copy of this consent will be left with you, and a copy will be taken by the researcher.*

## Appendix F: Family Recruitment Letter

UNIVERSITY OF VICTORIA

Phone: (250) 721-6369

Facsimile: (250) 721-6499

Web: <http://www.coag.uvic.ca/eolcare>

### **An Invitation to Participate in a Palliative Care Research Study**

Ann Syme, a doctoral candidate at the University of Victoria School of Nursing and employee of the BC Cancer Agency, is conducting a research project to help understand how patients and families experience leaving the cancer treatment centre and move into palliative care. Transitioning from cancer treatment towards palliative care often involves an enormous adjustment for patients and their families, and yet has not been very closely looked at. I believe a better understanding of how patients and families experience this transition will help us to develop health services that can best support patients and their family members at this time. This research will involve approximately 6 patients along with their family member who are leaving the cancer centre knowing that the cancer has not been cured. A further 6 clinician participants will be recruited to ask them what they believe patients and families need at this time. Participants will be drawn from the cancer centres in Victoria and Vancouver.

This letter is an invitation to you as the family member of a cancer patient concluding treatment to participate in this research. My objective is to learn from you about how you experience the transition of your loved one, and how you cope at this time. Participation is strictly voluntary and requires your informed consent. Your acceptance or refusal to participate in this study will in no way affect the care that you or your family receives from the health care system.

Participation in this study includes 2 parts. In the first part, you will be interviewed by me for approximately one hour. This will take place at the cancer clinic or your home, according to your preference. The second part will involve me re-contacting you after I have reviewed your interview and clarifying areas that may be unclear, or where I need to check my interpretation of what you have said. This second contact if necessary will take 15 minutes to ½ hour and will be by telephone.

If you agree to participate should be at least 18 years old, English speaking and be moving out of curative treatment at one of the two regional cancer centres.

If you are interested, please tell the nurse or oncologist or any other care provider at the cancer clinic and they will give your contact information to me myself or my Research Assistant, Jodi Graham. Alternatively you can contact me directly at 250 519 5608 or

[Ann.Syme@bccancer.bc.ca](mailto:Ann.Syme@bccancer.bc.ca)

Thank you for considering my request. Your participation will be an important contribution to helping us better understand what patients and their families need as they transition out of cancer treatment.

Sincerely,

Ann Syme, R.N., M.S.N., PhD©  
Provincial Leader Pain & Symptom Management  
BC Cancer Agency – Vancouver Island

## Appendix G: Family Member Consent

### ***Participant Consent Form – Family Members***

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You are invited to participate in a study entitled *Organizing transitions in palliative care: Being outside/inside cancer treatment systems* that is being conducted by Ann Syme.

Ann Syme is a PhD Student in the School of Nursing at the University of Victoria and you may contact her if you have further questions by calling 250 519 5608 or emailing [Ann.Syme@bccancer.bc.ca](mailto:Ann.Syme@bccancer.bc.ca)

Consent for this research is being sought by me, the researcher, who will answer questions you have about the research now, or later in the researcher process. I can be contacted at 250 519 5608 and emailed at [Ann.Syme@bccancer.bc.ca](mailto:Ann.Syme@bccancer.bc.ca)

As a graduate student, I am required to conduct research as part of the requirements for completion of a doctoral degree in Nursing, and as such the document (known as a dissertation) that will be produced from this research will be available to the public. The research is being conducted under the supervision of Dr. Mary Ellen Purkis. You may contact the supervisor at telephone # 250 721 8050 or email address [HSDDean@uvic.ca](mailto:HSDDean@uvic.ca)

This research is being partly funded by the Canadian Institute for Health Research under a New Emerging Team Grant for Palliative Care.

#### **Purpose and Objectives**

The researcher is interested in the experiences of patients and their family members when they transition from active cancer treatment to palliative care and how they perceive this transition period and the different environments to which they are exposed when such a transition occurs within the health care system. The researcher plans to better understand this transition period by talking with patients and their families about what it is like for them as they complete their treatment with their oncology team. The researcher is also interested in talking with patients and their families about what sorts of health concerns they have when their cancer treatment is over and who they have spoken to about those concerns.

#### **Importance of this Research**

Results from the proposed research will assist in several ways. Results may provide some understanding about what cancer patients and their families experience and need as they conclude their treatment and are perhaps moving into palliative care. Understanding this will lead to shaping our cancer treatment system and our relationships with palliative care community partners to better support patients and families at this time.

#### **Participants Selection**

You have been identified as a person who is eligible for this study and you are being asked to participate because your family member has finished treatment and may be moving towards palliative care, and thus are in a position to reflect on what it means to you and/or your loved one to move through this transition..

#### **What is involved**

Participation in this study is completely voluntary, and you may choose to participate or not. If you choose not to participate, you and your loved one will continue to be offered the best care available. If

you voluntarily agree to participate in this research, your participation will include an interview with the researcher which will be taped and transcribed into a written document. The interview is expected to take ¾ to one hour, and can be conducted at the cancer clinic or your home. If you need to be contacted subsequently to clarify or better understand the transcribed document, someone will call you first to ask for your consent by telephone to proceed.

**Inconvenience**

Participation in this study may cause some inconvenience to you, such as finding time to participate in the interview, or choosing to travel back to the clinic to do so. Expenses associated with travel will be supported by the researcher. Otherwise, there is no plan to pay you for participating.

**Risks**

Talking about your loved one moving out of treatment is likely to make you think of what is going to happen next. This may make you anxious or sad or both. Talking about this will not bring this on, it will only unearth this for you, and my skill is in understanding what this means for people, and I will offer to refer you to someone to help you with this if you wish.

**Benefits**

The potential benefits of your participation in this research is that you might be better able to understand what you and your loved one are experiencing as you move from treatment to palliative care, and perhaps better able to talk about and clarify for yourself what might help you and your loved one with this transition

Your participation in this research may help others who go through this experience in future and may benefit those responsible for planning such health care services.

The experiences you describe will contribute to the general state of knowledge on this topic and help others who read about these experiences in other provinces or countries.

**Voluntary Participation**

Your participation in this research must be completely voluntary. If you do decide to participate now, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study you will be offered an opportunity to withdraw yourself and your data, or yourself alone, and this option will be made clear to you. If you decide to withdraw, your family member may decide to withdraw with you or stay within the study. Any concerns about your decisions to withdraw can be discussed with the researcher at any time.

**Researcher's Relationship with Participants**

I will not be caring for either the patient or you, their family member participant. Your loved one will have been recommended to me by your oncology team, and you recommended to me by your loved one.

**On-going Consent**

To make sure that you continue to wish to consent to participate in this research, the researcher will be using what is termed process consent, where you will be asked to verbally re-consent with her to continue with the research if you are contacted subsequent to the interview.

**Anonymity**

The interview tapes will be given to a research assistant who will transcribe and erase the tapes. Your association with your answers will be known only to the research assistant and to me. Your anonymity is assured and your name or any identifiers that may connect you with the research will be protected when the research is published.

**Confidentiality**

Your identity will be kept strictly confidential. All documents will be identified only by code number and kept in a locked filing cabinet. Subjects will not be identified by name in any reports of the completed study. Data stored on computers will be password protected. Your privacy is protected by legislation that requires the researchers to ensure that access to the records is protected

**Dissemination of Results**

It is anticipated that the results of this study will be shared with others in the following ways: with yourselves and your loved one; within the BC Cancer Agency; at conference presentations; in published articles; in dissertation class presentations; and at scholarly meetings.

**Disposal of Data**

Data from this study will be disposed of in five years time by erasing tapes, and shredding paper copies.

**Contacts**

Individuals that may be contacted regarding this study include Jodi Graham, Research Assistant (250 519 5573, [jgraham@bccancer.bc.ca](mailto:jgraham@bccancer.bc.ca)).

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545) or [ethics@uvic.ca](mailto:ethics@uvic.ca) as well as the Research Subject Information Line in the UBC Office of Research Services at (604-822-8598) or if long distance e-mail to [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

*Name of Participant*

*Signature*

*Date*

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*A copy of this consent will be left with you, and a copy will be taken by the researcher.*

## Appendix H: Clinician Consent

### ***Participant Consent Form – Oncology Clinicians***

---

You are invited to participate in a study entitled *Organizing transitions in palliative care: Being outside/inside cancer treatment systems* that is being conducted by Ann Syme.

Ann Syme is a PhD Student in the School of Nursing at the University of Victoria and you may contact her if you have further questions by calling 250 519 5608 or emailing [Ann.Syme@bccancer.ca](mailto:Ann.Syme@bccancer.ca)

As a graduate student, I am required to conduct research as part of the requirements for completion of a doctoral degree in Nursing, and as such the document (known as a dissertation) that will be produced from this research will be available to the public. The research is being conducted under the supervision of Dr. Mary Ellen Purkis. You may contact the supervisor at telephone # 250 721 8050 or email address [HSDDean@uvic.ca](mailto:HSDDean@uvic.ca).

Consent for this research is being sought by the researcher, or alternatively a proxy, Dr. Maxine Alford, if you should have a relationship with Ann Syme where she is your practice supervisor. Ann Syme or Dr. Alford will answer questions you have about research now, or later in the researcher process. Dr. Alford can be contacted at 250 519 5607 and emailed at [malford@bccancer.bc.ca](mailto:malford@bccancer.bc.ca)

This research is being partly funded by the Canadian Institute for Health Research under a New Emerging Team for Palliative Care.

#### **Purpose and Objectives**

The researcher is interested in the experiences of patients and their family members when they transition from active cancer treatment to palliative care and how they perceive this transition period and the different environments to which they are exposed when such a transition occurs within the health care system. The researcher plans to better understand this transition period by talking with patients and their families about what it is like for them as they complete their treatment with their oncology team. The researcher is also interested in talking with patients and their families about what sorts of health concerns they have when their cancer treatment is over and who they have spoken to about those concerns. Finally, I will wish to speak to oncology clinicians who care for these patients so that I can understand how they see patient and families experiencing this transition

#### **Importance of this Research**

Results from the proposed research will assist in several ways. Results may provide some understanding about what cancer patients and their families experience and need as they conclude their treatment and are perhaps moving into palliative care. Understanding this will lead to shaping our cancer treatment system and our relationships with palliative care community partners to better support patients and families at this time.

#### **Participants Selection**

You have been identified as a person who is eligible for this study and you are being asked to participate because you have indicated that you have some thoughts to share about patients you care for who have finished treatment and may be moving towards palliative care, and thus are in a position to reflect on what

it means to support them as they move through this transition. Participation in this study is completely voluntary, and you may choose to participate or not. If you choose not to participate, your work will not be affected. If you voluntarily agree to participate in this research, your participation will include an interview with the researcher which will be taped and transcribed into a written document. The interview is expected to take ¾ to one hour, and will be conducted at the cancer clinic. If you need to be contacted subsequently to clarify or better understand the transcribed document, someone will call you first to ask for your consent by telephone to proceed.

If you are also someone who is involved with the Pain and Symptom Management Teams and may be supervised by the researcher, your consent and ongoing support in joining this research will be done through a proxy (third party) for the researcher, Maxine Alford.

### **What is involved**

If you voluntarily agree to participate in this research, your participation will include an interview with the researcher which will be taped and transcribed. The interview is expected to take ¾ to one hour, and will be conducted at the cancer clinic.

If I need to speak again with you to aid my understanding of the text, I (or my proxy) will first verbally obtain your consent to proceed.

### **Inconvenience**

Participation in this study may cause some inconvenience to you, such as finding time to participate in the interview. If there is any travel expense incurred (e.g. return to clinic on day off) expenses associated with travel will be supported by the researcher.

### **Risks**

There are no significant risks involved in participating in this research.

### **Benefits**

The potential benefits of your participation in this research is that you will be better able to understand what transitional patients are experiencing as they move out of treatment, and perhaps be better able to assist them with this transition.

Society benefits in that the health care system could be improved in its responsiveness to the transitional patient's needs. This is not insignificant as it is a demonstrated source of distress for cancer patients to leave the treatment centre towards an unclear future.

The state of knowledge will be added to in a description of what currently is poorly described in cancer and palliative care – that is the neither/nor in-between space of the transitional patient and their family.

### **Voluntary Participation**

Your participation in this research must be completely voluntary. If you do decide to participate now, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study you will be offered an opportunity to withdraw yourself and your data, or yourself alone, and this option will be made clear to you. Any concerns about your decisions to withdraw can be discussed with the researcher or the proxy at any time.

### **Researcher's Relationship with Participants**

The researcher may know the clinicians who volunteer to participate, and for a very few, the researcher may have a relationship with participants as their practice supervisor. If you are

supervised by the researcher, a proxy (third party) will contact you, explain the research and your contributions and your ability to refuse, or withdraw at any time you choose.

The proxy will explain the research and your potential involvement, including risks, benefits, and the exclusive role of the proxy to discuss consent and any issues that come up for you in the process of the research.

Your identity will be kept strictly confidential. All documents will be identified only by code number and kept in a locked filing cabinet. Participants will not be identified by name in any reports of the completed study.<sup>7</sup> Data stored on computers will be password protected.

If during the course of the research, the researcher observes practices that seem to fall short of accepted professional standards, she will report those observations to the practice leader with whom she shares the supervision of the employee, and the researcher's own practice supervisor. This 'duty to report' is required by the College of Registered Nurses of British Columbia (CRNBC) and will be noted during the consenting process with these professional team members.

### **On-going Consent**

To make sure that you wish to continue to consent to participate in this research, the researcher will be using what is termed process consent, where you will be asked to verbally re-consent with the her or the proxy to continue with the research if you are contacted subsequent to the interview

### **Anonymity**

The interview tapes will be given to a research assistant who will transcribe and erase the tapes. Your association with your answers will be known only to the research assistant and to the researcher. Your anonymity is assured and your name or any identifiers that may connect you with the research will be protected when the research is published. If it is clear from your disciplinary identification who you might be, you will not be referred to as from an explicit discipline, but rather as an oncology clinician.

### **Confidentiality**

Your confidentiality and the confidentiality of the data will be protected by storage of texts in a password protected computer and locking of printed texts in a file cabinet at the Vancouver Island Cancer Centre.

### **Dissemination of Results**

It is anticipated that the results of this study will be shared with others in the following ways: to yourselves; within the BC Cancer Agency; at conference presentations; in published articles; in dissertation class presentations; and at scholarly meetings.

### **Disposal of Data**

Data from this study will be disposed of by erasing tapes, and shredding paper copies.

### **Contacts**

Individuals that may be contacted regarding this study include Jodi Graham, Research Assistant (250 519 5573, [jgraham@bccancer.bc.ca](mailto:jgraham@bccancer.bc.ca)), Dr. Maxine Alford, Proxy, and/or the researcher and her supervisor.

In addition, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545) or

[ethics@uvic.ca](mailto:ethics@uvic.ca)) as well as the Research Subject Information Line in the UBC Office of Research Services at (604-822-8598) or if long distance e-mail to [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca).

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers.

*Name of Participant*

*Signature*

*Date*

---

*A copy of this consent will be left with you, and a copy will be taken by the researcher or proxy.*

### **Appendix I: Script for Proxy Consent**

The researcher you wish to work with is one who supervises your practice on the Pain and Symptom Management Program at BCCA. That is to say, the researcher in her administrative position with you has what is considered a “power-over” relationship with you. As such it is not appropriate for her to seek your consent, and myself as a third party proxy is retained to do this. This is done to protect your interests as an employee, and so you may participate if you wish, free of concerns in this regard. Do you understand this relationship and required process?

As such, you are asked to go through the consent process with me and also to return to me if you should have any concerns about the research process itself and/or your continued involvement in this research project. Do you understand your relationship through me with this research?

If the clinician participant is able to answer yes to these two questions, the proxy may continue with consent.

**Appendix J: University of Victoria Ethics Certificate**



**University  
of Victoria**

**Human Research Ethics Board**  
Office of Research Services  
Technology Enterprise Facility, Room 218  
PO Box 1700 STN CSC  
Victoria British Columbia V8W 2Y2 Canada  
Tel (250) 472-4545, Fax (250) 721-7836  
Email ethics@uvic.ca Web www.research.uvic.ca

**Human Research Ethics Board  
Certificate of Approval**

<u>Principal Investigator</u> <b>Charlotte Ann Syme</b> Ph.D. Student	<u>Department/School</u> <b>NURS</b>	<u>Supervisor</u> <b>Dr. Mary Ellen Purkis</b>
<u>Co-Investigator(s):</u> Dr. Anne Bruce, Committee member, UVic Dr. Helga Halgrimsdottir, Committee member, UVic Dr. Lynn Stevenson, Committee member, VIHA Dr. Maxine Alford, Proxy for consent, BC Cancer Agency Jodi Graham, Research Assistant, BC Cancer Agency		
<u>Project Title:</u> <b>How do Cancer Patients Transition to Palliative Care?</b>		
<u>Protocol No.</u> <b>08-225</b>	<u>Approval Date</u> <b>29-Aug-08</b>	<u>Start Date</u> <b>29-Aug-08</b>
		<u>Expiry Date</u> <b>28-Aug-09</b>
<b>Certification</b>		
This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.		
<b>This Certificate of Approval is valid for the above term provided there is no change in the protocol. Extensions and/or amendments may be approved with the submission of a "Request for Annual Renewal or Modification" form.</b>		
<hr/> Dr. Richard Keeler Associate Vice-President, Research		

08-225 Syme, Charlotte Ann

**Appendix K: BCCA UBC Ethics Certificate**

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University of British Columbia - British Columbia Cancer Agency Research Ethics Board (UBC BCCA REB)

UBC BCCA Research Ethics Board  
 Fairmont Medical Building (6th Floor)  
 614 - 750 West Broadway  
 Vancouver, BC V5Z 1H5  
 Tel: (604) 877-6284 Fax: (604) 708-2132  
 E-mail: reb@bccancer.bc.ca  
 Website: <http://www.bccancer.bc.ca> >  
 Research Ethics  
 RISE: <http://rise.ubc.ca>

**Certificate of Expedited Approval**

<b>PRINCIPAL INVESTIGATOR:</b> Ann Syme	<b>INSTITUTION / DEPARTMENT:</b> BCCA/Systemic Therapy - VA (BCCA)	<b>REB NUMBER:</b> H08-00151
<b>INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:</b>		
Institution		Site
BC Cancer Agency		Vancouver BCCA
BC Cancer Agency		Vancouver Island BCCA
Other locations where the research will be conducted: Participant's home if they so elect.		
<b>PRINCIPAL INVESTIGATOR FOR EACH ADDITIONAL PARTICIPATING BCCA CENTRE:</b>		
<b>Vancouver:</b>	Ann Syme	<b>Vancouver Island:</b> Ann Syme
<b>Fraser Valley:</b>	N/A	<b>Southern Interior:</b> N/A
<b>SPONSORING AGENCIES AND COORDINATING GROUPS:</b> Canadian Institutes of Health Research (CIHR)		
<b>PROJECT TITLE:</b> Organizing transitions in palliative care: Being outside/inside cancer treatment systems		

The UBC BCCA Research Ethics Board Chair, Vice-Chair or second Vice-Chair, has reviewed the above described research project, including associated documentation noted below, and finds the research project acceptable on ethical grounds for research involving human subjects and hereby grants approval.

**EXPIRY DATE OF THIS APPROVAL:** July 31, 2009

<b>DATE DOCUMENT(S) APPROVED:</b> July 31, 2008		
<b>LIST OF DOCUMENTS APPROVED:</b>		
Document Name	Version	Date
<b>Protocol:</b>		
Transitions	1	July 21, 2008
<b>Consent Forms:</b>		
patient consent	3	July 30, 2008
clinician consent	3	July 30, 2008
family member consent	3	July 30, 2008
<b>Advertisements:</b>		
flyer patients	1	July 21, 2008
flyer oncology clinicians	1	July 21, 2008
flyer family member	1	July 21, 2008
<b>Questionnaire, Questionnaire Cover Letter, Tests:</b>		
Proxy consent script	1	July 21, 2008
Proxy re consent script	1	July 21, 2008
Researcher re consent script	1	July 21, 2008
<b>Letter of Initial Contact:</b>		
letter of contact patient BCCA	1	July 21, 2008
Letter of contact family member BCCA	1	July 21, 2008
Letter of contact clinician BCCA	1	July 21, 2008

**CERTIFICATION:**

1. The membership of the UBC BCCA REB complies with the membership requirements for research ethics boards defined in Division 5 of the Food and Drug Regulations of Canada.
2. The UBC BCCA REB carries out its functions in a manner fully consistent with Good Clinical Practices.
3. The UBC BCCA REB has reviewed and approved the research project named on this Certificate of Approval including any associated consent form and taken the action noted above. This research project is to be conducted by the provincial investigator named above. This review and the associated minutes of the UBC BCCA REB have been documented electronically and in writing.

UBC BCCA Ethics Board approval of the above has been verified by one of the following:

Dr. George Browman,  
Chair

Dr. Joseph Connors,  
First Vice-Chair

Dr. Lynne Nakashima  
Second Vice-Chair

**If you have any questions, please call:**

Bonnie Shields, Manager, BCCA Research Ethics Board: 604-877-6284 or e-mail:  
reb@bccancer.bc.ca

Dr. George Browman, Chair: 604-877-6284 or e-mail: gbrowman@bccancer.bc.ca

Dr. Joseph Connors, First Vice-Chair: 604-877-6000-ext. 2746 or e-mail: jconnors@bccancer.bc.ca

Dr. Lynne Nakashima, Second Vice-Chair: 604-707-5989 or e-mail: lnakas@bccancer.bc.ca

**Appendix L: University of Victoria Ethics Renewal**



University of Victoria

**Human Research Ethics Board**  
 Office of Research Services  
 University of Victoria  
 Administrative Services Building - 2nd Floor  
 Tel (250) 472-4545 Fax (250) 721-8960  
 Email ethics@uvic.ca Web www.research.uvic.ca

**Human Research Ethics Board  
 Certificate of Renewed Approval**

<u>Principal Investigator</u> <b>Charlotte Ann Syme</b> Ph.D. Student	<u>Department/School</u> <b>NURS</b>	<u>Supervisor</u> <b>Dr. Mary Ellen Purkis</b>	
<u>Co-Investigator(s):</u> Dr. Anne Bruce, Committee Member, UVic Dr. Helga Halgrimsdottir, Committee Member, UVic Dr. Lynn Stevenson, Committee Member, VIHA Jodi Graham, RA, UVic			
<u>Project Title:</u> How Do Cancer Patients Transition to Palliative Care			
<u>Protocol No.</u> <b>08-225</b>	<u>Original Approval Date</u> <b>29-Aug-08</b>	<u>Renewed On</u> <b>13-Aug-09</b>	<u>Must Renew By</u> <b>28-Aug-10</b>

**Certification**

This certifies that the UVic Human Research Ethics Board has examined this research protocol and concluded that, in all respects, the proposed research meets the appropriate standards of ethics as outlined by the University of Victoria Research Regulations Involving Human Participants.

---

**This Certificate of Approval is valid for the above term provided there is no change in the protocol. Extensions and/or amendments may be approved with the submission of a Request for Annual Renewal or Modification form.**

\_\_\_\_\_  
 Dr. Richard Keeler  
 Associate Vice-President, Research

08-225 Syme, Charlotte Ann

**Appendix M: BCCA UBC Ethics Renewal**

Page 1 of 2



University of British Columbia - British Columbia Cancer Agency Research Ethics Board (UBC BCCA REB)

UBC BCCA Research Ethics Board  
 Fairmont Medical Building (6th Floor)  
 614 - 750 West Broadway  
 Vancouver, BC V5Z 1H5  
 Tel: (604) 877-6284 Fax: (604) 708-2132  
 E-mail: reb@bccancer.bc.ca  
 Website: <http://www.bccancer.bc.ca> >  
 Research Ethics  
 RISe: <http://rise.ubc.ca>

**Certificate of Expedited Approval: Annual Renewal**

<b>PRINCIPAL INVESTIGATOR:</b> Ann Syme	<b>INSTITUTION / DEPARTMENT:</b> BCCA/BCCA/Systemic Therapy - VA (BCCA)	<b>REB NUMBER:</b> H08-00151
<b>INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:</b>		
Institution		Site
BC Cancer Agency		Vancouver BCCA
BC Cancer Agency		Vancouver Island BCCA
Other locations where the research will be conducted: Participant's home if they so elect.		
<b>PRINCIPAL INVESTIGATOR FOR EACH ADDITIONAL PARTICIPATING BCCA CENTRE:</b>		
<b>Vancouver:</b>	Ann Syme	<b>Vancouver Island:</b> Ann Syme
<b>Fraser Valley:</b>	N/A	<b>Southern Interior:</b> N/A
<b>Abbotsford Centre:</b>	N/A	
<b>SPONSORING AGENCIES AND COORDINATING GROUPS:</b> Canadian Institutes of Health Research (CIHR)		
<b>PROJECT TITLE:</b> Organizing transitions in palliative care: Being outside/inside cancer treatment systems		

**APPROVAL DATE:** June 18, 2009      **EXPIRY DATE OF THIS APPROVAL:** June 18, 2010      **PAA#:** H08-00151-A001

**CERTIFICATION:**

1. The membership of the UBC BCCA REB complies with the membership requirements for research ethics boards defined in Division 5 of the Food and Drug Regulations of Canada.
2. The UBC BCCA REB carries out its functions in a manner fully consistent with Good Clinical Practices.
3. The UBC BCCA REB has reviewed and approved the research project named on this Certificate of Approval including any associated consent form and taken the action noted above. This research project is to be conducted by the provincial investigator named above. This review and the associated minutes of the UBC BCCA REB have been documented electronically and in writing.

The UBC BCCA Research Ethics Board has reviewed the documentation for the above named project. The research study as presented in documentation, was found to be acceptable on ethical grounds for research involving human subjects and was approved for renewal by the UBC BCCA REB.

**UBC BCCA Ethics Board Approval of the above has been verified by one of the following:**

<https://rise.ubc.ca/rise/Doc/0/N55OOD1S3IN43DBRMK2NTHR6D/fromString.html>      19/06/2009

Dr. George Browman,  
Chair

Dr. Joseph Connors,  
First Vice-Chair

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**Appendix N: Interview Guide Patients**

The following questions were used to interview the participating patients:

- I'd like to start the interview by asking you to tell me a little bit about your experience of receiving treatment for cancer here at the Cancer Centre:
  - How was the treatment process explained to you?
  - Who explained things to you?
  - Did you talk with other people about treatment?
  - Did things proceed as you expected? If not, what was different from what you expected?
- Over the time that you've been coming to the Centre, has the goal of your treatment changed? Can you describe how things are different now than before?
- What did this change call forward in you to meet with this new phase?
- Was there anything you can point to that has been particularly helpful to you in preparing you for this new phase?
  - Is there anything that you believe could be done to help you more at this time?

### **Appendix O: Interview Guide Family Members**

The following questions were used to interview the participating patients' family members:

- I'd like to begin the interview by asking you what it's been like for you to be caring for someone (your Mom, your Dad, your friend, your sister/brother/husband/wife) with cancer.
- What have been the most important events that have happened during this period?
- Has anything changed recently?
- How did this effect you? How do you think this effected your loved one?
- Can you point to anything – or anyone – who has been particularly helpful to you during this time of transition?
- Are there things that you can point to that you think would be helpful to you and your loved one at this time?

### **Appendix P: Interview Guide Oncology Clinicians**

The following questions were used to interview the participating oncology clinicians:

- How do you understand the process involved in how patients move from active cancer treatment to palliative care?
  - When does this happen?
  - What does this look like?
  - Why does this happen the way it does?
  - Have you seen this process managed differently in other contexts?
- How do you think your work in the cancer system contributes to this transition?
- What's most important, from your perspective, to ensure in terms of patient outcomes during this time of transition?
- Are there things that you specifically try to make sure of when you're working with people to achieve these outcomes?
- In your mind, what else contributes to this time of transition?
- Are there things that could be done to better support these patients and family members at this time?