Incurable & Invisible: Living with Advanced Disease in a Canadian Cancer Hospital

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy
Graduate Department of Anthropology
University of Toronto

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Abstract

This thesis follows the lives of people who are diagnosed with a cancer that is unlikely to be cured. This means that even if patients receive one or multiple rounds of the standard treatments of chemotherapy, surgery and radiation, there is a high probability that they will still die from their disease. Incurable illness presents a particular problem due to a combination of cultural meanings and values, both within biomedicine and within society. Drawing on 17 months of ethnographic fieldwork conducted in one Canadian cancer hospital, working with patients with lung and gynaecological cancers, the dissertation answers the question: What is life like for patients with advanced cancer as they live with their disease, post-diagnosis? Although its focus is primarily on the patients, it also includes the experiences of doctors and nurses at the hospital, and patients’ family and friends.

I explore some of the challenges and tensions produced from living with a diagnosis of advanced cancer. For example, patients are advised to ‘live in the moment,’ but this is a very challenging directive to follow as it is interlaced with the connotation that they are being entreated to do so because their futures are uncertain. Similarly, patients have to muster enough hope to be able to endure the emotionally and physically demanding treatments, but not so much hope that they
believe that the treatments will actually cure them of their disease. These entreaties require them
to straddle both the worlds of oncology and survivorship and the worlds of death, dying and
palliative care, which my findings indicate is extremely difficult to withstand on a day-to-day
basis. I argue that advanced cancer is a kind of ‘liminal’ space, an ambiguous territory that exists
between the hope for a cure and the imminence of death. Patients’ ambiguous position is made
even more challenging since contemporary cancer culture in North America tends to highlight
only cancer survivors or people who have ‘lost their battles’ from cancer, rendering the struggles
and experiences of patients who are living with advanced cancer but not currently dying from it,
both culturally silent and invisible.
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When I began doctoral studies in Anthropology, I entered a cohort with an extremely smart and talented group of women. Over the years, I have been grateful not only for the enduring friendship, but also for the intellectual gifts of Kori Allan, Lauren Classen, Lesley Howse, Daniela Jofre, Sharon Kelly, Anna Polonyi, Laura Sikstrom, Jessica Taylor, and Eugenia Tsao. All of these women have enriched my life and my work in more ways than I can count. Colleagues in other departments at the University of Toronto, including Filomena Calabrese, Melanie Elliott, and Christopher Klinger, provided support and encouragement at key points throughout this project. Colleagues at Lady Ann’s, including Chris Lo and Lynn Gauthier, exemplified what thoughtful, solid research on cancer should look like, and many conversations
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Last by not least, thanks to my husband, Richard. This fieldwork counts amongst the most difficult things I have ever done, challenging me emotionally, intellectually and physically. In the period of fieldwork and the years that followed, I feared I had become perhaps too close to cancer, and that I would never escape the dark tunnel that I had entered after watching people I cared about decline, and in some cases, die. Then unexpectedly in March of 2013, my very own modern day hero appeared in my life, took my hand and pulled me back into the sunlight. For loving me, for supporting me, for giving me a place to write and reflect, and for making me feel happy again from the inside out, I owe Rich my deepest gratitude.
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List of Principal Informants

Dario is a 57-year-old man with stage IV non-small cell lung cancer. He is married, the father of two children, and owns his own contracting business.

Deo is a 62-year-old man with stage IV non-small lung cancer. He is married, has two daughters, and before he was sick, worked in security. His wife’s name is Prisha.

Elizabeth is a 37-year-old woman with metastatic ovarian cancer. She is single, and a teacher for grades Kindergarten-6. She lives alone, and is very close to her parents, especially her mother, who attends all her appointments.

Isabelle is a 64-year-old woman with metastatic ovarian cancer. She is the mother of two sons, is university educated, and worked as a translator before she retired. Her husband’s name is Derek.

Jennifer is a 41-year-old woman with metastatic endometrial cancer. She is single, lives alone, and is employed as a teacher. She has a master’s degree and was interested in pursuing a PhD before she became sick.

Julia is a 49-year-old woman with recurrent ovarian cancer. She is a university professor, and is a single parent to a teenage son. She received care in South America and in the U.S. before moving to Canada.

Mary is a 54-year-old woman with stage IV non-small cell lung cancer. She is the mother of four boys. Her husband’s name is Robert.

Melody is a 70-year-old woman with recurrent ovarian cancer. She had breast cancer in her 50s, which was treated with a mastectomy, radiation, and chemotherapy. She lives alone and is retired. In her work life, she had many careers in sales. She is divorced, but has two children from earlier marriages.

Norma is a 57-year-old woman with metastatic ovarian cancer. She is single, lives alone, and was a teacher before she retired.
Olivia is a 32-year-old woman with recurrent ovarian cancer. She is a single woman, university-educated, and works as a writer and a journalist.

Pam is a 50-year-old woman with metastatic ovarian cancer. She is an early childhood educator, and works in the school board, as well as in children’s hospitals, providing one-on-one support to children with serious illnesses. She lives alone, and has never been married, but is very close to her sister who lives in England.

Paul is a 62-year-old man with stage IV non-small cell lung cancer. He is married, and the father of three children. He is college educated, and works in management for a large retail company. His wife’s name is Sue.
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Prologue
Facing the library wall

It’s April. Cancer awareness month. Tonight, I was working at the public library, when I came upon a mosaic of books about cancer displayed on the wall, under the heading “Daffodil Month for Cancer.” Out of habit, I glance quickly at their titles, seeing a wash of pink and what seemed to be a lot of books about food. I spot my least favourite specimen of this type of book – Crazy, Sexy Cancer Survivor (Carr 2008), a book by a young woman who survived her cancer and now exhorts other people to view their own insidious disease in “sexy” terms. My eyes glaze over as I review the other offerings, searching hopefully for a title that does not involve the word ‘choice’ or ‘survivor’ or ‘beating’ or ‘curing’ cancer, or that is not about nutrition or exercise options, but I do not find any. I decide to do a formal tally. A total of 17 books are displayed:

- 1 book on prostate cancer
- 3 on breast cancer
- 4 on food or nutrition
- 1 on having children after cancer
- 1 on melanoma
- 1 on chemo brain

These eleven books are somewhat substantive, with titles such as Prostate and Cancer or Your Brain after Chemo. There are an additional six books of the egregious type, such as Carr’s (2008) that extol the virtues of thinking positive and having the right approach to cancer. In addition to hers there is:

What Helped Me Get Through: Cancer Survivors Share Wisdom and Hope (Julie Silver, MD)

OUTLIVING Cancer: The Better, Smarter Way to Treat Your Cancer (Robert Nagamey, MD)

Chasing the Cure (William Bengston, PhD)

Learn to Live through Cancer: What You Need to Know and Do (Stewart B. Fleishman, MD)

I Choose to Live: A Self-made Millionaire Faces Cancer (Misca Weisz)

Where are pancreatic, lung, ovarian, and colorectal cancers – cancers that are much less likely to be curable, especially when they are diagnosed in late stages? Once again, the most talked about forms of men’s and women’s cancers, prostrate and breast respectively, have made the wall, but other kinds of cancer barely make an appearance.
The choice of books is likely the product of a very well meaning public librarian who decided to put together a sampling of what the library has to offer in terms of popular cancer literature. But where are the books that tell patients what cancer is really like? That you may survive, especially if your cancer is in its early stages, but that it is okay to be scared? That despite all efforts and treatments, conventional and alternative, many people still die of their disease (1 in 4 Canadians, according to the latest figures from the Canadian Cancer Society (2015)? Where is the harsh truth of metastatic disease, summarized by an American oncologist I met whom, upon hearing about my research, said very bluntly, “Metastatic disease always comes back. Except for prostate and thyroid cancers, it may take time, but it always comes back.”

How would I feel about this wall if I were a patient? A person currently undergoing chemotherapy and feeling lousy and then told I could “choose better” (like the millionaire) or “chase my cure” or “make my cancer sexy” or “learn to live through cancer?” Does Dr. Fleishman assume that it is possible for everyone to “live through it,” if they really pulled out all stops? No, once again, from good intentions comes a further proliferation of the positive twist on cancer, and the opportunity for growth, for eating better and for getting into better shape. But this wall does not speak to any of the experiences I witnessed. It does not speak to the awful reality of metastatic disease or the profound sense of living liminally – living between life and death – that metastatic disease creates. This thesis is about that reality.
Introduction

June 11, 2012

I am at a “cancer survivorship” event at Lady Ann’s. There is a panel of speakers: the hospital CEO, several clinicians, a well-known doctor who has a show on public radio, and a comedian who survived cancer, among others. The most commanding speaker is a petite, attractive, blonde woman. She is an American nurse who survived breast cancer. She begins by telling us that her talk will be about “living well, because of cancer, not in spite of cancer.” She says that if she could, she “would choose to have cancer again.”

She spins a powerful and familiar tale. She led a normal life, was a single mother raising a great son, working in hospital as a nurse administrator when she was diagnosed with breast cancer. Even though she is a nurse, her experience of the health care system was less than ideal, with several “bumps” along the road. For example, on the day she was scheduled for a mastectomy, she insisted that she read her pre-op report and found out that she was incorrectly slated for a double mastectomy. She gives a comical description of the stereotactic biopsy machine, deploring that it only has one hole for “one boob,” and joking, “Most of us have two!” She recounts how having cancer gave her a much lower threshold for looking good. She would go to the grocery store, without a shower and without any makeup on, and people would say, “You look fabulous!” As long as she wasn’t dead, all she had to do was “be breathing” in order to incite this similar comment from people she ran into.

She is a powerful speaker and her story moves me to tears at times. I notice that she is also moved to tears by her own tale. But as she winds towards her conclusion and begins to expand on the “silver linings” that cancer revealed for her, she starts to lose me. After 17 months of fieldwork at Lady Ann’s, I find this line of argument – that she is “better off” for having experienced cancer – particularly appalling. Because I am annoyed, I become distracted from her narrative, and it begins to lose its emotional pull. I start to notice other details. For example, I note that she is wearing a cordless microphone – the kind that attaches to her head and curves around to sit in front of her mouth. And something about that microphone bothers me. It reminds me of Tony Robbins or one of those motivational speaker types who splash their faces all over their book covers. Suddenly, I come to the late realization that this speech is very much rehearsed. She is dramatically re-enacting her experience, but it is a particular kind of drama: a performance of cancer survivorship.

In the question period afterwards, a young woman with a head of blond hair stands up and asks, “Where is the room for living with cancer as a chronic illness?” She says that she was diagnosed with ovarian cancer at 20, and is going through her second recurrence now at 32, and that her reality is missing from the discussion. I notice the room bristles a little – she is changing the tone of the discussion from positive reflections on cancer to the reality of living with still active disease. The nurse makes an attempt at a response by talking about the importance of “listening and hearing stories” so the health care system can better fit people’s needs. Then another audience member stands up and reveals that she has been dealing with breast cancer for the past year, and it has been “going pretty well,” but what she really wants to know and no one, including her oncologists, will talk to her about is, “What happens if it comes back?” She says
she finds it very disheartening to be “living your life in 6 month chunks,” which is how she interprets the message from her oncologists. She receives an odd response from the comedian who talks about how important it is to talk to family, completely evading the substance of her question, which is the recurring nature of cancer.

In fact, the panel does not seem to know how to respond to any questions they are asked, if they deviate from the script of “celebrating survivorship.” And suddenly I get it – they have no idea. The people on the panel who had faced cancer were able to live through it and to walk out on the other side of it. The nurse’s opening sentence was immediately revealing of that difference. Saying she would “choose” to have cancer again identifies her as a person without cancer. The sharing of her emotional story and challenges with the health care system seem to suggest, “Look, I’m just like you,” but in reality, the fact that she lived through cancer to tell her story (and travel in the U.S. and Canada, sharing that story) marks her as different. I recognize several faces in the room, and know they are living with incurable, life-threatening cancer. For them, cancer is not a “silver lining” that helped them to re-evaluate their lives and priorities; cancer continues to threaten their very existence. One cannot “live better” if one is not living.

Yet again, as I have many times throughout this fieldwork, I am confronted with the reality that patients with advanced disease face: they are left out. This event was billed as open to all cancer survivors, and cancer survivorship at Lady Ann’s is defined “from the moment of diagnosis forward” for patients, and includes their family and friends as well. Yet there was nothing in the event that dealt with the reality of those who would not leave cancer behind. Later, I meet and interview Olivia, the young woman who asked about living with cancer as a chronic illness, who confirms this.\(^1\) She tells me that she found out that some of her friends in an ovarian cancer support group did not go to the event “because they looked at the agenda and they looked at how it was being presented and they were like: ‘Screw this. There’s no place for me here.’” She continued by saying that the event organizers would never get this feedback because, the people who don’t agree with that approach and who don’t like this – this “Ra Ra cancer, gift, survival, look for the silver lining, things are so much better in my life now and I see more clearly” – don’t go. They don’t go because it’s frustrating and it makes them irate and they aren’t included in the conversation.

And that is why the culture of cancer isn’t being questioned or condemned, because the people who are in a position to do that are dying or they are so angry and kept out of that they don’t try to infiltrate it because it just pisses them off so much.

June 1, 2011

Today I spent from 10:30 am until 2 pm with Mary, a mother of four in her fifties, who has stage IV non-small cell lung cancer. She was here today for an outpatient palliative care appointment with Dr. Cho. I find her sitting in the waiting room of the breast clinic, with her oldest son.\(^2\) She gives me a bit of an update, since I saw her last on May 2\(^{nd}\). She tells me she just finished radiation last week. I was surprised because I thought she was almost done last time I saw her. She said yes, she had expected to be done earlier but they kept adding on days. By now she has had 40 different radiations, and many treatments per area to the leg, chest, and arm. She tells me that her fingers are working again. The last time I saw her she had lost feeling in three fingers of
her left hand, due to a growing metastasis in her upper arm. She had pushed for them to radiate there as soon as she began treatment in March, but it was only in this last round of radiation that that area had been targeted. In addition to receiving radiation, she had chemotherapy in there as well. She says that she thinks she did “pretty well” on that. At the end of this update on everything she has received in the past month, she says, “I wanted to be aggressive and I need to be because this disease is very aggressive,” immediately followed by, “But it doesn’t know who it picked its battle with.”

Today, she has a very sore throat, can hardly eat or swallow (even liquids), and is walking with a cane. She is worried about some new lumps, which have appeared on her back. She is wearing her wig, which looks nice. She tells me she is here for the “Pain clinic” (very interesting: all day I notice she does not use the words “palliative” although Dr. Cho uses it a few times). She doesn’t realize until we are called into the consult room that she has met Dr. Cho before, when she was admitted to the inpatient palliative care unit over the May long weekend for pain control. She says that the pain then was so bad that she could not even tell where it was coming from. She shows me her pain pump that she got during that admission and says it seems to be helping a lot. She says she is “much better now,” except for her throat.

But today does not provide her the pay-off she was hoping for, after submitting herself to all of those treatments. I go with her into the palliative care appointment, and then onto the lung clinic, and then sit through a consult with a clinical trials’ nurse. This is a long, trying day, as Mary and her son have to deal with the news that all the standard treatments she has been on are not working, and now the lung team’s recommendation for her is a clinical trial.

Later, at the end of the day as we are walking out of the last consult, 3.5 hours after I first sat down with her in the waiting room, she says something like, “I’d like to see how you are going to incorporate that into your data.” I don’t know what to say. There are no words to palliate the ‘knocking down’ she has just received. I just rub her back slightly. By the time we have neared the doors, she says another positive thing like, “I am still determined to keep fighting this” or “I will keep doing what I can to fight this,” but I notice that this time she seems kind of disheartened, or deflated.

The problem of advanced cancer

This thesis is about living with advanced cancer. It follows the lives of people like Olivia and Mary, who are diagnosed with a cancer that is “unlikely to be cured” (Canadian Cancer Society (CCS) 2010:3). These are cancers that have advanced beyond their early stages, and are sometimes given alternate labels, such as “secondary, metastatic, terminal and progressive cancer” (CCS 2010:3). This means that even if patients receive one or multiple rounds of the standard treatments of chemotherapy, surgery and radiation, there is a high probability that they will still die from their disease. Incurable illness presents a particular problem due to a combination of cultural meanings and values, both within biomedicine and within society.

Drawing on 17 months of ethnographic fieldwork conducted in one Canadian cancer hospital,
referred to here as Lady Ann’s, working with patients with lung and gynaecological cancers, the dissertation aims to answer the question: What is life like for patients with advanced cancer as they live with their disease, post-diagnosis? Although its focus is primarily on the patients, it also includes the experiences of other people who regularly come in contact with them – namely, doctors and nurses at the hospital, and patients’ family and friends.

The dissertation explores some of the challenges and tensions produced from living with a diagnosis of advanced cancer. For example, patients are advised to “live in the moment,” but this is a very challenging directive to follow as it is interlaced with the connotation that they are being entreated to do so because their futures are uncertain. Similarly, patients have to muster enough hope to be able to endure the emotionally and physically demanding treatments, but not so much hope that they believe that the treatments will actually cure them of their disease. These entreaties require them to straddle both the worlds of oncology and survivorship and the worlds of death, dying and palliative care, which my findings indicate is extremely difficult to withstand on a day-to-day basis. I argue that advanced cancer is a kind of ‘liminal’ or transitional space, an ambiguous territory that exists between the hope for a cure and the imminence of death. This ambiguous position is made even more challenging since contemporary cancer culture in North America tends to highlight only cancer survivors or people who have ‘lost their battles’ from cancer, rendering the struggles and experiences of patients who are living with advanced cancer but not currently dying from it, both culturally silent and invisible.

The cultural construction of cancer early in the 21st century is also a central motif of the dissertation, for cultural ideas about cancer have traction; they inform patients and their loved ones about what they are allowed to feel and how to respond appropriately to the diagnosis and they communicate social roles and potential identities that are culturally sanctioned. These cultural ideas and stereotypes about cancer form a powerful “exoskeleton” (Kleinman 1988:22) around patients, which they must deal with at the same time as they deal with their diagnosis. For example, Mary’s story illustrates that she is trying to embody the role of the “Fighter” in response to her diagnosis. Yet despite doing everything she can to “fight the battle,” cancer continues to grow and to spread to other parts of her body. Ultimately, no matter how hard Mary subscribes to the cultural figure of the “Fighter,” she cannot transform her present reality. Similarly, Olivia learns at the survivorship event that, while it claimed to include all patients “from the moment of diagnosis forward,” in practice it failed to accommodate a patient like herself who continues to live with active disease. Although the exclusion is cultural, its
consequences are individual, and must be dealt with by patients like Olivia and Mary, when they cannot fit their experiences to the cultural moulds they are offered. Since cultural ideas are often internalized to the extent that they seem objectively real (Sobo 2000), throughout the thesis I work to expose these cultural constructions of cancer, and to demonstrate the various ways they are being contested.

Although certain kinds of cancer patients are highly visible in our culture, as Olivia observes above, advanced cancer patients are often “missing” from the discussion. I found Olivia’s experience that day typical: patients with advanced disease are often excluded because people cannot distinguish between serious, incurable cancers and early stage, curable ones. This is partly due to the fact that patients with advanced cancer often look very much like non-sick people and thus ‘pass’ as the healthy. Before Olivia opened her mouth, she would have passed as a healthy young woman (her head of blond hair was actually a wig). No one in the room would ever have guessed what she had gone through – three rounds of chemotherapy, four abdominal surgeries, loss of her fertility at the age of 20 – had she not forced her actual experience into the room. Following Casper and Moore (2009:3), I argue that with respect to cancer, there are “the bodies we see, and some that are not there,” and attend to this “politics of visibility” for advanced disease. I contend that this invisibility has much to do with patients with advanced cancer status as external or “anomalous” (Douglas 1966) to the categories that contemporary culture recognizes, which often rely on stereotypes of the fighter, the survivor, or the person who lost his battle. In order to counter that trend, I present patients not as caricatures often dichotomized as ‘strong’ or ‘weak’, ‘fighters’ or ‘non-fighters,’ but as real people who know what it is to live daily with advanced cancer. Their experiences are at times inspiring, saddening, comical, frustrating, frightening, sickening, numbing – in other words, they inspire a diverse range of emotional, intellectual and physical reactions.

Although all the patients in my sample were diagnosed with incurable cancers from the outset, I observed very few conversations that were actually about death and dying. Death and dying came up in the hallways of clinics – between staff members, or sometimes in conversations with me regarding the eligibility of a patient for my study, but very rarely during consultations between oncologists and patients. Similarly, in my own conversations with patients and families, death was surprisingly absent. Conversely, patients were caught up in the world of treatment, often oscillating between oncology, treatment and testing appointments during their visits to the hospital. Before I began fieldwork at Lady Ann’s, I thought that patients
were perhaps not being told that the disease is incurable, or is as serious as it is. But in the clinics I saw everyday that patients are told, sometimes in very plain terms, that they are dealing with a cancer for which there is “no cure.” Regardless of the subtle differences in delivery, no oncologist says, “This is curable” or “You will get past this.” Notably, however, oncologists do not say either, “You have only 12 months to live” or “You are dying.” I observed that between the oncologist’s admission of “no cure” and her next sentence that focuses on “available treatments,” there is still enough room for patients to “emplot” (Mattingly 1994, 1998) the possibility that they will live. Patients endure a rollercoaster of emotions and physical symptoms produced by cycles of treatment and follow-up care, that has only two possible outcomes: still living with disease, or dying from it. That is what happened to Mary. She did everything she was told – she fought, pushed, and clawed her way through treatment after treatment – and yet she still died, less than 5 months after being diagnosed at Lady Ann’s.

Importantly, patients with advanced disease do not see themselves as dying because no one around them talks to them as if they are. In the consulting room, ‘treatment talk’ supersedes; questions focus on available treatments, side effects, and other routine aspects of care like exams and tests that must take place before a patient can go forward with a cycle of chemotherapy. While radiation therapy has existed since the early 1900s, and surgery well before that, the advent of chemotherapy in the 1950s has allowed for treatments to be given right up until the end-of-life (Baszanger 2009). But like the treatments that came before it, chemotherapy is also very limited in curing people with aggressive disease. So while the existence of chemotherapy was a source of hope for all patients, as it gave them ‘something to do’ in the face of a frightening and serious diagnosis, the focus on treatment displaced other important conversations, such as what would happen when the treatments ran out, which they inevitably did. At Lady Ann’s, I observed that so much attention is put towards living and maintaining life, that there is no space for death to enter the conversation (Kaufman 2005; Anderson 2007). This means that death floated around on the periphery until it needed to be talked about, and forced itself into the conversation only when a patient had declined so significantly that it could no longer be avoided.

Despite the availability of a specialized outpatient palliative care service at Lady Ann’s, a few of the patients I followed never received referrals or some did too late in their care to receive much benefit. In recent years, palliative care has seen unprecedented growth and public support in Canada, and international guidelines advise palliative care referral early in the trajectory of
life-threatening illness in order to improve symptom control, quality of life, and to initiate end-of-life conversations (Zimmermann et al. 2008; Addington-Hall 2007). Recent large-scale qualitative and quantitative studies have demonstrated that early referral to palliative care has resulted in improved mood, quality of life, and even longer survival for patients with advanced cancer (Zimmermann et al. 2014; Temel et al. 2010). Unlike in the U.S., where patients with cancer receiving health insurance through Medicare might have to agree to stop all anti-cancer treatments in order to receive hospice benefits (American Hospice Organization 2015), the public health care system in Canada allows patients to receive chemotherapeutic agents at the same time as early intervention palliative care. Patients at Lady Ann’s were much more fortunate than many patients with incurable illness living in other communities in Canada, where specialized palliative care may not even exist. At Lady Ann’s a confluence of factors were in favour of early intervention palliative care – access to an outpatient and inpatient clinics and specialized doctors and nurses, a highly supportive research and clinical environment, and growing public support – and yet it was not the case that all the patients in my sample benefitted from early intervention palliative care. As one palliative care doctor at Lady Ann’s observed, “We are still getting patients much sicker than they should be.”

In the literature, this problem is often attributed to a failure of oncology to work with palliative care: a general resistance on the part of oncologists to refer their patients to palliative care lest they give the impression they are “giving up” on them (Baider and Wein 2001). It has also been suggested that there are “definitional and boundary problems” (Clark 2007:437) in terms of the supportive care that oncologists provide and what palliative care physicians offer; in other words, there is potential role conflict and professional disagreement over who is in charge of the patient’s care. Some of these professional issues may produce what is now a well-recognized in medicine: patients with advanced disease receiving aggressive care right up until the end-of-life, leaving little time or space to prepare for death (Baszanger 2012; Earle et al. 2004, 2003). However, a narrow focus on “oncologists’ resistance” or “aggressiveness of care,” or on “boundary problems” between professions falsely simplifies a complex problem, and fails to take into account the powerful forces in contemporary culture that also support a persistent focus on treatment at the expense of preparing for death (Foley 2001). I will show throughout the dissertation that there is not one person or group of people (i.e., oncologists, patients) or system (i.e., hospital bureaucracy, public health care) that is responsible for the overarching focus on oncology, but rather a range of people, institutional dynamics and practices operating together
that make it very difficult to face the harsh reality of incurable disease.

Thus, patients learn to reside in the interstices between oncology and palliative care, a space I call the liminal space of advanced disease (Turner 1967, Van Gennep 1960 [1909]). In this space, patients consider the possibility that they will die, at the same time as they remain highly interested in trying to survive. As Hitchens (2012:14) has wryly noted, “this is a distinctly bizarre way of ‘living’ – lawyers in the morning and doctors in the afternoon.” My research builds on scholarship examining the challenge of existing in this kind of “double awareness” (Rodin and Zimmermann 2008; see also Jain 2007; Nissim et al. 2012; Frank 1995; Stoller 2004; Anderson 2007; Little et al. 1998), by ethnographically demonstrating what that kind of life actually looks like. As such, the substantive chapters of the dissertation explore different features of patients’ liminality: how the hospital is both a space and place of containment, which tries to ‘hold in’ and ‘hold off’ advanced cancer, but is ultimately limited in its ability to contain cancer due to its permeable boundaries (Chapter 2); how patients work hard to craft multiple, possible storylines for themselves in order to counter the life containing storyline of an incurable diagnosis (Chapter 3); how treatment becomes a way of life rather than one stop on the road to recovery (Chapter 4); and how patients move through various modalities of time, rather than just “live in the moment” which is what the literature on temporality and cancer seems to suggest (Chapter 5). The experience of liminality brought on by advanced cancer is compounded by the discourses of scientific progress and ‘survival’ that increasingly frame the disease.

**Medical progress and the new discourse of survival**

Nov 21/2011. Elizabeth, a woman with metastatic ovarian cancer, is telling me about a conversation she had with a friend of hers after she finished chemo. Elizabeth had been particularly frustrated to find out that the CT scan she had after she finished treatment was not able to detect whether the cancer was “still there,” which means she endured 6 months of chemo and is unsure whether or not she still has cancer. She recounts for me her friend’s reaction to this post-chemo news: “A friend of mine is like, ‘With all the medical advancements we’ve made, and all the technology and all the research money we’ve put into it, they can’t tell you (incredulous)?’ I said, ‘Apparently not.’”

In some ways, the experience of advanced disease early in the 21st century in Canada may be somewhat unique. Precisely because we live in a time of great progress in medicine, when we are always hearing about the latest developments in health and technology, and in a country in which many things can be done, the lack of curative hopes and technological limits of cancer can
seem incomprehensible. As Elizabeth’s friend articulates, we hear about the successes, the search for a cure, and the request for funds, but we do not hear about situations of profound medical uncertainty like Elizabeth’s, where despite the existence of a technology like a CT scan, and her access to it, it cannot provide the information she needs in order to move forward in her life.

Increasingly, cancer is framed as a disease that we are gaining on, and getting closer and closer to controlling. This has not always been the case. As McMullin and Weiner argue, “the historical inability to treat or cure cancer is emblazoned in our collective memories, reminding us that few people survived most cancers before the 1980s” (2008:12). According to the Canadian Cancer Society, survival in the 1940s was only 25%; now the likelihood of surviving 5 years post-diagnosis is 63% (2015). It is not uncommon to see papers beginning with introductory sentences like the following: “Once a virtual death sentence, cancer today is a curable disease for many and a chronic disease for most” (Aziz and Rowland 2003:248). Granted, such statements are often juxtaposed with an admission that “cancer remains, frustratingly, a rapidly fatal illness for some” (Rowland 2008:361). However, the authors often focus on the optimistic side of that story – the “many” who might be cured and the “most” for whom cancer will be a chronic disease. The possibility of fatality is grammatically subordinated, as are the people who still die from cancer. But they are not a small number. Cancer is the leading cause of mortality in Canada, and current mortality rates indicate that 1 in 4 Canadians will die from cancer (24% of women and 29% of men) (CCS 2015). The responses of patients in my study indicate that all the celebration of those for whom cancer is today a curable or chronic disease further marginalizes those people for whom cancer remains a fatal illness.

According to anthropologist Francine Saillant, this new North American discourse on cancer that “centre[s] on survival rather than death and articulate[s] themes of maintaining hope and morale” (1990:82) emerged from political and institutional changes in the U.S. in the late 1970s. Based on her own ethnographic fieldwork with cancer patients in Quebec, Saillant (1990) points specifically to the war on cancer launched by President Richard Nixon in 1971, which posited that with enough money and research a cure for cancer would be found. This positive twist on the cancer story – where cancer is no longer only associated with death, but rather suddenly also with the possibility of living on – is often celebrated in the literature as the product of medical advances such as improved “screening, early detection and treatment” (CCS 2015). Yet, as medical historian and internist Robert Aronowitz (2007, 2008, 2009) argues, the improvements in survival rates for breast cancer in the mid-twentieth century resulted not from
more effective treatments and prevention, but rather from changes in people’s health-seeking practices and better diagnostic techniques. His research into breast cancer rates from the 1920s until the 1980s reveals that, with the dawn of public health campaigns encouraging women to go and get tested for breast cancer, the number of diagnoses rose not because there was more breast cancer in the population, but because women were seeking testing in much higher numbers than seen before. He argues that mortality did not change during the campaign; instead, given the higher numbers of women being tested, the ratio of women who died of breast cancer to those diagnosed with breast cancer decreased rapidly (Aronowitz 2007, 2009:4). Thus, while the rise of the new discourse is often credited to better treatments, in fact what we have done is capture a greater number of potential ‘patients’ with more precise means of diagnosis, including some who may never have suffered any symptoms of their cancer (Aronowitz 2007, 2009).

The new discourse of survival thrives on increased survival rates and success stories. Aronowitz cites an article by Feinstein et al. (1985), which showed how changes in technologies for diagnosing cancers and separating them into disease specific “stages” resulted in what seemed to be improved survival. Feinstein et al. argued that new cancer technologies, such as the CT scan, allowed for cancer to be diagnosed more precisely (i.e., to see metastases that before would have been missed), resulting in a downshifting of many cancers. For example, a cancer that was a stage III C was reclassified downward to a stage IV. This meant that stage III cancers suddenly looked more survivable, but so too did stage IV cancers because that category now included a diagnosis that was less severe than what had previously been seen at stage IV. In other words, this meant that survival was improved in both stages “because downshifted cases were on average the worst of the original stage but the best of their new stage” (Aronowitz 2008:4). Aronowitz argues that it is precisely this kind of framing that is used to suggest improved cancer survival rates, but they are based on a false impression. Furthermore, these misleading figures are used to justify more investments in diagnostic testing and technologies, which give the impression of more “apparent progress” (Aronowitz 2008:4), creating a kind of tautology when it comes to survival statistics.

Advanced cancer displays the prowess of medicine juxtaposed against its deep and foundational uncertainty (Fox 1959). Instead of recognizing these limits to the progress narrative, we speak of further developments in cancer, like “personalized medicine.” This idea sounds nice intuitively, but the general population has such a poor level of understanding of the basic science of cancer and of genetics, that the statement is almost meaningless. At Lady Ann’s, we speak of
“conquering cancer in our lifetime.” A few of the patients I followed have wised up to this message, asking “Whose lifetime?” As Melody, a woman with ovarian cancer said to me one day, “I’d have to be a baby for that to matter to me now.” Rather than promoting increasing survival statistics as the sign of a hopeful future for cancer, the public might be better served by campaigns that take pains to demonstrate the complexity of the disease, and the many facets of cancer that scientists still do not understand.

Defining cancer culture

The thought of cancer never entered my head and she never mentioned it. I don’t think there could be such a revelation today without some kind of question, some probing about whether it was or it wasn’t. Cancerous or benign – we would want to know at once. The only way I can explain our failure to speak of it was that there must have been a cloud around that word like the cloud around the mention of sex. Worse, even….The word cancer made you think of some dark rotting ill-smelling creature that you would not look at even while you kicked it out of the way” (Munro 2012:273)

In writing about her experience of having a small growth “the size of a turkey’s egg” removed at the same time as her appendix when she was a child, Canadian writer Alice Munro provides a useful illustration of how the culture of cancer has changed in less than 100 years. The violence of her illustration is telling; when she was growing up in the 1930s, cancer was both unspeakable and vile. We have moved from a time when cancer was “obscene,” (Sontag 1990 [1978]) “ill-omened, abominable, repugnant to the senses” (Mukherjee 2010:37) to “crazy, sexy” (Carr 2008) and the catalyst for “post-traumatic growth” or even a “gift” (Bell 2010). Evidence of cancer as a central preoccupation is present in numerous forms of contemporary culture: from the ubiquitous Pink Ribbon culture and its associated “kitsch” (Ehrenreich 2001, 2008) and the branding of a range of products that you can buy for the cause of breast cancer (e.g., Chia pets, Ford cars, lighters, toilet paper), to the numerous runs and other “thons” you can complete for cancer research, many of which exude a joyous and celebratory vibe. Even the realm of politics is not immune, as the 2011 public mourning for late Canadian politician Jack Layton demonstrated; Layton died of cancer, but managed to relay a message of hope and optimism even in death. Once seen as a “dreaded disease” (Patterson 1987) and a disease of “repression” (Sontag 1990), cancer has recently morphed into something no longer to be ashamed of, but perhaps even to be grateful for as the literature on post-traumatic growth attests (Bell 2010:586).
The anthropomorphizing of cancer has also reached new heights; cancer is no longer just a “disease” (Rosenberg 1989) but a “Bully” (CCS 2015) and an “Emperor,” recently the subject of a biography by Dana-Farber oncologist Siddartha Mukherjee (2010).

Cancer culture is especially present in places such as Lady Ann’s, a site of congregation for people who are concerned about, living with, and working on cancer. Tertiary care or regional centres like Lady Ann’s, which only see patients with cancer, have become more widespread in Canada. Increasingly, these centres or hospitals offer services that are beyond the traditional biomedical model of disease; for example, at Lady Ann’s, a patient can receive psychosocial care, have chaplaincy consultations, and attend nutrition and exercise classes in the survivorship centre, in addition to receiving treatment and follow-up care from their oncologists. Lady Ann’s opens the door to a distinct “world of cancer,” as a patient remarked to me one day in reference to all of the classes she could take, supportive services she could access, and new people she could meet as a result of coming to reside in this unique world. A different patient similarly commented, “It’s like a world I never knew,” conveying his sense that only recently he had been oblivious to this culture and now it had become his daily reality.

North American cancer culture is all of these phenomena – the marathons, the pink teddy bears, the cancer centres, the survivorship classes – things that are visible and tactile or events that can be experienced – in addition to more abstract notions like the discourse of survival (Saillant 1990) that increasingly frames the disease. As anthropologist Sarah Lochlann Jain has argued, cancer “materializes as much in cultural interchanges as in its biological form” (2007:78). Like any culture, the culture of cancer is polyvocal, contested, and flexible. I use the term culture to indicate the patterns and “broad habits associated with certain contexts and questions, that give a certain consistency to [people’s] actions” (Kiefer 2007:126). In the contexts this thesis explores, culture does not imply the “other” (Sobo 2009:111), as it so often is used in medical research to designate a person’s ethnicity, race, religion or language, or to describe a “barrier” to good health care in an increasingly multicultural population (e.g., Vincent 2001). Rather, I employ the term to draw attention to the aspects of social life that rest on meanings and values that are shared “in the moral universe in which individual action is taken” (Kaufman 2005:329). Following Wardlow (2002), I recognize that the beliefs, behaviours and practices I am associating with the culture of cancer are not rigid or prescribed, but can be taken up in ad hoc ways by its members. For example, Pam, a woman with metastatic ovarian cancer rejected the idea that family and friends should also be called “survivors”; she found it insulting
to suggest that what they went through was equal to her experience as a patient. Even though she disagreed with that aspect of survivorship, the “culture of survival” was very present at Lady Ann’s; in fact, Pam was sitting in the gynecology waiting room when she first saw a poster proclaiming that survivorship included all patients and their support networks.

Although Western medicine has often presented itself as a “culture of no culture” (Taylor 2003), based on the conviction that its knowledge is external to culture because it describes a scientific reality, here I treat medicine and science as social enterprises, whose knowledge and practices are products of their social world (Lock 1988). The culture that is present in the hospital is a reflection of broader North American cultural values, including active treatment (i.e., ‘doing something’ in the face of disease even if that something will not prolong life), extending life as long as possible, regardless of its quality, and individual power and responsibility for shaping one’s future (Kaufman 2005). For example, physician Pauline Chen notes that when clinicians care for patients approaching the end-of-life, behaviour that might easily be perceived as inhumane or cruel, such as “evading difficult patient conversations and ramping up treatment in terminal diseases” are viewed as entirely rational to the “foot soldiers in the clinical trenches” (2007:xiv). As Pam’s poster and Chen’s example demonstrate, the hospital provides a site in which cultural scripts and expectations about cancer come into confluence.

Theoretical and Research Contributions

In examining the culture of advanced disease in one Canadian hospital early in the 21st century, my research draws on and contributes to three bodies of literature: contestations of cancer culture (Jain 2007, 2010, 2011, 2013; Saillant 1990; Stacey 2010); the anthropology of the clinical encounter and narratives of emplotment (Finkler et al. 2008; Mattingly 1994, 1998, 2009; Mol 2002, 2008); and the anthropology of liminality and classification (Turner 1967; Douglas 1966; Jackson 2005; Murphy et al. 1988; Malkki 1995). In the following sections, I provide a brief introduction to the key theoretical ideas that inform my analysis. In the section on contestations of cancer culture, I first describe how cancer is culturally constructed, and how various continuities in cancer culture have persisted through time, despite some notable shifts or transformations. I then examine several different ‘frames’ for the construction of cancer in the contemporary moment. I detail the kinds of resistance and critiques those discourses have received, highlighting the work of anthropologists, as well as other social scientists and
humanists who have helped to broaden the scope of the discourse on cancer. In the section on ethnographies of the clinical encounter, I briefly review the literature on “communication” in oncology, and demonstrate that these studies often limit their frame of analysis to a very short time of interaction. Instead, I propose that ethnography of the oncology clinical encounter offers an opportunity to explore how communication spreads out over time and beyond the consultation room, and to examine how patients and staff are involved in actively “emplotting” for different possible outcomes. In the section on liminality and classification, I demonstrate how advanced cancer produces a distinct liminal space, between the category of the “sick” and the “not sick”, causing patients to become categorical anomalies. Since patients have no opportunity for reintegration into society except for in death, their liminality makes them somewhat invisible.

I. Contestations of Cancer Culture

The cultural construction of cancer

Disease is at once a biological event, a generation-specific repertoire of verbal constructs reflecting medicine’s intellectual and institutional history, an aspect of and potential legitimation for public policy, a potentially defining element of social role, a sanction for cultural norms, and a structuring element in doctor-patient interactions (Rosenberg 1989:1).

In this section, I outline the contemporary construction of cancer drawing on Charles Rosenberg’s concept of “disease frames.” A prominent and influential medical historian, Rosenberg argued that insufficient attention is paid to the process of defining a disease and offered the important reminder that “a disease does not exist until we agree that it does” (1989:1). Applying this idea to cancer, Rosenberg’s concept prompts an understanding of cancer that not only includes cancer as a biological entity inside the individual body, but also cancer as a cultural construction manifest in the body politic (Schepers-Hughes and Lock 1988). For example, Sontag’s famous and much debated treatise Illness as Metaphor argued that cancer in the 20th century replaced tuberculosis in the 19th century, as the “great incurable” and most highly stigmatized disease (1990). An anthropological framing of cancer begins from the position that health is necessarily a social phenomenon, as a person only knows how to interpret his bodily experience by way of culture (Lock 1998; Kleinman 1988). Whereas cancer is increasingly framed as an individual health issue for which people are personally responsible (because of ‘blameworthy’ practices, such as smoking, poor diet, or lack of exercise or factors
beyond individual control, such as genetic makeup or heritage), an anthropological perspective rejects this narrow focuses and instead examines how the expression of a cancer illness and its healing are linked not only to an individual’s life history, but also to a society’s ways of seeing cancer, and the beliefs it holds about the proper ways to be sick, what counts as sickness, and supports or lack thereof for people with cancer (Skultans and Cox 2000).

Today, cancer is so present in contemporary culture that people begin to make assumptions about what cancer patients go through, even when they have no direct experience themselves. Kleinman argues, “cultural meanings of particular illnesses encase the patient in a visible exoskeleton of powerfully peculiar meanings that the patient must deal with as must those of us around the patient” (1988:22). Similarly, Rosenberg notes that, “each disease is invested with a unique configuration of social characteristics – and thus triggers disease-specific attitudinal responses” (Rosenberg 1989:10). Cancer’s exoskeleton presents itself in a particularly extreme form since cancer is perceived as “the emperor” of all maladies (Mukherjee 2010). For the cancer patient, the exoskeleton is comprised not only of the various stigmas of being ill, but also a heavy burden of cultural scripts and expectations, including: predictions of what will happen to the patient in terms of whether she will live or die, how friends and family should regulate their behaviour around her, how the cancer patient should appropriately respond to her illness (e.g., fight back, pursue treatment, eat certain foods, etc.).

One component of the exoskeleton is well-intentioned advice. Hitchens (2012:28) argues, “in Tumortown you sometimes feel that you may expire from sheer advice,” and cites examples of the “cures, and rumors of cures” that people offered him including macrobiotic diets, chakras, the peach pit cure, and testosterone injections. Cancer patients experience an outpouring of advice derived from the good intentions of others that communicate the kinds of things they should do to get better. For example, chatting in chemo one day, one participant told me about an email she had just received from a well-meaning friend, about “foods that would cure cancer.” I knew she had been living with metastatic disease for several years, and asked “What do you think when you get things like that?” She replied, “How ignorant…I mean, c’mon. It’s almost like saying, “Part your hair on the other side,” pointing to how arbitrary it seemed. As a woman who knew well the gravity of what she was dealing with, she found these kinds of ideas preposterous and this kind of “advice” particularly unhelpful. These ideas only add further layers to the exoskeleton, as a person becomes encumbered with each new suggestion. Not only must the patient deal with the daily discomforts and challenges of her illness, she must now navigate
the myriad popular health articles that touch on cancer. Thus, sharing popular health articles containing diet and lifestyle modifications that a person can do to “cure cancer” disregard the severity of metastatic disease and actually produce the opposite effect than they were intending, as the research-based play *Handle with Care* (Gray and Sinding 1999) vividly dramatizes.¹⁵

Cancer’s exoskeleton can also exert a “dreadful cost” for the person who feels that they must bury their own experiences under “a cosmic layer of cheer” (Ehrenreich 2008:41). King (2006:102) argues that the dominant discourse of breast cancer survivorship “leaves little room for alternative, less positive, understandings of the disease experience and its long-term effects.” It confines or contains cancer experiences to those that can be uttered aloud. Analogously, Conway shows that childhood sufferers of polio were forced to turn their experience into something positive for the March of Dimes fundraising telethons.¹⁶ One survivor, Charles Mee recounts that neither he nor any of his fellow patients at Sherman Hospital were as well as the telethons suggested. Mee says that the culture around polio, “made me live a lie, confuse myself about who I was and what I felt and how life was for me” (1999:93 in Conway 2007:28). Thus, polio’s exoskeleton required that children deny their own experience, and by doing so betray themselves (Conway 2007:29). Similar to the experiences of polio patients, cancer patients who do not conform to society’s expectations feel like the problem, in need of an attitude adjustment, when in fact it is our cultural categories that are in need of revision. Given that the contemporary exoskeleton of cancer is built up of our cultural prescriptions and stigmas concerning cancer, it becomes a kind of ‘cultural baggage’ that people with cancer must carry around. As anthropologists are known for unpacking the elements of cultural baggage and exposing its various components, here I seek to dissect and discard these metaphors, making space for more honest appraisals of experience to enter public discourse.

A brief review of the cultural history of cancer demonstrates that, although some ideas and reactions to cancer have changed significantly in the last 135 years, there have been several continuities. One continuity is the tendency to stigmatize the person with cancer and to “blame the victim,” exhibiting the belief that people are responsible for their own health (Patterson 1987:25). Another is the continued presence of “alternative” treatments and practitioners (what Patterson calls cancer’s “counterculture”), which contrast with what “orthodox” medicine has on offer (1987:20).¹⁷ This counterculture has exponentially expanded in the digital world since Patterson’s study. The goal of early detection of cancer, which is never realized in practice, is another persistent challenge. Patterson demonstrates that especially when there were few
treatments to offer, doctors realized that early detection might be the only possibility for cure for advanced disease. In 2015, the problem of advanced cancers being “often deep and slow-growing and painless in the early stages” (Patterson1987:29) continues to thwart curative goals, and delays diagnosis until cancer has already metastasized. Lastly, the “desire of both physicians and patients to maintain hope and avoid stark confrontations with mortality” (Aronowitz 2007:5) remains a deep-seated continuity, leading to the kinds of problems of liminality that this thesis investigates.

Within the framing of the contemporary culture of cancer, I draw broadly on two types of sources: the work of anthropologists and social scientists who use ethnographic methods and social theory to study cancer; and the work of academics and public intellectuals with a history of cancer who often draw on their own personal experience to challenge cancer culture. Within the anthropology of cancer, three important scholars stand out: Saillant (1990), Livingston (2012) and Jain (2007, 2010, 2011, 2013). I have already discussed Saillant’s (1990) important contribution in naming the “new” discourse of cancer survivorship that emerged in the 1970s. Recently, Livingston’s (2012) work demonstrated that the majority of the research on cancer in the U.S. and in Canada, and countries of the global north, have nothing to do with the experience of cancer in Africa – and especially in Botswana – where “cancer without oncology” means that many patients do not receive anything close to adequate treatment. One example she provides is telling. While in sessions I sat in on at Lady Ann’s, I observed that the term ‘palliative care’ is tiptoed around by some oncologists and does not enter the discussion until far too late, Livingston points out that palliative care carries no such stigma in Botswana, as people are often arriving at the clinic far too late for treatments with any cure potential. Over 50% of women with breast cancer arrive at Princess Marina Hospital with “massive, fulminating, necrotic breasts,” and cancer so advanced it is inoperable; the surgeries that cut off these advanced tumours are referred to as “toilet mastectomies” (Livingston 2012:53). Within this context, care for the dying and any relief of patients’ suffering is always seen as a good thing (Livingston 2012). Jain, who has a history of cancer, has also used the traditional methods of ethnography to examine how cancer fits with American culture. While her previous work points to the problems of “living in prognosis” (2007), the “ghosts” of clinical trials (the people who enrol in trials and die but are never talked about) (2010), and “cancer survivorship” more broadly (2011), her recent book (2013) ties together these themes into a multi-faceted exploration of American cancer culture. My work aims to follow these same critical perspectives, and to add to these by
focusing in-depth on the experience of advanced disease at a top cancer hospital, in a country where all patients have access to anti-cancer treatments because of Canadian Medicare.\textsuperscript{20}

The second body of literature I reference is a scholarly literature, but often not based in social science research. Often part memoir, part academic treatise, these works begin from the perspective of an affected author – a narrator who has experienced cancer herself (e.g., Conway 2007; Stacey 1997; Frank 1997, 2002; Hitchens 2012; Stoller 2004, 2009; Ehrenreich 2001, 2008; Mullan 1985, 1990). Having survived their experience with cancer, these authors then turn their critical eyes towards the disease and take it up as subject. Although some of these authors are social scientists, they do not often draw on original research, but rather on previous research, or only on their own experience to discuss cancer. Paul Stoller’s (2004) book reflecting on learning to be a sorcerer in Niger, and its parallels with his own experience of entering the world of the sick by getting cancer treatment in the U.S., is a good example of this body of work. Having faced death themselves, they see cancer differently than a person who has not. However, many of these authors lived through the threat of cancer, managing to take up their regular lives again and write books about the subject (with the exception of Hitchens, who wrote Mortality while he was dying). Thus, the authors are not in the same position as the patients whose lives I am describing. Some of these authors offer scathing critiques of the culture of cancer (e.g., Hitchens 2012; Ehrenreich 2001, 2008) or use a broad brush to demonstrate the flaws in the contemporary culture.\textsuperscript{21} But they often do not conduct social science, systematic research – there are no interviews, no fieldwork – and rely more heavily on secondary sources, in addition to their own experiences.\textsuperscript{22} As medical historian Barbara Clow (2001) has shown, Susan Sontag similarly did not base her famous book on illness metaphors on any systematic research. Clow revisits the historical period on which Sontag based her book, and finds evidence to challenge some of Sontag’s most renowned claims (2001).

My research aims to balance those critiques to some extent, by providing original research that enters into a discussion with these personally informed memoirs and academic pieces. While they offer important insights, they are grounded in author’s experience first, and deal with others’ experiences as points of comparison. You will see over the course of my dissertation that my research participants share some of these experiences and feelings but not all of them. For example, these personally informed pieces may fall short in recognizing how nuances and dualisms are almost always present and how even in the same moment, a “cultural narrative of triumph” (Conway 2007) can be both inspiring and challenging, and can produce contradictory
emotions within the same person. Thus, I draw on original research collected for the purpose of an academic project to recount patients’ stories, but infused with the “experience-near” perspective of cancer that authors with a personal history provide.

In the following sections, I briefly sketch out some of the layers of cancer’s exoskeleton, by examining the principal ways that cancer is framed in the contemporary moment. These methods including framing cancer: as corporate cause; as metaphor; as agent; as gift; as survivorship; as chronic disease; and as source of entertainment. I demonstrate that, although these various discourses surround the patient with advanced cancer, they all tend to remain somewhat silent on how they might actually pertain to a person living with incurable disease. This gap between their experience and the discourses that surround them creates a problem of alienation for patients; “solitude is created within the interstices of the contradictions of existence and institutionalized norms transmitted by discourses, values and tactics” (Saillant 1990:101). In other words, I am arguing throughout this thesis that patients with advanced disease have been excluded from contemporary culture with a scaffolding that we ourselves have built.

**Cancer as corporate cause.**

Cancer fundraising and corporate sponsorship activities form the most visible layer of the cancer exoskeleton today. We have moved from a time when women walked the streets in the 1970s and 1980s to draw attention to the environmental causes of breast cancer and to the large corporations that might be responsible for increasing its incidence (Kaufert 1998; Klawiter 2000) to a time of “corporate sponsorship” where breast cancer is the “apple-pie” cause (King 2006:111) everyone wants to identify with, and many multi-national corporations that in fact manufacture known carcinogens also raise money for cancer efforts (e.g., Avon make-up, Ford cars) (Pool 2010). Although the pairing of industry and cancer is at its greatest height today, there has been a longstanding partnership between those who were trying to attract attention to cancer research and business interests (Mukherjee 2010). Samantha King’s book, *Pink Ribbons, Inc.*, focuses explicitly on “organized giving” to breast cancer; she argues that breast cancer is “no longer a political struggle, but a consumerist one” (2006:117). Corporate sponsorship hinges on the fact that “there’s nothing even vaguely controversial or political or even provocative about a visible declaration of concern about cancer” (Walker 2004:23). Anthropologists and other social scientists have critiqued how, increasingly, these movements displace actual patients or people living with the disease, in favour of promoting a cause and
making a good name for a business (Klawiter 2000; Batt 1994). For example, in noting how many ridiculous “tchotchkes and accessories” one can purchase in the name of breast cancer (including clothing, pins, scarves, candles, night lights, bank checks), Ehrenreich wryly notes that she could not help noticing that the “existential space” provided by pink ribbon culture “bore a striking resemblance to the mall” (2008:23).

The dominant ideology that directs much of the fundraising, research, and corporate branding of cancer is often aimed at the pursuit of a “cure”: thus patients with advanced disease often fall out of the purview of these activities. In my dissertation, I draw on these critiques and attempt to expand the frame of analysis to include cancers that are not often the target of business or industry. My findings indicate that this exclusion functions as an occlusion that actually increases the stigma and invisibility of those diseases. For example, Jennifer, a woman with metastatic endometrial cancer remarked one day, “breast cancer is the cancer to get.” She felt that she was “being left out” because she did not have breast cancer – “I just have this,” she said apologetically, pointing down towards her belly. It is no coincidence that Ovarian Cancer Canada used to tour a presentation in hospitals and schools called, “The disease that whispers.” Ovarian cancer has a much higher mortality rate than breast cancer, and yet it has nowhere near the level of philanthropic support that breast cancer has achieved. I attended several walks and other fundraisers for ovarian cancer, and noted a relative absence of teal (the colour of ovarian cancer) products in comparison to the number of pink products I had seen at breast cancer events.

If ovarian cancer has less of a limelight than breast cancer, lung cancer fundraisers are practically non-existent. I never attended or heard about any activity that was raising money for lung cancer, although a national society does exist. Unlike breast cancer, which has often been portrayed as ‘pretty’ or even ‘sexy’ (Ehrenreich 2008), lung cancer is actually quite ugly, as the ads that became required by Canadian law in the 2011 on all tobacco products demonstrated.

Thus, despite the many justified critiques of the cancer “brand,” in my work I attempt to draw the reader’s attention to those diseases that are not represented in this most visible form of popular culture and to the effects on patients’ identity and well-being in cases where people do not recognize your disease (as in the case of ovarian cancer) or believe that you caused it yourself (as in the case of lung cancer).

Cancer as metaphor.
Cancer has been described as “insidious,” “mysterious, “lawless,” “savage,” “relentless,” and “the Great Scourge” among many other labels, and often submitted to terror-inducing, over the top “ghoulish prose” when it has been featured in newspapers and magazines (Patterson 1987:3). These metaphors and descriptors for cancer are illustrative of the cancerphobia that Patterson found has been present in American society since the 1880s.\textsuperscript{28} Whereas in the 1880s, when little was known about the disease and metaphors focused on fear-mongering, in the 1930s, as knowledge increased, metaphors were replaced with more “active” approaches to cancer. For example, the American Society for the Control of Cancer ran a campaign in the 1930s with the slogan \textit{Fight Cancer with Knowledge} (Patterson 1987:93). Current representations of cancer in popular culture tend to stress the “fight” of cancer, medical progress, and cure; in doing so, they limit the kinds of ideas people have about cancer. Metaphors characterizing cancer as a “battle” or a “war” abound (Clarke and Everest 2006).\textsuperscript{29} For example, obituaries regularly report deaths that followed an often “long battle” with cancer. Patients learn that there is only one acceptable way to respond to a diagnosis; “the cultural message [they are] getting is ‘fight, fight, fight, chemo, chemo, chemo’” (Garmon 2008). These metaphors do ideological work by shaping expectations for the way a person should react to a cancer diagnosis; all alternatives are thus portrayed as “cowardly”.\textsuperscript{30} The war and battle metaphors are so engrained that it is difficult to find words to speak of cancer without referring somehow to a war analogy. As Lakoff and Johnson (1980) show, this is how metaphor works systemically – when we fail to see the figure of speech or the symbol, and just see the expression as the natural way of speaking about a subject. Emily Martin’s (1990) work has demonstrated a similar phenomenon of speaking of the immune system as a system of defense that wages war on any hostile, foreign organisms that penetrate the body.\textsuperscript{31}

Drawing on social scientists and other writers who have questioned the typical metaphors associated with cancer (Stacey 1997; Conway 2007; Clarke and Everest 2006; Edes 2008), I examine how these metaphors hurt patients with advanced disease, by not offering up other options for approaching their diagnosis. One by one, I watched patients take up these metaphors, and I watched the metaphors fail them. For example, metaphors mislead by offering a promise they cannot fulfill: if you fight hard enough, you will win (Conway 2007). Not so, with advanced disease. Some patients “fought back” – taking every treatment that was offered to them, whether aggressive or palliative – and they still died.\textsuperscript{32} These metaphors also do them a disservice because being at war means focusing on the enemy, being vigilant about signs of danger, and
being away from family; these activities preclude noticing opportunities for joy, relaxing or spending time with family (Edes 2008). The metaphors can also be destabilizing for patients who find the “conquer and terminate” strategy disturbing because their body becomes the locus of warfare (Hitchens 2012:28). So language fails them not only because it does not provide other ways to approach their cancer that is not war-like, but also because it makes it seem that they have more control over the outcome of their illness than they actually do. The battle metaphor may work for those who beat cancer and survive long term. But long-term survivors of cancer cannot be the ones to define the terms, because their experiences offer Unrealistic expectations for patients with advanced disease.

**Cancer as agent.**

Rosenberg demonstrates that once defined, a disease becomes a kind of “social actor and mediator” (1989:10). In the late 1880s, people imagined cancer as “living, moving creatures” that invaded the body like “uninvited beasts” (Patterson 1987:31). Recent literature has described cancer as an “Emperor” (Mukherjee 2010), a “Bully” (CCS 2010) and an “Alien” (Hitchens 2012), resulting in the transformation of cancer, the disease, into Cancer, the agent. For example, Dana-Farber oncologist Siddartha Mukherjee in describing the process of writing a “medical history” of cancer says, “it felt, inescapably, as if I were writing not about something but about someone” (italics his, 2010:39); thus, he re-conceptualized his project as a “biography” of cancer. The Canadian Cancer Society released a series of postcards in 2010 that drew explicitly on the characterization of cancer as a bully. One postcard featured a dark, closed gate guarded by a menacing dog, and the shadows of what appears to be a large group of people just around the corner. The postcard read: “Just remember, Cancer, when you mess with them, you mess with us.” Another one in the series portrayed a young woman, seated in front of a vanity mirror and removing her wig to reveal a bald scalp. The caption read: “Hey Cancer, if you thought chemotherapy hurt, wait ‘til you get a load of some of the new things we’re working on.” As in the first postcard, cancer is being called out and bullied in a reversal of roles, turning the Tormentor into the Tormented. Whether seen as Bully, an Emperor or an Alien, cancer becomes personified or reified into a single enemy figure that is easily recognizable, and the patients may begin to feel as if they are transformed into the object of cancer’s assault.

In these pages I will not grant cancer similar agency, and will aim to demonstrate how this kind of anthropomorphizing of cancer serves to accord it even further rhetorical power. Agency
has long been the subject of anthropologists, who have examined the various ways that unexpected people gain agency in unique ways (e.g., Wardlow 2006, Ortner 2006). In terms of health care, agency is more commonly referred to as “empowerment,” or often “patient empowerment.” Anthropologists have also critiqued this tendency as well, often demonstrating that while empowerment or agency might be the aim, it is difficult to achieve when the differences between patients’ and medical practitioners’ knowledge is so vast. Therefore, following anthropologists whose work have questioned empowerment as necessarily a positive goal, I suggest that by anthropomorphizing cancer, we contribute to an image that may not ultimately be helpful for patients. Recall that at the beginning of this chapter, Mary invokes the disease as agent, in saying, “it doesn’t know who it picked its battle with.” This kind of language suggests that she is a worthy opponent for cancer – as though they are somehow equals. She can never win in such a scenario. If cancer is a bully, it is a merciless and indiscriminate one. By pitting herself against a non-human entity, which has no intention, she will always lose. Furthermore, the tendency to anthropomorphize cancer helps to reproduce the idea that cancer is one disease with one cure. But this is patently not true. As Patterson points out in his cultural history of cancer, there are already over 200 different types of cancer, each with their own natural histories (1987). Cancer is not one disease, but many, many diseases. Thus, I will not speak of cancer as the “powerful monster,” (Mukherjee 2010:45) or the “blind, emotionless alien” (Hitchens 2012:11) but as a complex disease, that may be characterized by immortality, but it is still nonetheless a non-person, non-agent, a biological and social entity that must be understood as a cultural construction of the time and space in which we live.

**Cancer as gift.**

Contemporary cancer culture encourages patients to “consider the ‘gift’ of cancer” (Jain 2007:79) and view their disease as an opportunity for growth. These discourses emerged in the last 20 years, and seem to only be increasing in frequency. Anthropologist Kirsten Bell (2010) recounts that a panel entitled, *Benefit Finding and Growth After Treatment for Cancer*, which she attended at a 2010 cancer survivorship conference, was one of the most popular sessions. Conway offers a critical perspective on typical illness memoirs, in which authors often “express gratitude for illness as an opportunity for personal growth” (2007:2), which results in what she calls, “narratives of triumph.” The lesson of this narrative that comes with the end of illness is to “triumph and share with others the lessons they have learned” (Conway 2007:20; see also
“heroic narratives” (Stacey 1997) and “quest narratives” (Frank 1995). Importantly, the triumph narrative is so widely pervasive in our culture that people who are sick cannot just take it or leave it, but they must “contend with it in the media, in personal interactions with doctors, in conversations with friends and family, and even in themselves” (Conway 2007:37). These discourses make cancer into a self-help project – a “teachable moment” that provides an opportunity to “remake the self” (Bell 2010) – and they have become “not merely descriptions of cancer survivorship but prescriptions for how survivors should conduct themselves” (Bell 2012:596). The nurse’s narrative that began this chapter showcases perfectly Conway’s (2007) “cultural story of triumph.” Her story contained all the requisite elements: it was emotional and gritty, and demonstrated not only how cancer threw her life off course, but also how she was able to rise from its ashes and appreciate the insight it had provided her (Stacey 1997).

I draw on these various critiques of the post-traumatic growth and gift discourses (Bell 2012; Little et al. 2002; Sinding and Gray 2005) to demonstrate how they appeal explicitly to people who will outlive their cancers, and as such, they are very limited in speaking to the experiences of patients with advanced disease. Firstly, the message of the post-traumatic growth literature is both confusing, and at times offensive. Bell traces the uncomfortable parallels between “post traumatic growth” and “post traumatic stress”; she notes that although they mobilize similar definitions of “trauma” – using terms that stress violence and war, and relate to situations of rape, genocide, and natural disasters – it would be offensive to suggest that a nation should see war as an opportunity for growth, or a woman should see rape in this way, even though that is exactly the message that is conveyed to cancer patients (2010:589). Secondly, these discourses suggest a false truth; that patients have choice and control over how they fare with their cancers (Lewis 2013), and only those with a bad attitude or those who are not willing to embrace cancer’s myriad “gifts” will do poorly. But this is a kind of “hysterical denial” that assumes that “by chanting ‘triumph’ we can ward off mortality” (Conway 2007:18). Lastly, as Ehrenreich (2008:30) has argued, implicit in these discourses is the idea that “cheerfulness is required, dissent a kind of treason”; promoting the “bright-side” of cancer as the only side of the disease further alienates people who do not see their disease in this light. The post-traumatic growth literature promotes a view that it is gracious to accept cancer and its lessons, and that it is only those who do that are deserving of social acceptance and admiration (Little et al. 2002:176). My research with patients with advanced disease demonstrates just how insulting these discourses are for people who have watched a loved one struggle and succumb to the disease, or
who are facing end-of-life themselves. Olivia revealed that the nurse’s narrative about losing one breast, while she herself had lost her fertility and undergone multiple surgeries and chemotherapies, was particularly unhelpful to her. She said listening to the nurse describe how she was “doing SO much better now because of cancer” made her want to “kick her in the teeth.”

Cancer as survivorship.

The recent emergence of the “cancer survivor” is another product of the multi-faceted discourse of survival, discussed above. The term “survivor” has a fairly recent history within discourses of cancer. In North America, prior to this term being predominantly associated with the cancer community, survivors were popularly understood to be victims of war or genocide, or survivors of abuse – people who had lived through some kind of physical, mental or emotional trauma and come out the other side (Marcus 2004). In 1986, the founding members of the American National Coalition for Cancer Survivorship (NCCS) proposed a new understanding of what it was to be a survivor. Whereas before, the title of ‘survivor’ in the context of cancer had been reserved for people who were five years post-recovery, now an individual “could call herself or himself a survivor from the moment of diagnosis” (Rowland 2008:362). The shift towards a more inclusive definition had several motivations, one of which was a “powerful message of hope” (Rowland 2008:363) so that any patient could identify as a survivor, regardless of her position on the illness trajectory. The broadening of this definition helped to establish the “cancer survivorship” phase as a critical and at that time highly overlooked point on the cancer care continuum, resulting in the seminal National Cancer Policy Board publication From Cancer Patient to Cancer Survivor: Lost in Transition in 2006. The cancer survivorship field has seen unprecedented growth since the launch of the NCCS in 1986, yet the debate about how to appropriately define a survivor continues unabated, with some researchers and national organizations choosing the broader definition (e.g., National Cancer Care Strategy, National Cancer Institute) and others a narrower one focusing on life after primary treatment has ended (e.g., Canadian Cancer Society; Journal of Cancer Survivorship). For example, in an Institute of Medicine leading publication in the field of survivorship, the authors define survivorship inconsistently in the book chapters, indicating there is still some ambivalence about who ‘counts’ as a cancer survivor.40

I demonstrate that the success of the survivorship movement has in some ways even further eclipsed the experiences of those who will not survive their cancers. Patients with metastatic
cancers for which there is no cure are included in the broader definition, but often excluded from survivorship programs and services, which tend to emphasize getting back to ‘normal life’ after primary treatment has ended. For example, at Lady Ann’s, survivorship events and programs tended to focus on overall health and wellness through patient education, healthy diet, and exercise, and thus did not seem targeted towards people whose time was still dominated by treatment regimes. Additionally, the bulk of survivorship research and practice concerns the needs of “long-term survivors,” defined as people who have exited the treatment phase and have not yet experienced recurrence or died from their cancer (IOM and NRC 2006). Thus, the broad definition of a “cancer survivor” offers patients with advanced disease honourary membership to a club with no substantive benefits. Highlighting high numbers of cancer survivors attracts research money towards the cause, and brings attention to a once neglected aspect of the illness trajectory: life after treatment. But its means of doing so is problematic, because the survivorship discourse is founded upon a lumping together of a diverse range of cancer experiences and trajectories. In other words, to argue that “6 million cancer survivors, 3 million of whom have lived five years past treatment, are living testament that cancer is no longer an automatic death sentence” (Ganz 1990:8) attracts funding and attention to survivorship services, but it obscures the many people for whom cancer still is a death sentence.

Cancer as chronic illness.

Cancer is increasingly being recognized as a “chronic” illness, often attributed to “better survival rates that have resulted from effective treatments” (Kramer-Kile et al. 2011:199). But what does the label “chronic” mean? Even experts in chronic illness have no easy answer to this question, with the authors of a recent textbook recognizing that the term as “complex” (Kramer-Kile et al. 2011). The authors work to define the term in opposition to “acute”; whereas acute illness involves the “sudden onset, signs and symptoms related to disease process itself” and ends in a “relatively short time, either with recovery and resumption of prior activities or with death,” chronic illness involves “the irreversible presence, accumulations, or latency of disease states or impairments,” “continues indefinitely,” and takes over a person’s identity (Curtin and Lubkin 1995 in Kramer-Kile et al 2011:6). Cancer seems like it can be counted as “chronic” in contexts where it refers to the long-term iatrogenic effects of treatment for cancer survivors, or to those cancers that are kept at bay with longitudinal pharmaceutical intervention (e.g., the use of Tamoxifen indefinitely for women who have completed treatment for breast cancer). But does it
count when patients continue to deal with the signs and symptoms of the disease itself, or when they do not survive long enough to suffer the long-term side effects of treatments? Olivia characterizes her disease as “chronic” when she stands up at the survivorship event, but I am unsure whether anyone on her health care team would agree with her. If living longer is the definitive measure for categorizing cancer as a chronic illness, then patients with advanced disease would seem to be excluded. Similar to their marginalized position within the category of “survivors,” they seem to have to live past primary treatment in order to benefit from the relatively stable periods of illness.

Here, I follow the work of historian George Weisz (2015) who argues that the ‘chronic’ label has been constructed to serve a variety of social and political purposes over time (2015). He takes issue with the generally recognized assertion that the concept of “chronic disease” emerged because of medicine’s ability to combat infectious diseases. Rather, he argues that chronic disease is a “metaconcept,” and one that is “exceptionally elastic and fluid” due its capacity to absorb a large number of conditions under its umbrella, depending on the need of the person or groups who are currently using it (Weisz 2015:2). Weisz illustrates that what counts as “chronic” has always been a mystery; in the 19th century it seemed to be defined by “lengthy temporality” but “there was little consensus about what length of time constituted chronic – was it 40 days? Longer?” (Weisz 2015:2). With regards to cancer, he argues that when it was conceived of as “incurable” it was not seen as a chronic illness, but with the advent of some successful treatments, it became viewed by some in the public health as “the emblematic chronic disease” (Weisz 2015:49). Yet others disagreed; they saw that patients were either saved or died, and thus considered it an acute condition. I suggest that calling cancer a “chronic” illness and grouping patients under that umbrella is not that different from calling all cancer patients “survivors.” Cancer patients represent a large and well-funded research lobby. A chronic illness definition that includes metastatic cancer increases its target population by the millions; it is not difficult to see how it would be politically very useful to encourage cancer dollars to flow into the chronic illness ‘pot.’ Similar to labelling patients with advanced disease as “survivors,” calling cancer a “chronic illness” has very little bearing on actually helping patients with advanced disease, whose conditions could equally be categorized as chronic or acute.

Cancer as entertainment.
One contemporary manifestation of cancer, demonstrating the sea change it has experienced in recent years, is that several popular television shows were created around characters with terminal cancer. Popular TV heroes and heroines such as Bryan Cranston’s Walter White (Breaking Bad) and Laura Linney’s Cathy Jamison (The Big C) demonstrate impossible strength, intelligence and fitness, causing Mark Lewis to name them the “terminally empowered” (2013). Living in the shadow of death, which is the premise of both shows, allows both Walter and Cathy to be stronger, more honest, risk-taking versions of their former selves.

For example, season 2 of The Big C ends with Cathy completing a marathon. She does end up having to walk most of it and limp her way to the end, but she still does make it to the finish line—this, from a woman who is living with stage IV melanoma and has not only completed standard chemotherapy, but also experimental therapy. Similarly, in Breaking Bad, Walter White takes over and runs a very successful drug cartel, all the while living with stage IV lung cancer. Very little screen time in either show is dedicated to the experience of being ill, and neither character actually looks very ill.

The presence of these “terminally empowered” (Lewis 2013) fictional characters who manage to accomplish almost impossible feats while living with cancer contributes to the blurring of lines between popular ideas of cancer and the reality of living with advanced disease (Lewis 2013; Segal 2011). They create impossible ideals for real patients to live up to. In The Big C, Cathy’s sardonic take on cancer and her ability to laugh it off allows her to emerge as some sort of martyr who holds in her suffering and her fears and refuses to give into the cancer stereotypes. Elizabeth, a woman with metastatic ovarian cancer, appreciated the show’s humorous take on cancer, but she found other aspects of the show troubling, like how Cathy actually first confesses her diagnosis to her neighbour, a woman whom she dislikes immensely, and does not tell her family. Elizabeth found this portrayal completely unrealistic, saying the first thing she did was call her parents and her closest, trusted friends. She needed people who knew her to help her to come to terms with her diagnosis—that she was now a person with cancer.

Jennifer, a woman with metastatic endometrial cancer, told me that she liked the show, but found it hard to believe that Cathy looked and acted so well. Where I saw Cathy’s appearance and composure as one of the show’s failings, demonstrating a lack of critical awareness on the part of the show’s writers, Jennifer interpreted it as her own failing. She said that watching Cathy live through the illness and still be able to do all of the things she did (e.g., put in a backyard pool on a whim, cash out her 401K, buy a sports car, confess to her husband all she dislikes about him)
made her feel like she “did cancer wrong.” For Jennifer, watching this fictitious character become “empowered” enough to joke about her situation and start living her life more in line with what she wanted made her feel as though she had not responded well to her diagnosis – as if she should have been able to do those things as well. Thus, these fictional portrayals of people liberated through their own sense of mortality may actually do more harm than good by minimizing real people’s experiences. Rather than question the validity of these representations of cancer or reject characters’ experience as pure fiction, patients who actually have advanced cancer may be led to question the validity of their own experiences.

II. Ethnographies of the clinical encounter

This work also contributes to ethnographic studies of the clinical encounter for cancer (Livingston 2012; The et al. 2000; Good et al. 1990; Bluebond-Langner 1978; Gregg 2003; Gordon and Paci 1997; Hunt 1994; Bennett 1999; Germain 1979) and for other serious illnesses (Kaufman 2005; Seymour 2001; Slomka 1992; Taylor 1988). Qualitative research on cancer often takes up one of three lenses: the patient experience (e.g., illness narratives or personal memoirs (Frank 1995; Stacey 1997); the hospital or the clinic (e.g., linguistic approaches to communication in the clinic (Barton 2007), oncology studies on breaking bad news (Baile et al. 2002; Barclay et al. 2007; Goncalves et al. 2005); or the culture (e.g., social critiques or cultural histories of cancer (Jain 2013; Mukherjee 2010; Clow 2001; Patterson 1987). Hospital ethnography (Finkler et al. 2008; Van der Geest and Finkler 2004) can demonstrate how these three sites – patient, clinic, and broader culture – interrelate and run in confluence with one other.

Specifically, I expand on Cheryl Mattingly’s work on narrative and ‘therapeutic emplotment’ (1994, 1998, 2009) to show how patients and oncologists view each oncology consultation as a “narrative-in-the-making.” Mattingly articulates a way of seeing the self that seems particularly relevant to patients with advanced cancer. She demonstrates that although narrative is often used as a kind of reflection of the self, a way to look back and to offer some order and structure to the ‘chaos’ of life as experienced, she says that our lives are actually not that discordant at all and that life unfolds using the elements of narrative.

Narrative helps to shape our initial sense of the flow of time and of whom we are as selves unfolding in time. In other words, we experience ourselves as being in the thick of and living out stories. However, this narrative sense of self is not necessarily all that coherent or continuous. Rather than experiencing ourselves as living out a
single “life story,” we find ourselves continually poised, with an eye to the future, toward multiple possible plots, multiple possible selves (Mattingly 2009:250).

I use Mattingly’s (1994) concept of therapeutic emplotment to demonstrate how patients and oncologists together engage in crafting stories that sketch out patients’ futures. Patients tend to be more hopeful and cast their stories within a frame of optimism, while oncologists tend to be more realistic, and cast their stories within a frame of pragmatism. But as I show in Chapter 3, the difference between ‘hopeful’ and ‘realist’ plots are not always clear, and certain actions on the part of the oncologists, such as giving patients many options for treatment right up until the end-of-life, may relay a message that is different from what they were intending; in other words, these actions may result in patients being more optimistic about their futures than they should be. I demonstrate that there are certain sub-plots, such as the fear that their doctors do not care about them, or the belief that there is no one looking after them, which could be described as “threatening plots” (Mattingly 1998:149) because they disrupt patients’ hopeful plots.

In addition to Mattingly, I draw on the work of Annemarie Mol (2002, 2008) to help situate a contemporary discussion of the culture of the hospital. In *The Logic of Care* (2008), she offers an astute critique of the recent rise of patient choice in health care, and demonstrates that it results in less than ideal care for patients. The book constitutes a kind of manifesto against patient choice, arguing instead that health care be motivated by a logic of care, and demonstrating through many examples of doctor-patient interactions, what good care looks like. Mol argues that when health care is motivated by a logic of choice, the patient is viewed primarily as an autonomous consumer, capable of making informed decisions; conversely, when health care is motivated by a logic of care, the patient is viewed primarily as a sick person in need of care, whose ill body and insufficient medical knowledge must always be recognized as factors working against her ability to make true ‘choices’ when it comes to her care (2008:35). Her conceptualization of contemporary health care as ultimately a question of ‘care’ rather than one of ‘choice’ helps to re-frame the kinds of narratives or plots that oncologists might be capable of sustaining. In other words, even when oncologists cannot, in good conscience, promise a ‘cancer-free’ future for patients with advanced disease, they can still be motivated by a logic of care and work towards recognizing and supporting patients’ ‘hopeful’ plots.

While Mattingly and other social scientists applying her conceptual framework use “emplotment” to discuss the actuality of what occurs during a consultation, and thus only examine the time of the encounter between provider and patient, here I expand the lens much
wider to demonstrate that ‘story-making’ is what makes up life and that patients and doctors live in different kinds of reality all the time. During fieldwork, I became aware of these ‘plots’ sitting in waiting rooms before consults and after appointments, debriefing with patients in the hallways of clinics or in the coffee shop. I observed that they would sometimes interpret things in a way that seemed inconsistent with what I had just understood to have happened. For example, a patient was given bad news, and yet she would emerge from the appointment with a positive twist. Or she would pick up on one positive thing that was said, and celebrate that small victory, and seem to ignore the more negative aspects of the conversation, such as the fact that the cancer would likely “come back.”

In this way, patients use what happens in the clinic to build their own narratives, and they carried with them the fictions or plots they needed to survive day to day. Sarah Franklin’s (1997) work with women undergoing IVF similarly found that women would interpret the doctor’s words in the most positive light, and sometimes see themselves as “partially pregnant.” Since “partial pregnancy” does not exist – a woman is either pregnant or not pregnant – this was a kind of ‘fiction’ the women needed to subscribe to in order to go forward with the demanding regimen of IVF. But it is not only patients who do this. Doctors and nurses might add or subtract certain details to allow certain patient stories to carry more weight. They may also sustain their own fictions. I heard Melody’s doctor joke with her, “You’re not dying, Melody!” The doctor, too, must hold onto certain ‘plots’ in order to have hope for Melody and hope for her practice, which contains many patients like Melody, who face incurable illness and thus are all, in a sense, ‘dying.’ But in another sense, there is still very much living that is going on, and this doctor recognized and encouraged Melody’s vivacity as well. Mary-Jo Good and her colleagues at Harvard did interviews with oncologists in the late 1980s and found that they often felt pressured to speak in a language of hope that encouraged patient optimism (1990). Notably, they found that oncologists were more likely to give explicit and frank information when the disease had more chance of a cure, and that “frankness of disclosure decline[d] precipitously as a function of the survival rate” (Good et al. 1990:77). It is exactly this kind ambiguity that helps to sustain multiple and sometimes contradictory plots for patients, as well as for doctors. By examining communication as emplotment, I show how doctors and nurses, as well as patients, carry these ‘stories-in-the-making’ with them in order to move forward in their own lives.

By showcasing how patients and doctors ‘emplot’ (Mattingly 1994) different possibilities for patients’ futures and how those ‘plots’ exist in tension with one another, I contribute to a
substantial, and long-standing interest in oncology on communication (Rodin et al. 2009; Hagerty et al. 2005; Nelson et al. 2011; Pollak et al. 2007; Fagerlind et al. 2008). In general, this literature has demonstrated that communication in advanced cancer often focuses on active treatment options (Koedoot et al. 2004; The et al. 2000), and that both patients’ and doctors’ desire to focus on treatment may result in belated discussions of what will happen when the treatments run out (Cherlin et al. 2005; Lofmark et al. 2005). Psychosocial issues, such as coping and psychological wellbeing, are discussed infrequently (Fagerlind et al. 2008). Despite the nature of metastatic disease, not only do patients overestimate their likelihood of survival and make treatment decisions based on an inaccurate understanding of their prognosis (Weeks et. 1998), but sometimes their doctors do as well (Glare et al. 2003). Heyland et al. (2009) found that in cases with seriously ill patients only 18% of patients and 30% of families recalled a discussion about prognosis, but that those who did reported greater satisfaction with end-of-life care. The challenge of discussing incurability is demonstrated by the fact that discussions about negative prognoses are rarely documented in patients’ charts (Bradley et al. 2001), and there may be little concordance between physician and patient accounts when end-of-life discussions do take place (Desharmais et al. 2007).

In studies focusing on the physician’s experience, research has shown that oncologists find discussions involving no further curative treatment or hospice to be the most difficult (Baile et al. 2002), and are uncomfortable discussing death and having ‘nothing to offer’ (Baider and Wein 2001). They also fear losing control when they are breaking bad news (Friedrichsen and Milberg 2006) and feel that they are inadequately trained for discussions about death and end-of-life care (Cherny and Catane 2003; Gilewski 2001). In studies focusing on the patient and family’s experience, patients have demonstrated that they want their doctors to be realistic in discussing prognosis (Hagerty et al. 2005). A recent large survey of lung cancer patients found that physician communication on key topics was rated very poorly, especially communication about emotional symptoms, practical needs, spiritual concerns, and hospice (Nelson et al. 2011).

Importantly, patients and families also may not always understand what is meant by certain terms such as ‘palliative’, ‘incurable’ and ‘treatment’. For example, in one Canadian study, participants all had some form of incurable cancer, and had been referred to receive palliative radiotherapy in order to improve their quality of life (Chow et al. 2001). Patients were asked to complete a survey prior to their first appointment, which revealed that 35% of patients believed that their cancer was curable, 20% expected that palliative radiotherapy would cure it, and 38%
thought that palliative radiation would prolong their lives (Chow et al. 2001). Over 75% of patients reported that they were given insufficient information prior to the commencement of treatment. This study prompts several questions: How is it that some patients were sent for treatment with a significant misunderstanding of its intended purpose? Was it that the medical team had not clearly explained the incurable nature of the diagnosis, in terms the patients and families could understand? Or perhaps did patients only hear what they wanted to hear, which was that some ‘treatment’ was available? What other factors could have contributed to the lack of clarity (e.g., limited consultation time, undefined terms so all participants were not on the same page, mixed messages arising from several staff on the same consultation)?

My observations from sitting in on oncology consultations revealed that there are often multiple, crisscrossing variables at play, which the majority of qualitative studies do not account for because they often examine the oncology consultation as an ‘event’ that can be separated from the context in which it unfolds. This literature broadly follows three main methodologies: 1) record interactions and do a content analysis of what was said; 2) send a questionnaire or survey to oncologists asking them about their regular practices in communications about the end-of-life; and 3) send a questionnaire or survey to oncologists asking them about what they would do in hypothetical end-of-life conversations. In a famous example of the first method, Pollak et al. (2007) recorded 398 conversations between oncologists and patients with advanced disease, and coded their transcripts for the presence of “continuer” statements by oncologists, which offered empathy and allowed the patient to continue to express emotion, as well as “terminator” statements, which shut down the conversation and discouraged further disclosure. When an empathic opportunity presented itself, oncologists responded with “continuer” statements only 22% of the time, which the authors interpreted as potentially contributing to increased patient anxiety and lower adherence to therapy (Pollak et al. 2007). Similarly, Gattellari et al. (2002) examined whether patients are well-informed about prognosis and treatment options, and they found that although over 50% patients were well-informed about the anti-cancer therapies and the incurable nature of the diagnosis, less than half were offered any alternative to treatment or were informed about how treatment would affect their quality of life.

This method, which relies entirely on the transcript of the recorded interaction, has some significant shortfalls. For example, in Gatellari et al.’s (2002) study, oncologists only checked patients’ understanding with 10% of patients; therefore, although the transcripts confirmed that prognosis had been discussed, there was no way to ascertain patients’ actual comprehension and
retention of what had been discussed. The transcript can also provide only a surface-level account of what occurs, as the following excerpt from a consultation I observed between an oncologist and Jennifer, a 41-year old woman with endometrial cancer, demonstrates.

Weight had always been a sensitive issue for Jennifer, and before her cancer she had been almost obsessed with daily exercise. In fact she was of average, even perhaps under-average weight. While taking chemo, she asks her oncologist whether she should be also be exercising:

Dr. Girard: No, no not for now. You need to be healthy. (switching gears) Are you back on the horse?

Jennifer: No, there is too much snow where I am.

In this instance, without more context or consideration of this conversation as just one of many between this care provider and patient, this comment could be misunderstood, or worse, considered irrelevant. In fact, it demonstrates at least two points not immediately evident: 1) that Dr. Girard remembers something personal about this patient, in this case, that she is an equestrian; and 2) that the oncologist manifests care and concern in shifting the conversation from one about weight (a sensitive issue for this patient) to one about how disease has affected her lifestyle. If this transcript were considered in isolation, and only as a verbatim transcript of what was said (which is all the researchers have access to if they were not present), this demonstration of a caring practice would have easily been missed.

The second method asks oncologists to remember the cases they have covered in a recently defined period, and thus contains an inherent recall bias. Oncologists are extremely busy; in the clinics I observed, the doctors easily saw 20-30 patients every morning or afternoon. On a survey, they may be tempted to report on their ‘ideal’ behaviour, but not the behaviour that is actually exhibited in daily practice. In other words, although they might be able to outline a communication strategy, drawing on particular terminologies or gestures they have found to work in the past, they might actually behave somewhat differently during the bustle of a busy clinic, where time and staffing might require them to abridge or abandon certain messages they were hoping to convey.  

The last method of study is based on hypothetical circumstances. Nancy Keating and colleagues (2010) found that in the U.S. most doctors do not discuss end-of-life options with terminally ill patients who are feeling well. Instead, they wait for symptoms to worsen or until they have no more treatment to offer before initiating such discussions. Importantly, the study’s conclusions advocate that “more research is needed to understand physicians’ reasons for timing
of discussions and how their propensity to aggressively treat metastatic disease influences timing” (Keating et al. 2010:998). The factors related to understanding these key timing issues are unlikely to be uncovered using the method of hypothetical patient cases.

While all these methods provide important and useful information on the nature and content of oncology interactions, they are all predicated on the assumption that the doctor-patient interaction can be excised from the surrounding hospital environment, and the social, cultural, and familial contexts in which it unfolds. They posit that the consultation is a kind of ‘event’, and that it is the only time that communication occurs. By reframing communication as ‘emplotment’, I use the method of ethnography to situate consultations within the broader context of hospital life, and to show how communications extend beyond the consultation and take up meaningful space in peoples’ lives. Thus, this research advocates for more grounded, realist approaches to understanding what people with life-threatening illness actually endure through sustained and engaged methods like ethnography.

III. Categorical Anomalies: From the Lands of the Sick to the Space of the Liminal

How do you attend to the thoughts and concerns of the dying when medicine has made it almost impossible to be sure who the dying even are? (Gawande 2010:4)

My research provides a rich example of the importance of the cultural categories distinguishing health, disease and illness, both within biomedicine and within broader society (Kleinman 1988; Lock and Gordon 1988). Since its inception as a separate sub-field in the late 1960s, medical anthropology has had a demonstrated interest in what these categories mean and how people go about defining them, often in ways that note how flexible and variable they are. Categories of illness have a high degree of visibility not only in biomedicine, about also in popular culture. Anthropologists have greatly contributed to the understanding of disease as the objective medical category, and illness as the subjective experience of being ill (Kleinman 1988); they have also shown through cross-cultural research that these categories do matter in distinguishing the healthy from the sick, in respecting social taboos around people who are seen as sick or unwell, and in understanding the meaning of illness in a culture or place (e.g., Barrett 2005; Lock 1993). For example, in the 19th and 20th centuries in North America, illnesses such as TB and epilepsy were highly stigmatizing; being diagnosed with either of these conditions meant that a
person had a “spoiled” identity (Rosenberg 1989; Sontag 1990). Cancer has now taken up the place, and has become one of the major culturally marked illnesses of our time (Kleinman 1988:20). While cancer is often compared to illnesses such as heart disease (as a cause of mortality), or diabetes (as a similar chronic condition), neither of these illnesses takes over the person’s identity in a similar way, and neither has the extensive exoskeleton that cancer has. Even though they are equally serious (heart disease, as the second leading cause of mortality in Canada, and type I diabetes, as a chronic condition that requires precise intervention and management), neither condition requires that people give up their identities in the way that cancer does. They are just diseases that happen to a person, not diseases that become the person (Rosenberg 1989:12; Jain 2013). The associations and assumptions that people make about a person with cancer are not easily escaped.

Using Van Gennep’s (1960) tripartite structure for a way of examining rites of passage, and Turner’s (1967, 1969) subsequent development of the liminal stage of initiation rites, I argue that being diagnosed with an incurable cancer situates patients in a liminal space – an ambiguous territory located between the curative hopes of oncology and the threat of approaching death. Van Gennep’s (1960) important concept of the rite of passage has often been used in classic ethnographies to describe the rites of birth, social puberty or initiation, marriage and death.46 Van Gennep stated that all rites of passage can be divided into three main stages: 1) separation; 2) margin (or limen, the latin term for threshold); and 3) aggregation. Turner expanded on Van Gennep’s framework, choosing to focus on the marginal or what he called the “liminal” stage of initiation rites (e.g., social maturity or cult membership), and described it as the “interstructural” position between two states.47 Van Gennep (1960:146) argued that the transition rites associated with death are so symbolic and highly charged that their liminal stage can be granted a sort of autonomy, and examined separate from the ritual context.48 My research focuses on death’s transition rites by examining what happens to the patient, as ritual subject, and to his community before death, when the patient is very much caught up in staying alive.

Applying these concepts to practice, the moment of diagnosis might serve as the point of separation, where a person becomes detached from a fixed point in the social structure (Turner 1967). The patient then enters a liminal or ‘marginal’ phase, which has particular features: (often physical) seclusion; breaking of taboos; formation of communitas with other members; and deference to ‘guides’ to help the initiates through (Turner 1967, 1969). As liminality is a state that is intended to be short-lived – a kind of means to an end – to bring about the structural
recognition of a status change of an individual or group, the third phase of “aggregation” or “reintegration” into society is key. In cancer, it most certainly is, for those patients who can emerge from the throes of treatment and take up the identity of survivors. But many patients with advanced disease will not become long-term survivors (i.e., > 5 years). Therefore, patients are not temporarily part of the “anti-structure” (Turner 1969) but rather remain liminal until they die.

I demonstrate that patients with advanced disease are made somewhat ‘invisible’ in our contemporary culture, because they do not fit into culturally available categories, which requires that people be viewed as either “sick” or “not sick” (i.e., well). Following Jackson (2005), whose work examines the stigma and liminality associated with chronic pain sufferers, I examine how advanced cancer produces liminal beings that are highly stigmatized. Jackson (2005) argues that the stigma associated with chronic pain results from the belief that these patients are not truly “sick”, since physicians cannot find a physical manifestation of the problem in the body. Here, I attribute the stigma and categorical anomaly to the inability to accept that there are many possible nuances that exist between “sick” and “not sick.” Douglas defines ambiguity as “a character of statements capable of two interpretations” and anomaly as “an element that does not fit a given set or series” (1966:37). Patients with incurable illness straddle categories – between sick and well, acute and chronic illness, living and dying, and curative care and palliative care. Thus, the status of patients with incurable cancer is ambiguous in the sense that their condition is capable of two possible interpretations – actively living or actively dying – and anomalous in the sense they are in a specially marked time between life and death, where they are living with their disease, but not yet dying from it. Moreover, people with cancer are inherently disturbing or threatening, and therefore seen as potentially “polluting” because of taboos associated with the interstructural state (Douglas 1966). Liminal beings “are seen by those around them to threaten prevailing definitions of the social order” (Jackson 2005:332). Chronic pain patients transgress normal moral boundaries between when it is ok to be sick and to receive treatment, sympathy and compassion and when it is not (Jackson 2005). Patients with advanced cancer threaten the social order by their association with death – by providing the unwelcome reminder of “our lack of control over our own and others’ death” (Kleinman 1988:20).

As Gawande’s (2010:4) quote above illustrates, modern medicine has made it very difficult to tell who is in fact “dying” and who is “not dying.” Douglas (1966:36) argues that the act of “perceiving” is how we come to recognize particular things in our culture. In other words, we encounter the world not in consideration of a memorized list of what exists, but through the act
of perceiving, and we slot things into categories in our minds that do not challenge what is already there. She outlines that when we encounter people or things that are ambiguous or anomalous, we do not often choose to adjust our categories because this takes work. Rather, we find a way to treat anomalous beings so that we do not have to change the categories to which we hold fast. One of these reactions is “avoidance” (Douglas 1966:39). Here, I see the avoidance as an indirect kind, such as if a person asks a patient if treatment is “over” and the patient answers, “Yes, but…” and the interlocutor is no longer listening. Treatment that goes on indefinitely is not generally recognized in our culture, and thus it is difficult to accept.

Throughout the dissertation, I work to demonstrate how the patients I followed suggest a gap in the language because the regular health vs. illness framework does not apply. Susan Sontag began her famous book *Illness as Metaphor* by stating “everyone who is born holds dual citizenship in the kingdom of the well and the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place” (1990:3). Sontag’s much cited comment has contributed to the pervasiveness of place-based metaphors, which distinguish “health” and “illness” as separate places. Over the years, Sontag’s powerful metaphor of the “dual passports” (1990:3) has produced many off-shoots, which all have at their core this similar idea: Hitchens’ “Tumourtown” and “Wellville” (2012:44); Stoller’s “village of the sick” and “village of the healthy” (2008, 2009:148); Mullan’s “land of cancer survivorship” (1990:160).

The majority of these place-based metaphors mark out distinct places for health and sickness. For example, Hitchens describes looking back at his first 911 call as “a very gentle and firm deportation, taking me from the country of the well across the stark frontier that marks off the land of malady” (2012:2). In the afterword to *Mortality* (2012), Carol Blue, his wife, describes how “[they] were living in two worlds” on the day he found out he had cancer (Hitchens 2012:97). Similarly, Mullan describes the “land of survivorship” as a place where anyone diagnosed with cancer is transferred to by means of a “one-way ticket” – a place where “where family and friends, doctors and nurses can visit but where the survivor becomes a permanent resident” (1990:160). I point to these place-based metaphors in order to draw attention to their limitations; by implying clear borders and boundaries on these categories of existence, they limit the frames of discourse for seeing the many nuances that exist between the “sick” and the “well”. My findings indicate that rather than be confined within any one particular “land” post-diagnosis, patients with advanced cancer shift constantly between the worlds of the
well and the sick, and it is their constant shifting or ‘in-betweenness’ that makes them difficult to recognize.

In analyzing the liminal states of patients shuttling between these two worlds, I build on the work of several scholars who have acknowledged that cancer often introduces a middle ground between sickness and wellness (most notably Jain 2007, Frank 1995, and Stoller 2008, 2009; see also Nissim et al. 2012 and Little et al. 1998). Anthropologist Sarah Lochlann Jain proposes “living in prognosis” as an “uneasy alternative” to the survivorship identity because it acknowledges that the identity of a person living with cancer contains “contradictions, confusion, and betrayal” (2007:90). But as I demonstrate in Chapter 5, many of the patients I followed were never given a “prognosis,” so Jain’s term does not adequately capture their experiences.

Sociologist Arthur Frank proposed the idea of the “remission society” many years ago, after he recovered from cancer, to capture people who, like himself, “were effectively well but could never be considered cured” (1995:8). Frank argued that sickness and wellness “shadow” into each other; he argued that people with a history of cancer, a chronic illness or a disability would never be re-admitted to the land of the well and thus inhabited a kind of “secret society in the realm of the healthy” (1995:9). Similarly, anthropologist Paul Stoller, based on his own experience of cancer, suggests that patients who have been touched by cancer and move into remission never fully re-integrate back into the “land of the healthy” and live rather in a state of “continuous liminality” (2009:148). Both Frank and Stoller discuss how people often just want to “get back to life” after serious illness, but the life that is lived post-illness will never be the same as the life that was lived pre-illness. Each author describes a liminal status where cancer is allocated to a past life, not a present problem. The challenge for the member of the remission society or the “continuously liminal” is to learn to live among the healthy after suffering from serious illness.

This problem does not translate to the patient facing advanced cancer. Many of the longitudinal patients I followed never went into remission; I never heard any oncologist refer to their condition using the word “remission” even when it was acknowledged that the cancer was temporarily not growing. Cancer was always there, always present in the body, growing or waiting to grow again. Thus, I seek to distinguish the case of advanced cancer from Frank’s “remission society” (1995) and from Stoller’s “continuous liminality” (2009), and to demonstrate that liminality exists as a ‘space’ of in-betweenness, rather than a ‘place’ of health or illness. Rather than further entrench place-based metaphors, I employ the ‘space’ of the liminal to invoke
that these lands are not as distinct as they might appear to be. The liminal space gives patients the flexibility to move between these different categories of health and illness, and between various discourses of survivorship, chronic disease and palliative care – none of which alone adequately accounts for their experiences. Importantly, the kind of liminality I am describing is not the case of a transition between sickness and survivorship – between the lands of the “sick” and the “healthy” (Stoller 2009) – but rather an ambiguous disease state that is the transition between the worlds of the living and the dying.

My work represents what we know intuitively – that we are not often ‘well’ or ‘sick’ but often somewhere in between – we are using both passports (Sontag 1990) at the same time. In other words, the land of the well is the land of the sick. Mary, whose story was included above, said at her first consultation with the lung cancer team, “Aside from this cancer, I am healthy.” She clearly indicates that she does not see herself as “sick,” even though she presented on that first day with such aggressive disease that it had already metastasized to her bones and was making itself visible by popping up in nodes on her arms and back. Rather than dismiss her statement as ‘delusion’ or ‘denial’, I explore how that statement could be an honest appraisal of where she stood, given the current culture of medicine and technology that she was living in. As definitions of health change, we are all potentially caught in these categories of illness.

Timmermans and Buchbinder (2010) point out that in contemporary times a person can be diagnosed and treated for a cancer being completely symptom free; in early decades he might never have known the cancer existed and it might never have caused him any problems. They have described this phenomenon as “patients in waiting” – increasingly broader categories of illness and expanding medicalization into states of wellness – so that even a person who has no symptoms of illness can still be called “sick” (Timmermans and Buchbinder 2010). While their research examines molecular testing for newborn babies, their concept serves as a catch all for many types of “potential patients”, such as people who have tested positive for a cancer gene (e.g. BRCA1 and BRCA2) that predisposes them to illness but who may never become sick.

My findings indicate that patients’ status is fluid between states of sickness and health, with each status according its own advantages and disadvantages. Once they were off treatment, patients with advanced disease often wanted to “put cancer behind them” and tried to get back to their usual routines, and in this way, they wanted to pass as the “not sick.” For example, they wanted to return to work, attend family and friend outings, and make plans for their future. And yet, other times I noticed that when people treated them as “not sick,” or just like everyone else
(because they often looked like everyone else), they worked to re-assert their “sick” status, reminding people that they were not, in fact, “back to normal”. The sick role, originally described by Parsons (1951) has some advantages; its social contract requires that patients 1) want to get well; 2) seek technically competent help; 3) co-operate with the appropriate helper in order to get well. As long as patients do this, they can be excused from normal social responsibilities, just like the liminal initiate (Turner 1969; Parsons 1951). But it also has some disadvantages: friends and family may draw away from them because they do not know what to say, or they may stop inviting them to events or outings because they know they are not well enough to attend.

Being liminal in the long-term has real and tangible consequences on the lives of patients with advanced disease. Patients’ inability to identify their positioning caused a problem – a problem for themselves, and a problem for their family and friends. People around them do not know quite how to categorize them. Are patients who have received treatment for advanced cancer, but currently on a break from treatment, still patients (i.e., “sick”)? Or are they considered “not sick” since they are getting a break from the usual slog of the hospital routine? Friends and family may think the patient is “better” especially if she has returned to work and to her usual routine, but this may not be the case, as happened in the case of Elizabeth, a teacher I followed with ovarian cancer. But what if the patient is no longer receiving treatment, and therefore not doing weekly or monthly visits, but has not returned to work, as happened with Dario, a contractor I followed with lung cancer? Why is Deo “better enough” to be off treatment (for the time being), but not “better enough” to come back to work and run his business? The liminal space also produces tensions for doctors and nurses, who work within the limits of medicine to keep patients as well as they can, for as long as they can. The default is to continue to push for treatment; patients and doctors are “colluded” in this primary goal (The et al. 2001). But more treatment does not solve the liminal challenge; it just makes patients’ liminality fuzzy again, or less visible. Once treatment begins again, patients enter back into a realm that is much more identifiable: regular treatment, tests, and follow-up appointments, and so they readily seem to ascribe to the “sick” role again. But that treatment period could be very short-lived, which was the case for several patients who started on clinical trial drugs and were soon kicked off the trial due to disease progression.

Elizabeth told me a story that clearly showcased this nuanced perspective towards her “sick” status. She described a time when someone gave up his seat on the streetcar and “insisted”
she sit in it. She had gotten on at a stop close to the hospital, and having lost her hair to chemo, was wearing a headscarf, so he could likely guess she was a patient. She did not really want his seat, but figured “I might as well use this for something” (pointing at her headscarf, i.e., the cancer). I got the sense from her story that in fact she didn’t want to be seen as the cancer patient, but just as Elizabeth, the woman she was before cancer took over part of her identity. Although patients like Elizabeth would very much like to give up the sick role, their disease does not allow it. Even if they think they have returned to normal life for a brief time, the illness always calls them back to Lady Ann’s. Advanced cancer patients are thus not “patients in waiting” as Buchbinder and Timmermans (2010) describe, but eternal patients, ‘permanent patients’ unable to relinquish their patient status regardless of their efforts to leave it behind.

In the thesis, I outline two key factors that contribute to their liminality, which are often not acknowledged or talked about: 1) treatment as a way of life rather than one stop on the road to recovery; 2) the ambulatory nature of outpatient cancer care. People think that treatment is a one-stop activity in the pursuit of a cure. But treatment for advanced disease is limited in its ability to make the cancer go away forever and never come back. Thus, treatment becomes a way of life for patients, rather than one stop in their cancer journey. Additionally, cancer care at Lady Ann’s for solid tumours is delivered on an ambulatory basis, which means that patients are always coming to and going from the hospital. Entries and exits are normally portentous (Van Gennep 1960), especially in relation to hospital admission and discharge, but not so for the patient with advanced disease. The fact that patients are not contained or having to stay in the hospital adds to their anomalous position in society. They walk around, go to work, see friends and family, and all the while cancer grows and changes inside their bodies. For brief periods of time, especially when their bodies seem reasonably normal in appearance and function, patients may themselves forget that they have a serious or advanced cancer. But these moments are often fleeting, as patients are brought back to full awareness as soon as they attempt to make any plans for their future. As one can imagine, it is difficult for patients to be “sick” when they are surrounded by “not sick” people and living (to some extent) their pre-sick lives. Thus, ambulatory cancer care makes it harder for people around them to recognize patients’ challenging position, and in a sense, it conceals their liminality.

Patients with advanced disease not only straddle the categories between the well and the sick, but they also straddle categories between different models of care. These primary models of
care include: survivorship care, chronic illness, and palliative care. Even though there are aspects of each discourse that appeals to patients with advanced disease, not one adequately captures the experience of living with metastatic cancer. The survivorship model is seductive, since every patient wants foremost to survive, but given that patients with advanced cancers are not expected to “survive” their cancers long-term, it falls short on its fundamental promise. The chronic disease model has appeal by its associations to patients with diabetes, arthritis, or fibromyalgia – all conditions that are made tolerable and manageable through the aid of pharmaceuticals and other supports. However, the “chronic” label belies the seriousness of advanced cancer and, in some cases, how quickly death is approaching. The palliative care model is the one that is most likely to include them, since its catchment area is people living with a life-threatening illness. Crucially, however, patients do not self-identify with this model either. Without a model that appeals to both what they are feeling (their experiences) and what they desire (their hopes), they spend their time trying to map their own experience onto various models in a piecemeal way. As this dissertation will show, that task requires a substantial amount of work, and, at the end is not rewarded with what they most desire: to not have cancer.

Visible disease, invisible illness: the politics of erasure of advanced disease

Although cancer is one of the most visible diseases today, the unique pathways of patients with advanced disease result in making their cancer experiences somewhat invisible. Compared to other chronic or serious conditions, cancer is highly desirable because of its visibility in society. Jackson spoke to several sufferers of chronic illness who wished they had cancer, rather than chronic illness, because cancer is a “known diagnosis with treatment possibilities” (2005:340). There is a certain irony that other sufferers would choose cancer over their own conditions, and yet the illness experience for patients with advanced disease is unaccounted for. But they are not an insignificant epidemiological group; as noted above, cancer will be the cause of death for one quarter of all Canadians (CCS 2015). In a recent volume, Casper and Moore (2009) attend to the “politics of visibility” when it comes to certain bodies being absent from contemporary society. Drawing on Judith Butler’s theory of materialization (1993) and Donna Haraway’s attention to “selective blindness” (1997:10 in Casper and Moore 2009) the authors attempt to understand why some bodies are “hyperexposed, brightly visible, and magnified,
while others are hidden, missing, and vanished” (Casper and Moore 2009:3). In particular, they draw on Butler’s argument that it is useful to examine how bodies come to matter and to materialize, which she posits occurs through “processes of reiteration” (Butler 1993:8). Here, I build on their attention to “corporeal visibility and erasure” (Casper and Moore 2009:3) to ask, how is it that with respect to cancer, a highly visible disease, there are some patients whose illness experiences are so invisible?

Invisibility with respect to advanced disease has several layers. One layer of the invisibility is the categorical anomaly, discussed above. Another is the sometime absence of the physical signs of illness. Both lung and gynaecological cancers are somewhat invisible because they attack organs that are hidden within the body. They may often only show “visible” signs, such as nodes that appear under the skin in the case of lung cancer, or extreme bloating in the case of ovarian cancer, after they have already metastasized. Pam, a woman with ovarian cancer, told me about a particular interaction with a home support worker that had irked her. Although Pam had lost her hair twice due chemotherapy, when she encountered this woman, she had a full head of hair because her current treatment did not have hair loss as side effect. Additionally, although many cancer patients become very thin or cachectic, Pam often gained weight when on treatment. The support worker who came into her home to provide assistance with cleaning and laundry made the offhand comment to Pam, “You don’t even look sick.” Pam quickly replied, “Don't you forget that I am.” Pam recounted this story to me in frustration, because she could see that, from the support worker’s perspective, it was difficult to recognize her as a cancer patient, since she was missing the most obvious visible signs of cancer: a bald head and extreme weight loss. The comment put her on the defensive, feeling the need to justify the support services she was very entitled to receive. Since Pam was undergoing her fourth round of treatment for ovarian cancer, she was well aware she would not soon leave it behind. The embodiment of illness does not look the same in all patients; not looking like the ‘typical’ cancer patient means that people with advanced disease may ‘pass’ as being in better health than they are.

Much of the work of medical anthropology and sociology has pushed back against the erasure of sufferers from medical discourses in order to reveal their profound suffering, which is only increased when it goes unacknowledged (Jackson 2005; Mol 2002; Charmaz 1993; Kleinman 1988). In critiquing the typical advertisements for blood sugar monitors, which depict healthy people living life with the help of an invisible technology, Mol (2008) argues that the person suffering from diabetes is never shown; her work is aimed at recovering the suffering
person to discourses of diabetes. Similarly, here I work to draw out the “missing bodies” (Casper and Moore 2009) and experiences of patients with advanced cancer, and to make them materialize. Thus, one goal of this dissertation is to bring visibility to the experiences of people who have become eclipsed by a culture that loudly proclaims that cancer is a chronic and curable disease for most people.

Research Limitations

This is an ethnography of advanced disease – particularly the experience of and cultural response to advanced disease early in the 21st century. The dissertation examines the lives of patients as I encountered them – at Lady Ann’s, in the community, at their homes – but it is limited in its ability to speak to the full lives of people like Paul, Olivia, and Melody. Although cancer came to dominate their days, it is still only one part of complex lives. I went to Paul’s funeral about eight months into my fieldwork and was struck by this realization; I had been to his house, met his wife, seen pictures of his children, and had talked to him extensively about what he was going through, yet listening to his friends and family members speak about him in the many other various roles he occupied, I realized everything I knew about him added up to such a small fragment of his life. Cancer did not define him. It disrupted his life in profound ways, taking over his time and identity in his post-retirement years, and causing him untold suffering and an early death, but he was not cancer and cancer was not him.

Although I had intended to examine the experiences of care providers as well, I quickly became absorbed into the world of the patients. Their stories were powerful; in order to grasp them fully, I proceeded into their world, spending the majority of my time in their company at Lady Ann’s. So while you will meet Dr. Lawson and Dr. Girard and their exceptional teams of nurses and support staff, this is primarily not a story about them. In order to do justice to the experience of providing care to patients with advanced disease, a follow-up study would be required, using the same lens I have directed towards patients here. Rather than ‘follow the patient,’ I would follow the oncologist and the nurse, to see what their work is like day in and day out. The data I did collect on oncologists and nurses while sitting in their clinics revealed that their work is exceptionally meaningful and intense – they manage high numbers of sick patients in very little time – and that is just the work I saw take place in the clinic. Staff often referred to other activities I did not observe, such as patient rounds, calling back patients and
families, various meetings and trainings, and a colossal amount of paperwork. Thus, any comprehensive ethnography of the social world of oncologists and oncology nurses would need to include these activities as well. While the literature has taken a very narrow focus on the work of oncology by examining only the communication that happens in the consult room, this research would take the form of an in-depth examination of the daily complexities of working in the liminal space of advanced disease.

**Outline of the Thesis**

Chapter 1 provides a summary and description of my research methodology. I review the preparations I underwent to begin fieldwork, and describe the methods of data collection and the typical illness trajectories of the patients that I followed. I discuss some of the challenges produced by working with patients with life-threatening illnesses. Like other qualitative researchers studying “sensitive” topics such as cancer, suicide, and violence (Dickson-Swift et al. 2007), I experienced some challenges in the field, particularly related to positionality and the emotional impact of the research. Despite these challenges, I argue that ethnographic methodology provided a unique lens on the experience of cancer, because it allowed me to become ‘close’ to cancer in a way that most cancer researchers, using short-term methods like the qualitative interview or more quantitative approaches like surveys or instruments, do not. I believe that the close, sustained relationships I formed with patients throughout the period of fieldwork contributed positively to the quality and the depth of the data that I was able to collect.

Chapters 2 and 3 introduce daily life at Lady Ann’s, and the kinds of interactions that take place regularly within its walls. Chapter 2 begins with an introduction to the history of the specialist cancer hospital and the context of care that unfolds daily at Lady Ann’s. I present Lady Ann’s as a space and a place of containment, and show how Lady Ann’s tries to ‘hold in’ negative experiences that take place there, and ‘hold off’ the disease from progressing as long as possible. But true containment is difficult to achieve, and the chapter reveals many border breaches in terms of both structural and emotional containment of cancer. I argue that Lady Ann’s boundaries are firm and porous at the same time, and show how these institutional qualities work in conjunction with outpatient cancer care to produce the perception that patients with advanced disease are doing better than they are.
Chapter 3 examines how ‘incurable cancer’ is made real and emerges in daily consultations at Lady Ann’s. A large proportion of the medical literature focuses on bad news ‘delivery,’ which provides a narrow and literal reading of communication, and gives the impressions that information is passed unidirectionally from doctor to patient. Instead, I argue that communication is a relational process, and discuss communication as “therapeutic emplotment” (Mattingly 1994, 1998). I argue that patients and staff alternately draw on narratives of hope and realism in daily practice, and that they often manage to hold onto multiple, and contradictory ‘plots’ about the future. Thus, I situate conversations about incurability within the context of everyday practice at Lady Ann’s (Mol 1998, 2002), and demonstrate how both patients and staff grapple with the content over time and beyond the consultation room.

Chapters 4 and 5 draw extensively on the anthropological literature on liminality and temporality to argue for contemporary applications of these classical concepts in the context of advanced disease. In Chapter 4, I examine how the ritual of ringing the bell at the end of a round of chemotherapy as a symbol of cancer patients’ transition towards survivorship fails to take into account the unique pathways of patients with advanced disease, who will ring the bell over and over again because they are never quite done with treatment. Thus, I show how the rituals that are used to mark different periods of the cancer experience often make no accommodation for patients with advanced disease. Liminality is contingent on the modern availability of cancer treatment, and I show how treatment becomes a way of life, rather than one stop on the way to recovery. I argue that once liminal, patients have difficulty reintegrating into society because the category of the ‘not-surviving-not-dying’ cancer patient is not recognized.

In Chapter 5, I draw on classical and contemporary anthropological approaches to the study of time to examine how patients with advanced disease are often situated ‘out of time’ and how this is a form of exclusionary politics. While the literature on cancer and temporality has emphasized that people living with cancer tend to focus more on the quality rather than the quantity of the time that remains, I demonstrate that the patients I followed still thought of time much the way they did before diagnosis. Moreover, even if they would like to contemplate more time-worthy activities, their attachment to the hospital and to regular treatment schedules means that their time is not their own, but rather greatly constrained by the bureaucratic time of the hospital. I illustrate four primary “modalities” of time that patients experience, and argue for a more honest appraisal of patients’ struggles with time, suggesting that they are exemplary not of life-threatening illness, but of the human condition more generally.
A Note on Style

In this thesis, you will meet people like Olivia, Mary, and Melody, and read their stories about how they live with the diagnosis of incurable cancer and move forward in their lives, even as they are called back and back to the hospital. These are some of the narratives about their lives – their struggles, their inability to fit into the categories that were offered to them, their optimism even in the face of dismal odds. It is about life lived with cancer, in spite of it, and in its shadow. But they are not merely stories, for they are not static. Some of the people you will meet continue to live with advanced disease. They survive, in the most basic and literal sense of the word.

Other people are no longer alive. By revealing this now, I am telling you the ending before you have read the story. Does it defeat the purpose of reading? It is an intentional strategy. Most memoirs of cancer tend to be written after the threat of death has passed, and in doing so, “they tend to gloss over the continuing difficulties of the experience and to write after the fact, imposing retrospectively a story of triumph” (Conway 2007:17). Couser, writing about memoirs of illness, remarks on the unusual style of Middlebrook’s memoir Seeing the Crab: A Memoir of Dying (1996); he says, “no other retrospective autobiographical account with which I am familiar takes for granted from the beginning the eventual death of the narrator” (italics his, 1997:75). By intentionally writing sometimes in the present tense and sometimes in the past tense, Middlebrook rejects a linear account of her illness (Couser 1997). Similarly, Jackie Stacey in Teratologies: A Cultural Study of Cancer (1997) both a memoir and a cultural critique of cancer, refuses to write her narrative in chronological order. She tells the reader from the outset that “stories of progress and rationality” are seductive, but they “leave no room for the futility of pain and the arbitrariness of disease, the unbearable pointlessness of suffering” (Stacey 1997:15). Although she herself sought comfort in the “conventional” narrative form – where heroes triumph, people who fought hard emerge the victors – she is too aware that this type of narrative structure privileges “the triumphs of a few at the expense of the majority” (Stacey 1997:15).

Thus, following Stacey (1997), Middlebrook (1996) and Conway (2007), I will not tell patients’ narratives in a neat and tidy order. You may read about a person’s death in one chapter, and then encounter him or her again in the next chapter. Illness is not neat, tidy or coherent. On the contrary, life-threatening illness can throw a person into chaos (Frank 1995; Hagestad 1996; Batt 1994). While you encounter Deo, Mary, and Pam and others in these pages, pay attention to the ways they are spoken to, and the ways that they speak about their lives. Couser demonstrates
that in illness memoirs “without exception, then, the narrators are, or claim to be, better off at the end than at the beginning” (1997:39). For patients with advanced disease, there can be no story of “triumph” (Conway 1997); the story ends with them continuing to live with cancer or with cancer having cut their lives short. Thus, their narratives fall outside the typical plot of most illness narratives. As they already exist on the margins, I will not force their experiences into a form that does not fit.

Lastly, because these words are inscribed on the page, and in doing so give form and shape to people’s lives, this writing is a kind of “defense against mortality” (Conway 2007:16). In this case, it is not only my own mortality, but also that of the patients that I met and worked with, who so generously gave their time to me when their time was of the essence. For those who have died and for those who remain, it is my hope that through this ethnography, you will see them live.

Notes
1 All names included in this dissertation are pseudonyms. Names have been changed to protect the confidentiality of participants.
2 As I discuss in Chapter 2, palliative care is a “homeless” outpatient clinic at the hospital; as it has no dedicated space in the hospital, it moves around different sites, most of which are named after the primary tumour site (e.g., “Breast”, “Gynecological”, “Lung”, “Head and Neck”, etc.). Plans are underway to remedy this problem, and to build it a permanent space at Lady Ann’s.
3 Language is problematic in cancer, and these terms are not all used with the same frequency. Throughout the dissertation, I will use “metastatic” and “advanced” interchangeably. “Metastatic” was used more frequently inside the hospital, as it is indicative of a specific medical phenomenon: the cancer having progressed past its primary tumour site (CCS 2015). “Incurable” cancer was also used by physicians and nurses, but it is dependent on first defining the cancer as metastatic (i.e., the cancer metastasizes from its primary tumour site, resulting in it being qualified as “incurable”). However, in the literature, “advanced” seems more frequently used to discuss this population of patients. The adjectives “advanced” and “progressive” have positive connotations (since in most cases, something more advanced is something more developed and better), but when juxtaposed with cancer the connotations turn negative, exposing how metastatic disease produces yet another contradictory effect. Interestingly, I rarely heard anyone (doctors or patients, in referring to their own condition) use the word “terminal.” Baszanger notes that in the 1970s there was an active effort to dissociate “incurable” cancer from “terminal” cancer (2012).
4 Throughout the thesis, I use the subject “patients” to refer to persons living with advanced cancer. In cancer, identity categories have always been political. King (2006:107) documents the shift away from the “cancer victim” or “cancer patient” and towards the “cancer survivor” that took place in the 80s and 90s, remarking that, “the empowered patient – the activist-expert, the survivor – has become institutionalized and incorporated into the fabric of the cancer establishment.” For reasons that have hopefully already become clear, I will not use the category of “survivor” to refer to this demographic group (see also Rosenthal 2009). No one I spoke with
indicated that they had any problem with being seen as a “patient,” and this was the primary means by which I came to know them, i.e., as “patients” at Lady Ann’s hospital. Additionally, as I show in later chapters, although people living with advanced cancer might like to give up their “patient” status, and return to normal life, this is often not possible for them. The label should not be taken to suggest that I believe people living with cancer to be passive or without agency.

5 Palliative care encompasses care that is given when cure or complete reversal of disease is not foreseeable. It may relieve suffering and even prolong life in individuals with advanced disease (Butler et al. 1996), and includes pain and symptom management, psychosocial support, and coordinated end-of-life care. Palliative treatments are intended to slow down the disease and improve symptom control and management (e.g., pain), but they are not expected to make the disease go away forever (Butler et al. 1996). Palliative care often directly involves an interdisciplinary team, including physician, nurse, social worker, chaplain, and volunteers providing total care to the patient and his/her family (Saunders 1990).

6 For example, the doctor in gynecology, in telling me about a particular patient, would say something like, “She will die within 6 months for sure.”

7 Before germ theory and the development of anti-sepsis in the 1860s, surgery was often not recommended for patients with cancer. Within the Galenic theory of medicine (persistent since 200 AD and based on the four humours), cancer was categorized as “black bile.” It was believed that surgical removal would leak this bad humour into other areas of the body, and thus tumours were generally not cut out and left undisturbed (Mukherjee 2010).

8 The city where I completed fieldwork was a research and university hub; it presented numerous options for outpatient palliative care, as well as palliative care in the community. As such, it is not representative of the services generally available across the rest of the country, where specialized palliative care may not exist. For example, recent research has revealed that First Nations people in Canada do not have adequate access to palliative care (Kelley 2010).

9 Clark argues that palliative care and oncology “share a history that is intertwined at several crucial points” (2008:432) and that palliative care now finds itself at the “centre” of modern cancer care (2008:430). Notwithstanding the notable expansion of palliative care in Canada in recent years, this statement seems slightly optimistic, i.e., I am somewhat doubtful that all oncologists at Lady Ann’s would agree that palliative care is “central” to their work. His comment about the potential overlap of professions because they both offer supportive care is a very subtle hint towards the very real political differences that exist between professions, and their challenge in working together.

10 Earle et al. (2003, 2004) define “aggressive care” at the end-of-life as indicated by: starting new anticancer treatments very near death; a high number of ER and inpatient visits or days spent in the ICU near the end-of-life; and a high number of patients not enrolled in hospice or admitted in the last few days of life or dying in an acute-care setting.

11 Feinstein et al. (1985) called this the “Will Rogers” phenomenon, in describing the migration patterns of people from Oklahoma who migrated to California during the Depression. On average the people leaving Oklahoma were not as bright as the average Oklahoman person, but more intelligent than the average person from California. This produced an effect where both states saw a rise in their average IQs.

12 For example, after observing the Susan G. Komen Run for the Cure in Washington, D.C., Samantha King noted, “it is possible to deduce from these events that breast cancer is a fully curable disease from which people no longer die” (2006:36).

13 The term ‘culture’ has a long history and has been subject to debates within the field of anthropology in general and within medical anthropology in particular. Historically,
anthropology defined culture as an abstract set of beliefs/values/attitudes, that are acted on appropriately by society, that are learned (not biological), shared (not individual) and symbolic (giving names to tangible things); more recent definitions emphasize that culture is also contested and dynamic (Gregg and Saha 2006). See Wardlow (2002) for a brief summary of the debates in medical anthropology and a thoughtful discussion of how culture might be usefully applied in studies of health and illness. Wardlow (2002) suggests that rather than abandoning culture due to fears of essentializing or obscuring structural constraints, that we use culture, but recognize that the beliefs, behaviours and practices we associate with it are flexible and can be taken up in ad hoc ways by its members.

14 Medical practitioners are encouraged to be ‘culturally competent’ or ‘culturally sensitive’ and in the past, the pedagogy involved in obtaining this knowledge often resulted in memorizing key information contained in cultural ‘boxes’ (e.g., Spector 2000). However, critiques of these kinds of essentializing approaches to understanding and appreciating cultures have arisen from anthropologists (Gregg and Saha 2006) as well as from other researchers in health (Kumas-Tan et al. 2007).

15 The research-based theatre production Handle with Care? (Gray and Sinding 1999), based on women’s experiences living with metastatic breast cancer, dramatized this phenomenon in a very memorable way. One woman, the patient, stood in the middle of the stage, while other actors walked by citing advice, such as “here’s the latest studies on cancer” or “here’s some foods that will help you get better” or “you should be trying this natural health remedy.” Each person mimed handing over a bunch of papers to the woman, so in the course of the scene she was literally buried by advice (much of which contradicted itself). The scene ended with the patient telling her friends and family what they could actually do to be helpful to her – practical tasks that would make her daily life easier such as: make a meal, help with laundry, or take her to appointments. See also Marchetto (2006).

16 In a critique of the “triumph narrative” of typical illness memoirs, Kathlyn Conway (2007) demonstrates that this invisible exoskeleton had very real consequences on childhood survivors of polio. The March of Dimes, an American fundraiser for polio, often featured happy children who could walk across the stage, crediting American generosity for their progress. Stories about suffering and the reality that children were tethered to iron lungs were not newsworthy; rather, the children were encouraged to see their experience as potentially leading to “insight” (Conway 2007:28).

17 Interestingly, Patterson reveals that because of the general lack of medical knowledge and treatments in the late 19th and early 20th century, physicians were not seen as more trustworthy than so-called ‘quacks’ or other healers (Patterson 1987:20).


19 Nor are there always adequate treatment options for people arriving early. Thus, the conditions and context of Livingston’s (2012) research site in Botswana are completely opposite to those in my research site at Lady Ann’s. In her fieldsite, inadequate resources and staffing results in few chemotherapeutic treatment options, with many patients having to undergo amputations because tumours are necrotic. Whereas in my fieldsite, even patients with advanced disease had several
treatment options to consider, including enrolling in clinical trials, which further extended these options.  

Canadian Medicare is delivered through the provinces and territories, which means that each province decides what drugs to fund. Although the publicly funded health care system allows people to receive treatment at no individual cost, there are of course disparities in terms of cancer treatment across the country. The Canadian Cancer Society regularly reports cancer statistics by province, which makes these differences in incidence and mortality rates explicit. For example, certain cancer drugs are funded in one province, but not another, resulting in some patients not being covered for more expensive or newer cancer drugs. For example, Avastin, a drug made by Roche, is a drug that is being used in several types of cancers. It was adopted as “experimental” for ovarian cancer during the period of my research, but I believe has since been made available off clinical trial.

For example, Conway’s (2007) introduction, where she is critiquing the post-traumatic growth literature, reads a bit too simply. She cites well-known popular examples, such as alternative health gurus such as Deepak Chopra and Andrew Weil, but they are easy targets. So it may be true that “triumph narratives” are needlessly or impossibly positive, but she is using the most obvious examples as evidence. Also, she seems unaware that there is a large academic literature on illness and health that could complement her discussion. She mentions how there is a “new” focus on literature on illness and mentions anthropology and the medical humanities, but does not draw on this work to support her points. Rather, her discussion draws most heavily on popular sources and personal experience, so it comes across as seeming less academic.

This point was made evident when I participated in a small workshop on cancer survivorship in 2011. We began with personal introductions around the table, and out of 16 participants I was one of a minority who did not begin her introduction by describing a personal history of cancer.

Mukherjee (2010) describes Dr. Sidney Farber’s realization that as a scientist, he needed to work hard to cultivate relationships with the upper elite in Boston in order to get Children’s Hospital built, where he trialed the first chemotherapies on children.

The return on investments for companies is well chronicled in the documentary based on King’s book (Pool 2011). In a very memorable scene, product after product is placed one on top of the other, showcasing the litany of products and causes that have been attached to breast cancer. Most disturbing perhaps is the example provided by the NFL; at a time when scandals concerning several players and domestic abuse were on the rise, the NFL took up the pink ribbon, and wore pink gloves, had a pink ribbon on the field, cheerleaders in pink ribbon costumes, with the explicit message: The NFL supports women with breast cancer (benefitting of course from the other, implicit message: the NFL does not condone domestic abuse).

At a fundraiser for research for “all women’s cancers” in the city where I conducted fieldwork, the crowds were awash with a sea of pink. Even though ovarian cancer was included in this event, there were very few teal ribbons or products to be found. Activists such as Sharon Batt (1994) would note that breast cancer has been so successful in making itself into a public health issue because women worked hard to bring national and international attention to it in the 1980s and 1990s, when no one was interested in paying attention (see also Klawiter 2000). In a queer twist of plot, some of the hard work done by feminists to draw research money to breast cancer in the 80s and 90s has now been co-opted by the pink ribbon culture, which makes many women with the disease quite angry (see Pool 2011 for examples).

Interestingly, speakers at these events often expressed a desire to attract more sponsorship to ovarian cancer so that there would be more ‘teal’ products on the market. I saw this largely as a problem of visibility; women were fighting to bring attention to ovarian cancer, and they saw any
publicity as good publicity. A few patients were similarly encouraged when actress Angelina Jolie published a piece in the New York Times in 2013, describing that she had undergone genetic testing for ovarian and breast cancer. Having discovered she had inherited the BRCA1 gene, she wrote about her choice to pursue prophylactic mastectomy and hysterectomy as prevention. This piece brought significant media attention to ovarian cancer.

27 These ads feature pictures of real people with lung cancer, and its various complications (e.g., gum disease, rotting lungs). As such the campaign focuses on painting smoking as an individual choice, and ignores other social factors that might impact a person’s desire to smoke (Tobacco labels 2015).

28 A cartoon from the 1950s is indicative of this culture of fear. It depicts a large crab with two men caught in its claws. One claw encircles the first man’s core and another man tries to pry open the claws, while a woman looks on. Another man’s leg is caught by a claw, and he hangs dangerously over a precipice (National Library of Medicine in Patterson 1987). It is difficult to imagine such a graphic cartoon being published today.

29 Most literally, in President Nixon’s 1971 declaration of a “war” on cancer.

30 As Thomas Edes (2008) points out in a recent editorial, the war metaphor may not be useful when we apply it to the personal decisions that physicians or patients make as individuals when faced with advanced disease. He reviews the case of his good friend who is dying from cancer, noting that when she told her doctor she did not want to pursue aggressive chemotherapy when her cancer came back a second time, he responded, “Well, if you just want to die, you might as well commit suicide.” His friend chooses to enjoy her last days as she plans them, not as they are dictated by a chemotherapy schedule. She rejects the metaphor her oncologist readily subscribes to and for this decision she is treated as somehow less courageous or less honourable (Edes 2008:2483).

31 As Martin demonstrates, when the body is equated with the nation state, and simultaneously as a police-state where cells contain “proof of identity” to distinguish from “illegal aliens,” these metaphors are working to reflect and reinforce racial tensions and anti-immigration sentiments in the U.S. (Martin 1990).

32 Mukherjee (2010) notes that renowned surgeon William Halsted, whose procedure the “Halsted radical mastectomy” became standard for breast cancer in the early 1900s, chose the term “radical” to invoke the Latin meaning of the term, which is “root.” He wanted to convey that his surgery would remove all the tumour, since the etymology of “radical” implies getting to the root of something. But as Mukherjee notes, “‘radical’ also meant ‘aggressive,’ ‘innovative,’ and ‘brazen,’ and it was this meaning that left its mark on the imaginations of patients. What man or woman, confronting cancer, would willingly choose non-radical, or ‘conservative’ surgery? People tend to want the strongest thing on offer” (2010:70).

33 Patterson demonstrates that there is some historical precedent here. Cancer was known in the late 1800s as an “alien and living invader” that ate people by tearing at the flesh, and ravaging their private parts. Cancer was compared to a dinner guest that arrives uninvited, eats all the food, and then consumes the family itself (Patterson 1987:30-31).

34 Empowerment is rarely juxtaposed with “doctors” as it is assumed (correctly, I believe) that doctors are often already empowered enough, especially in the hospital setting (Foucault 1994[1973]; Good 1990).

35 For example, with regards to diabetes, Annemarie Mol (2008) argues that even in a consultation where patients are given “informed choices,” their sick bodies preclude them from ever being full agents like doctors.
Here are some examples of “lessons” cancer provides: Ehrenreich, reading online breast cancer blogs, noted with horror that many women shared statements like “breast cancer taught me to love in the purest sense” (2008:29). Similarly, Lewis notes that the once very popular Livestrong foundation, founded by cyclist Lance Armstrong, suggested that cancer should be viewed as an opportunity to “triumph over adversity” (2013:660).

Similarly, Hitchens (2012) notes that the whole idea of “what doesn’t kill you makes you stronger” is a farce. He says a sign of post-traumatic stress disorder (PTSD) in veterans is the usage of that exact sentence; it is one of the manifestations that denial takes.

For example, Lance Armstrong built his whole Livestrong foundation on the notion of ‘re-crafting’ the self, as he did so successfully after prostate cancer, coming back to win the Tour de France as a cancer survivor. But his recovery was anything but “typical,” given his above average income, access to the best medical treatment and level of fitness (Casper and Moore 2009:164).

I was introduced to Barbara Ehrenreich’s work on cancer through a radio interview on the Canadian Broadcasting Corporation (CBC), when Bright-Sided: How Positive Thinking is Undermining America (2008) was first published. On hearing her disparaging remarks, I wondered, “Who is this caustic woman who refuses to be placated, no matter how hard the interviewer tries to get her to say something nice about cancer?” Her often-cited essay, Welcome to Cancerland, first published in Harper’s (2001) is now a classic, and was an early critical offering pushing back against the prevailing pink ribbon culture that assures women that breast cancer can be “pretty,” “sexy,” and life-changing in a good way.

The authors’ introduction indicates that they will use completion of primary treatment as their marker for inclusion in survivorship, but will also include “those individuals with cancer living with disease on an intermittent or chronic basis” (IOM and NRC 2006:19). Later in the book, in a section entitled, “When does survivorship care start and end?” the authors state, “survivorship care lasts until recurrence, a second cancer, or death” and that in the two cases that are not death, patients enter into the “acute” phase of care, and then may go back to survivorship (IOM and NRC 2006:189). Thus, it is difficult to know whether or not patients with advanced disease are included in cancer survivorship research in any meaningful ways.

In the inaugural issue of the Journal of Cancer Survivorship, editor Feuerstein (2007:5) acknowledges that “it is well recognized that there are survivors who continue with ‘treatment’ or management and that it may be unclear when primary treatment ends” and says that the journal will consider those people “survivors” as well (2007:6). Yet even researchers and clinicians who embrace the broad definition in theory often choose to apply that definition in practice more narrowly.

Interestingly, Weisz notes that affluent groups wanting to advance cancer research as a single agenda did not want it associated with other chronic conditions, such as venereal diseases (2015).

My own reading of seasons one and two of The Big C, which I watched after completing fieldwork, is that they got a lot of things right and a lot of things wrong. There is a wonderful scene where Cathy attends a support group that is overwhelmingly positive and encourages her to see cancer as a “gift” that pokes good fun at the whole post-traumatic growth movement. But other absences struck me as odd. For example, the character rarely looks sick. She undergoes chemo but does not lose her hair (perhaps this is true of melanoma drugs) but even on a clinical trial in Season 2, she rarely looks sick. Also, she jokes all the time about “how she is dying so it doesn’t matter,” but no patient I ever met spoke like this. When you are living with serious illness, one’s life is not a laughing matter. Also the drastic level of her actions – cashing in all of
her retirement savings, having a marital affair – were very over-the-top. The patients I met did not similarly upend their daily lives, mostly likely because they were all hoping to live.

44 If I were asked, as an instructor, to complete a survey about how I had handled difficult students in the past, or how I would handle hypothetical difficult student X, I would answer as honestly as possible, but I would have the benefit of time to reflect on what I wanted to say and how I wanted to present myself. So my answers would have this bias: given the best circumstances, this is how I would react. But this is likely somewhat different from how I would react if a student arrived unannounced at my office door and was in my face with a complaint and needing to be dealt with. We all want to believe in ideal versions of ourselves – whether in oncology or in the mundane activities of daily life such as parenting. But how we react in practice as an action unfolds might be different from how we wish we might have reacted or how we hope we might react in the future, given the benefit of time, distance and reflection.

45 Ronald Barrett (2005) demonstrates that leprosy in India is so highly stigmatized that even after people receive treatment for the disease, they are still discriminated against. Thus, the stigma of the disease remains with a person, even once they have been cured of it.

46 Although examples such as birth, puberty, and funerals demonstrate what might be called ‘life-crisis’ rituals, Van Gennep (1960) showed that rites of passage may also take place for any change to status or state.

47 Turner defined a state as “the physical, mental or emotional condition in which a person or group may be found at a particular time” (Turner 1967:94).

48 Van Gennep was speaking specifically about the transition rites of mourners, in terms of how long it might take them to be “aggregated” back into society (i.e., referring to the duration of mourning and the length of time people would keep up symbols of mourning, such as wearing all black clothing).

49 Stoller describes the village of the sick as a place where “the routine of treatments and side effects consumes your conscious thoughts and soaks up your time”; he contrasts this with the path of “continuous liminality” which is characterized by the “calm waters of remission” (2009:35).

50 As Hitchens notes about his doctors finding signs of his cancer in his clavicle, “it’s not at all good when your cancer is “palpable” from the outside.” (2012:3-4). Mary found these cancer nodes on her arms and other parts of her body very disturbing, but they never seemed to garner much attention from her team.
The kind of liminality I am looking at is the transition between life and death and the strange space patients exist in when they are diagnosed with a kind of cancer for which cure is a less likely outcome. I am exploring everyday life for the patients who have metastatic cancer, as well as for the professional staff who care for them. Some of these patients are told they are moving towards dying and for some it is more ambiguous. My focus is on everyday life with that knowledge and how the hospital system and culture factors into how patients and staff manage the tensions of advanced disease. So for my patients it is kind of a period of extended liminality. There is no 'reintegration' in mine either, but for different reasons than yours. I am following a small number of people through the process - originally 11 - now 8 - and spend time with them when they come to the hospital, sitting in waiting rooms and observing some of their interactions. So I've become close to people in a way I didn't anticipate. There is a particular kind of connection that is made possible when you sit with people and witness very personal and life-changing news. I am trying to see the whole experience from their perspective, but of course in doing that, I become implicated in the experience as well.

This excerpt from an email, written in December 2011 to a colleague I had recently met at the American Anthropology Association meetings, provides a glimpse into the methodological issues I encountered in my fieldwork. In a condensed format, it touches on many of the themes explored in this chapter: doing ethnography in a hospital setting; working with patients who are ambiguously positioned between life and death, the death of participants over the course of the study, and becoming implicated in people’s care by nature of being a witness to the conversations that shape the contours of their lives. Like me, this colleague was a junior scholar, whose research project focused on life-threatening illness and involved close and sustained contact with patients. I felt compelled to go up and speak to him after I heard his talk, which focused on the emotional nature of fieldwork, because after 10 months of fieldwork I had not come across one other person who captured so precisely the unique challenges I was encountering in my research at Lady Ann’s.

For over two years, I maintained contact with a small number of patients with advanced cancer and their caregivers. I watched as they waxed and waned with the inherent uncertainty of metastatic disease, hoping to be better, and never knowing, when they were feeling better, if and for how long it would last. These experiences left a permanent mark on me. Geertz has described the goal of anthropological writing as the ability to convey that the author has “been there”
In this chapter, I build on Geertz’ terminology, arguing that sensitive topics such as advanced disease require a kind of physical and emotional proximity or “closeness” between the ethnographer and informant. “Being close” to cancer conveys this dual sense of proximity, produced by being present with patients in the various spaces of Lady Ann’s and by trying to understand their lived experience of disease. Sitting long hours in waiting rooms and treatment areas alongside patients allowed for a special relationship to develop between us. As a witness to their experience of the hospital, and to the intimate details of their bodies and their lives, I saw aspects of their everyday life that were difficult for them to share with others, even supportive friends and family members. Because patients did not depend on me to receive treatment or care, they could be more open and honest about how they were doing than they could with their health care team.

As a researcher, “being close” meant that I opened myself up to the fears that patients faced, as it is very difficult to try to write about cancer and the kinds of aching uncertainties it presents once it has come into someone’s life, without at times experiencing some of the fears, worries and nervousness yourself. The research required many times that I react not like a researcher, but just as a fellow human being. Doing this research brought me securely into the world of cancer, and it is not one easily left behind. Having been inducted into this world means that, similar to patients and medical staff, for whom cancer is their daily reality, I now imagine too well the possibilities of someone’s future when I hear he has metastatic disease.

This chapter presents the methodology for my study, and the rationale for using ethnographic methods to examine the culture of advanced disease. As Murphy and Dingwall point out, ethnography is the “gold standard for the study of processes, a study that is as important for policymakers and practitioners as the study of outcomes” (2007:2230). Ethnography is an apt methodology to examine the culture of cancer because its intention is to describe a system of relationships, “to show how things hang together in a web of mutual influence or support or interdependence” (Becker 1996:56). These goals differ significantly from those of medical research on cancer care, which are often focused on controlling for the conditions of everyday life in order to examine a single relationship between two discrete variables. To answer the research questions, the ethnographer observes and interviews individuals; however, the focus of analysis is not individual behaviour, but rather the patterns that underlie people’s behaviours and actions. As such, ethnography “attempts to clarify the
relations of individuality, both as output and input, to its sociocultural and material contexts” (Levy and Hollan 2015:314).

I begin by discussing the preparations that preceded the fieldwork period, including gaining access to Lady Ann’s first as a volunteer and a part-time staff, and then as a researcher. Taking up the latter role included a lengthy process of re-crafting my anthropology proposal into a protocol that would be suitable for the hospital’s Research Ethics Board (REB). I then provide a summary of the research program, including participants’ characteristics and the kinds of data I collected. Participant-observation and interviewing (informal, unstructured and semi-structured) were the primary modes of data collection. I delve deeper into some of these methods, such as unstructured interviewing; although it is not a common source of data in qualitative health service research, where semi-structured interviews tend to be the method of choice, I demonstrate that unstructured interviewing is an ideal method to understand “the lived experience of fellow human beings” (Bernard 2002:204). Less frequent semi-structured interviews proved useful for checking the accuracy of my observations, and for allowing participants to consider several substantive themes removed from the busy time and space of the clinic. Lastly, I discuss some of the implications of doing research with patients with advanced cancer in terms of the emotional impacts of fieldwork on the fieldworker (Coffey 1999).

Despite the very significant challenges I encountered in doing this fieldwork, throughout the chapter I am advocating that cancer research needs more grounded, in-situ approaches like ethnography, which take as their focus the “everyday world” (Becker 1996:61) of participants. This everyday world is not an ‘ideal’ world – where model conversations about advanced disease and approaching death unfold between oncologists and patients – but the world that actually exists, and is grounded in the practices and interactions that take place everyday in the hospital (Mol 2002, 2008). For scholars trying to understand the lived experience of serious and life-threatening illness, there is no better discipline than anthropology, “the most fascinating, bizarre, disturbing, and necessary form of witnessing left to us at the end of the twentieth century” (Behar 1996:5). For quintessentially human, emotionally charged topics such as life and death, the “intense, intersubjective engagement” (Clifford 1983:119) offered by ethnography is a unique mode of knowing that emerges from human connection and human relationships.
Getting In, Part 1: Gaining Access as a Part-Time Staff and Volunteer

My introduction to Lady Ann’s was greatly facilitated by one of my co-supervisors, who holds a clinician-researcher position there. He introduced me to the research culture at Lady Ann’s and supported my project in explicit ways – by serving as the P.I. for the REB application (as a non-staff research student I could not submit an application), by helping to develop my research protocol and plan, and by contacting several oncologists whose clinics I hoped to observe. Through a connection to him, I was fortunate to become employed as a research assistant at Lady Ann’s on a project evaluating a brain cancer support group in the summer of 2007. This position provided me temporary access to patient charts, and it was in completing work for that project that I observed how seldom palliative care was mentioned in the formal medical record, even for patients who were diagnosed with incurable illness. Conversely, treatment, even if it was for palliative purposes, was a prominent feature of the written accounts of what had been discussed during consultations. This job required that I attend a hospital orientation, and update my immunizations so that occupational health could give me clearance to work at Lady Ann’s.

In the fall of 2007, I began training as a volunteer at Lady Ann’s, as a way to become more familiar with the hospital and with its patients. At that time, I was starting to think about my research proposal. I was accepted into a new and unique psychosocial volunteer program. While a “clinical” volunteer group already flourished at Lady Ann’s, regularly stepping in to assist staff with tasks such as copying, clinical reception, and transporting services, this new “psychosocial” group was primarily intended to assist patients, by providing information about the hospital, navigational assistance, and emotional support. I attended 2.5 days of excellent, intensive training, which began with a general orientation to the program and ended with role-playing scenarios. I was placed in a palliative care outpatient clinic that was situated in the gastrointestinal (GI) tumour site, and for my first few shifts I was shadowed by a supervisor and given detailed feedback. I began volunteering on Monday afternoons in February of 2008 and had my last shift at the end of January 2011, as I was set to begin research on February 1st. By that time, I had amassed over 400 volunteer hours.

Both my experiences as a part-time staff and a volunteer were crucial in helping me to shape a research proposal that reflected issues I was witnessing in the field. Through a period of
three years, I came to know the hospital, its organization, its staff composition and how the different clinics were set up. Reflecting on how long it took me to get my bearings made me realize just how much patients do not know when they step foot for the first time into Lady Ann’s (and I had the benefit of not being sick while I was learning the institution). On the suggestion of a senior faculty member in our department, I kept fieldnotes about my evolving understanding and general experiences, which later proved very useful for the exact reason she had suggested: they helped me to remember that I had once found it all very confusing.

Every week as a volunteer, I spoke at length with dozens of patients facing various kinds of cancer in waiting rooms, in consultation rooms, and in random places around the hospital. I found that some patients spoke quite candidly and openly about their cancer, while with others, small talk was a better approach. I was surprised by the expertise many patients exhibited regarding their care and their comprehension of their illness; yet with other patients, confusion reigned over where to go, the nature of their appointment that day, and what questions they had for their practitioners. Some of the conversations I had were very memorable and spurred questions that became part of my research. For example, although I was working in an “outpatient palliative care clinic,” my training binder instructed me explicitly to not mention the word “palliative” when I was speaking to patients unless they brought it up first. I believe this instruction was intended to prevent volunteers from answering questions that were better suited for patients’ doctors and nurses. But avoiding it was not always possible. On more than one occasion, while I was walking patients to the consult rooms for their appointments in palliative care, I was asked, “What is palliative care?” It seemed to me this was a question that should have prefaced their referral and was certainly not something they ought to be hearing from a volunteer they had just met.

Another memorable and frequent experience was watching very sick-looking patients approach the clinical desk and check in for the Phase I Clinical Trial clinic, rather than the Palliative Care clinic. The Phase I clinic also ran out of the GI site on Monday afternoons. These patients looked very unwell – pale, emaciated, and sometimes arriving in wheelchairs – and the patient flow coordinator (PFC) (i.e., receptionist) and I would assume they were checking in for the palliative care clinic and try to call them over to our station. To both our surprise, we would see them check in with the station beside us, where a different PFC registered patients for the Phase I clinic. Based on physical appearance alone, they seemed very unlikely candidates for the Phase I team, who needed patients to be well enough to withstand what were often very
demanding and difficult treatment regimens. Mistaking these sick patients as palliative care patients, when they were actually research oncology patients, foreshadowed the overarching focus on action and on treatment that I would later observe in my research.55

My volunteer placement also allowed me to learn how the clinics worked, and to build relationships with different members of the staff – from PFCs with whom I worked most closely, to the doctors and nurses running the clinic – and all of this existing rapport proved extremely helpful once I began formal data collection, as I was somewhat of a familiar face around the hospital. I helped keep up the flow of the clinic by bringing patients into consult rooms, by retrieving hospital blue cards from the printer (located in another site), by taking patients up to CT scheduling to try and get their appointment times rebooked, and by accompanying patients to the library and helping them to find appropriate resources. I intercepted arguments, sat with crying patients, and gave lots of hugs and smiles as a volunteer. I loved being useful and how something that came easy to me – being friendly, sharing a smile, giving a hug – could make a small difference in someone’s experience at Lady Ann’s. I remember an older gentleman, who had been coming to the outpatient palliative care clinic for a long time and knew me well, saying to me, “You’re the best thing that happened to me today” and how that compliment made me glow and feel good about the work I was doing.

I thought that the volunteer work would prepare me for the fieldwork, and it did in many ways. I did begin my research with a far greater understanding of the setting and the people than most anthropologists conducting research for the first time. However, I believed naively that the numerous conversations I had with patients as a volunteer would be similar to those I would have as a researcher. And they were – in terms of the content. What changed, when I started my fieldwork, is that I came to know the people in a much more in-depth way. I knew their families and friends, and I knew what they had worked at before their lives had been interrupted by cancer. Seeing them as mothers, daughters, fathers, grandpas, managers, teachers, contractors – as central figures in lives interrupted by cancer – made watching them deal with the inevitable ups and downs of treatment much more difficult. I found out that sitting and chatting with patients during a four-hour volunteer shift once per week was not at all the same as sitting and chatting with a patient whose case I was following. As a researcher, I became much more involved and invested in patients’ lives, to a level that I had not anticipated. It made the disease uncomfortably more personal, and more threatening.
Getting In, Part 2: Gaining Access as a Researcher

After passing my research proposal defense in the Department of Anthropology in early November of 2008, I then began the lengthy process of crafting yet another research proposal – this time one that would be suitable for submission to Lady Ann’s REB. The entire process of re-writing my proposal and preparing all the supporting documents that were required for the REB submission, as well as completing the hospital trainings so that I could conduct research there, took close to two years.\(^56\) Much of the research conducted in hospitals follows from the biomedical model, and takes the form of the gold standard – the double-blinded randomized controlled trial (RCT) – and thus hospital REBs are set up to review studies with this methodology. The required REB forms reflect the RCT model, where hypothesis, design, instruments, and intervention are all made explicit before the study begins. Within RCTs, research participants are “discovered and revealed in isolation of circumstantial factors” rather than seen as members of a social community, who are shaped and reshaped in social interaction (Oeye et al 2007:2302). While these studies may be very appropriate for testing new drugs and treatments, their efforts to isolate the variables in order to demonstrate a causal relationship in essence cancels out all the extraneous and contextual factors that are anthropology’s subjects (Sobo 2009). In considering how to re-craft my proposal into a protocol, I was guided by the substantial literature by anthropologists and other social scientists critical of how the RCT model frames hospital REB expectations (Sobo 2009; Gotlib 2005; Gotlib Conn 2008; Oeye et al. 2007; Murphy and Dingwall 2007; Fluehr-Lobban 2003).

My submission to the REB at Lady Ann’s required that I strip the theoretical and anthropological rationales from my proposal, and re-write them in the language of health services research (Sobo 2009). My 30-page double-spaced proposal written in prose was rewritten into a 9-page single-spaced ‘protocol’ template, with numerous required sections and sub-sections. Once I had a working protocol draft, highlights of that draft were entered into another standard template REB form, the LAREB, which was actually the main submission.\(^57\) This form limited the number of characters in each section, and many frustrating hours were spent trying to revise and shorten each entry. For example, I had 230 words to explain the entire study design and methodology, which included articulating all methods of data collection and their rationales (e.g., field observations and interviews, specifying where and when they would take place, and with whom). This exercise, once completed, proved to be an excellent lesson in
writing succinctly, and in writing anthropology for a non-anthropology audience. My first draft of the research protocol was completed in April 2009, but it was not until December that I had a submittable version. By the spring of 2010, I had solid versions of all the required additional documents, and my co-supervisor began setting up meetings with oncologists so that we could obtain and include their support in the REB submission. Meetings took place in the summer of 2010, concurrent with the finalizing of all documents. Finally, in October of 2010, the REB application was submitted. The study went through one round of revisions in November, and received approval in mid-January 2011. After approval was obtained, I submitted my proposal and copy of approved LAREB form to the University of Toronto’s REB for administrative approval, which was obtained in two weeks’ time.

In some part, the submission process was so lengthy because my co-supervisor and I were unsure what Lady Ann’s REB would make of our proposal. We hypothesized that our submission would go one of two ways: 1) it would be reviewed very closely, as the idea of following around patients and being present as a silent observer might seem highly suspicious and as challenging patients’ right to privacy; or 2) it would be reviewed very quickly, as talking to people and observing them might seem harmless in comparison to giving them potentially life-altering drugs, as the RCTs of new drugs were doing. I was very wary of the first scenario, having met with two junior researchers who had also completed anthropological fieldwork in teaching hospitals in the same city and who had gone through lengthy and not very friendly battles with the REB in order to gain their approval. Both of these researchers shared their ethics submission documents with me, which were extremely helpful in demonstrating how to translate anthropology’s theory and methods into terms that would be understood by a hospital audience. I also benefitted from looking at many successful REB submissions by members of my co-supervisor’s research team.

In the end, we had very minor edits (suggested re-wording essentially), and we received approval with very little delay. But I am confident that our speedy approval was in large part a reflection of the extensive editing and revisions that the documents underwent prior to submission. The senior research staff member working with my co-supervisor provided invaluable assistance throughout this process. She had submitted and supervised many REB applications under her tenure, and she patiently and tirelessly read all of my drafts, commenting on any wording she thought could be potential ‘red flags’ for the REB. At her suggestion, I also met with a senior staff person at the REB, and she provided additional suggestions for the
wording and the kinds of documents to include in my submission in order to demonstrate that we were serious about protecting patient confidentiality in the research process.

In reflection, having to complete the forms for REB review at the hospital had two concrete benefits: 1) it helped me to clarify what I would do in the field; and 2) it gave me time to complete the many required trainings and clearances I needed in order to conduct research at Lady Ann’s.\(^{61}\) Firstly, looking back at my original proposal, I outlined methods of data collection that were simply not plausible. For example, I originally envisioned following patients and oncologists out of the consultation room, and interviewing each party separately for 4-5 minutes afterwards. But that method would have never worked because oncologists often have very little time between consultations, and any time they do have is occupied with prepping for the next patient. Being ‘in the field’ (in essence) allowed me to benefit from ongoing conversations with other researchers, hospital staff and patients and to include what I was learning in my ethics submission. Thus, I did not encounter any feasibility issues, common among anthropologists who are drafting proposals at home, away from the field. My proposal reflects for the most part what I actually did once I began official fieldwork. Secondly, the time enabled me to work on obtaining various people’s permissions and institutional clearances for research students. Having achieved these clearances, my hospital badge displaying my picture and my status as a “Research Student in Psychosocial Oncology” meant that I could move freely within the hospital. Since oncologists’ support for the project had already been secured, when I did receive REB permission to begin recruitment I only had to let them know and I could immediately begin attending their clinics. Therefore, having passed all of the institutional checkpoints to begin research, I was actually quite free to proceed into fieldwork with few obstacles.

**Doing Fieldwork: Research Overview**

This dissertation is based on 17 months of full-time ethnographic fieldwork between February 2011 and June 2012 in one cancer hospital in Eastern Canada, here called Lady Ann’s.\(^{62}\) During this period, I spent hundreds of hours at Lady Ann’s, observing the everyday activities of patients and staff drawn primarily from two oncology clinics (Gynaecology and Lung). These tumour sites were chosen for recruitment of patient participants because both gynaecological and lung cancers are often diagnosed late, when the cancer has already metastasized. So although they are both treatable, they are not often curable. Within these clinics,
I spoke to doctors, nurses, clinical trial nurses, patient flow coordinators, patients, and their families and friends, trying to figure what it was like to live everyday in the world of advanced cancer. From these two clinics, I approached patients for one of two types of participation in the study: longitudinal follow-up or one-time observation.

My main research activity centred around 11 patients with advanced cancer, who were followed longitudinally throughout their care (7 with gynaecological cancer; 4 with lung cancer). In aiming to understand their experience as much as possible and to see the hospital through their eyes, I literally followed them around the hospital: accompanying them as they sat in oncology waiting rooms, had consultations with doctors and nurses, received treatment in chemotherapy, were sent for specialized tests such as CT scans, ultrasounds or EKGs, and picked up drugs at the patient pharmacy. Patients’ level of participation was always open for negotiation on any given day we met. At the beginning of our meeting, I would check in with them verbally to see if it was okay for me to accompany them into the consultation, wait for them in the waiting room, sit and talk to them while they were receiving chemotherapy, or whether they would rather I not spend time with them that day and check in with them at their next appointment. Flexible participation in the study gave patients control over how much or how little they wanted to see me. This was important, given that Lady Ann’s was a teaching hospital, and there were often extra people present during their consultations that patients sometimes did not feel comfortable (or were not given the opportunity) to refuse. I believe that knowing they could say “No” to my observing any particular event, and not having it impact their continued participation in the study, helped to make patients and their families feel as comfortable as possible during the times I was present with them.

Thus, I have various sources of data for each of the 11 longitudinal patients, ranging from observing 1 consultation and multiple unstructured interviews for one patient to upwards of 20 consultations and multiple unstructured and semi-structured interviews from recruitment in February 2011 until the end of fieldwork in June 2012 for another patient. The nature of advanced disease also contributed to the variability in data, as some patients declined rapidly very soon after recruitment, and it was not possible to conduct semi-structured interviews with them. Additionally, I developed different relationships with each patient. Although initially each relationship began as that between researcher and informant, feeling a strong sense of connection with some participants meant that it was transformed over time into something more akin to
friendship. From the eleven patients whom I followed over time, I came to know nine of them quite well. Their stories, experiences and voices form the foundation of the dissertation.

**Patient participants: living with advanced cancer**

Longitudinal participants from the Lung site in the study were diagnosed with stage IV non-small cell lung cancer, which is incurable, so all treatment was considered palliative in intent. Lung cancer is the leading cause of cancer death in Canada for both men and women. Canadian cancer survival statistics group all patients with the same tumour type (regardless of stage), and the relative survival ratio (RSR) for lung cancer is 17% (CCS 2015).\(^64\) In the U.S., where they are able to provide survival statistics also by stage, the RSR for stage IV lung cancer is 3.8% (SEER Cancer Statistics 2011).\(^65\) The longitudinal patients with lung cancer include both patients coming to Lady Ann’s for the first time and beginning treatment (e.g., Mary and Deo), as well as patients who were mid-treatment when I met them (e.g., Dario and Paul). First line chemotherapy for lung cancer for stage IV disease typically included one round (6 treatment cycles) of a combination of two drugs.\(^66\) After completing that, patients’ treatment trajectories diverged considerably. If first line treatment went well, and the cancer was reduced or “stable,” patients often received a break from treatment and were put on two-month follow-up. After two months, they would return to the clinic with recent blood work and a chest x-ray. Lung cancer patients often also received radiation concurrent with (then called “adjuvant therapy”) or after chemotherapy to various parts of the body (e.g., to the lung (the original tumour site), but also to parts of the body where lung metastases typically go, such as the bones and the brain). For example, Dario’s treatment trajectory up until June of 2012 included: radiation to the lung; one round of 1st line or standard chemotherapy; one round of 2nd line chemotherapy; several doses of radiation to his back; two doses of radiation to his whole head.\(^67\) He had also attempted to enrol in several clinical trials, but was “kicked off” one and was not deemed eligible for the second.

Longitudinal participants from the gynaecological site in the study were diagnosed with metastatic disease, which in gynaecological cancer can occur at stages II, III and IV. Most participants included have gynaecological cancer can occur at stages II, III and IV. Most participants included have stage III or stage IV (recurrent) ovarian cancer. Ovarian cancer has an overall RSR of 45% (CCS 2015). One patient has metastatic endometrial cancer, which is grouped with cancers in the body of the uterus, which have an overall RSR of 85%.\(^68\) Participants all had surgery to remove as much of the tumour as possible, followed by at least one round of chemotherapy.\(^69\) Similar to the lung cancer patients, after first line treatment was
exhausted, patients’ trajectories diverged. For example, Elizabeth began a clinical trial with her first round of treatment, so in addition to standard chemotherapy, she received a trial drug. Although she completed the standard treatment after six cycles, she continues on the trial drug to the present day. Thus, though continuous, her treatment trajectory has been fairly straightforward. Pam, on the other hand, was also enrolled in a clinical trial from day one, and received two rounds of standard chemo in addition to the trial drug. When the trial drug stopped working, she was enrolled in a different clinical trial, and then a third one, followed by one cycle of compassionate chemotherapy. As of December 2015, she was receiving her third round of the standard (1\textsuperscript{st} line) treatment.

This study aimed to recruit patients with metastatic disease. Recruitment in each clinical site was greatly facilitated by the oncologist and her primary nurse, who made suggestions about which patients to approach. The longitudinal patients with whom I spent the majority of time included three men and eight women. Due to the gendered nature of one my tumour sites, this uneven split is not surprising. Although I only had three male participants, I also had regular contact with a few additional men: one spouse who was very involved in his wife’s care, and one friend, who often accompanied the patient. I found that there were some gender differences that stood out: men were often more forth-coming and direct in their conversation style, and they were more willing to talk about negative experiences at Lady Ann’s than women were. In the semi-structured interviews, men used euphemisms much less frequently than women, and spoke more frankly about the difficult position they found themselves in.

The majority of patients I interviewed were Canadian-born and spoke English as their first language, but several also came from the U.K., Italy and South America. All four patients with lung cancer were married or common-law, but only one of the patients with gynaecological cancer was married. The remaining women were never married or divorced. The majority of patients I met were from my parents’ generation (aged 50-65), born in the post-WWII period.\textsuperscript{70} The youngest person I interviewed was 32, and the oldest was 70. Based solely on their occupations (e.g., three teachers, a translator, a manager, a contractor owning his own business, a university professor, a security guard), the majority were middle-class, but I did not ask specific questions about income level. Income came up naturally in conversation with single women and with one family of a patient with lung cancer. For these participants, not being able to work or having to work less while undergoing cancer treatment caused a financial hardship. Many, but not all participants were able to go onto long-term disability and receive some compensation, but
for at least one family, it was a struggle to get access to these funds. Long-term disability requires the oncologist to complete and sign off on multiple forms, and thus income often materialized in the consultation rooms when patients would nervously raise the issue of whether the “forms” were ready to be picked up yet. Since my sample is small, I cannot make too much of these distinctions. Even for those who had been born elsewhere, Canada had been home for them for some time, and their experiences of the health care system did not seem to differ in any significant way. All similarly had the experience of having cancer interrupt their lives and take over.

In addition to the longitudinal patients, I recruited an additional 15 patients (nine in Gyne; six in Lung) for a one-time observation of their oncology consultation. One of these patients was also subsequently interviewed. The additional observations of consultations in each site provided an interesting contrast to the data I gathered on the longitudinal patients, for I knew only that they were diagnosed with metastatic disease. Sitting in on these consultations, with patients I had never met before, helped me to see how limited are research studies that use recorded transcripts of consultations as their sole source of data (e.g., Pollak et al. 2007; Fagerlind et al. 2008).

**Staff participants: working in the cemetery**

Prior to commencing research, my co-supervisor and I met with the heads of both the Lung and Gynaecology tumour sites, and then approached individual staff for their permission. Two oncologists, Dr. Lawson and Dr. Girard (pseudonyms) expressed interest, and after meeting to discuss the project, both gave me permission to recruit patients and observe the everyday activities of their clinics. The majority of the staff participants (doctors, nurses, physicians, patient flow coordinators (PFCs)) are women. Since both Dr. Lawson and Dr. Girard are women, it is possible that by conducting research in two female-led clinics, I missed aspects of the clinical culture observable in male-led clinics. However, the profession of medicine has been until recently a very male-dominated profession. Becker and colleagues’ famous examination of medical school culture in the U.K., *Boys in White* (1961), completely disregarded the experiences of female doctors. Although it may have been the case that in 1961, female physicians were in the minority, and therefore an unlikely focus of studies on the practice of medicine, that is certainly not the case today, where female students outnumber male students at many of Canada’s medical schools. Both Dr. Lawson and Dr. Girard have positions of significant power and demanding of respect at Lady Ann’s. Thus, I perceive this gendered view of oncology as a
necessary corrective to years of women being trivialized or minimized in social studies of doctors.

It is noteworthy that because of Lady Ann’s’ position as one of the country’s top research centres, the oncologists working there tend to be leaders in their profession. A patient with advanced lung cancer going to a general hospital in Canada is likely to be treated by a general internist or oncologist who treats all tumour types of cancer. Conversely, a patient with advanced lung cancer going to Lady Ann’s is likely to be treated by an oncologist who specializes both in lung disease and in the type of lung tumour that the patient has, and who has participated in and published clinical trials about lung cancer. The oncologists and fellows I saw everyday were top-notch clinicians and scientists, often principal investigators and co-authors on studies aimed at determining standards of care and improving the lives and survival of patients with cancer. So the oncologists and nurses at Lady Ann’s are specialists’ specialists – they have a very high degree of knowledge and experience because they see many patients with very similar tumours over the course of even one week of practice.

Many patients end up at Lady Ann’s because they have run out of options in their home communities; their cancer is so advanced that it requires the intervention of a specialized oncologist or the possibility of a clinical trial. The oncologists and nurses are thus working with very sick patients on a regular basis. One study of medical oncologists in the U.S. revealed that on average they give bad news more than 35 times per month (Baile et al. 2002), which is more than once per day. Furthermore, the Institute of Medicine has recognized that “the diagnosis of incurable, progressive disease that is expected to prove fatal is among the most difficult and sobering judgments that physicians make” (1997:30). At Lady Ann’s I observed that for oncologists and oncology nurses the disclosure of bad news is a daily experience of being at work. One brief example from the Lung clinic illustrates this stark reality.

When I first started observing in the Lung site, Dr. Lawson’s primary nurse, Eve, gave me the physical tour and helped to orient me to the work of the clinic. Dr. Lawson’s team regularly saw the toughest cases: patients with stage IV non-small cell lung cancer. Eve recounted that without treatment these patients would be “dead in 6 weeks.” One afternoon she showed me her filing system. It was a little card box, containing index cards she had completed for each patient, listing their basic information and contact numbers. This little box helped her to keep track of her new patients, as she explained to me that she only filed them away after they had “launched” – i.e., when she had seen that they had successfully completed the first few cycles of
chemotherapy. Until then, she kept the index cards close by, so she remembered to call and check in on them after the first few cycles. But every once in a while she needed to go through and remove the patients who had died. Thus, she actually called her card box her little “cemetery” because one third of the people in there were dead.

I share Eve’s story here as an important reminder that oncologists and nurses are regularly having to deal with the loss of their patients (Shanafelt et al. 2003; Pierce et al. 2007). I came to know 11 patients, and found it highly distressing when the majority of them declined and died. The staff in Lung and Gyne clinics see hundreds of patients each month, many of whom will not survive their cancers. “Bad news” conversations, which I discuss in Chapter Three, are thus the norm, not the exception. For Eve, the necessity of cleaning out the “cemetery” was a regular feature of her experience of being at work. Yet, oncologists are often critiqued for being “poor communicators” with little attention paid to this context of their work. My aim in including some of their experiences here is to underscore this difficult reality of their work.

**Participant observation**

This research provides a unique perspective to studies in cancer care by focusing on the “everyday world” (Becker 1996:61) of advanced cancer. Ethnography, which stretches out over time and space, is uniquely placed to interrogate the complexity of a clinical environment like a hospital, where a diversity of staff, patients, and families interact with each other and with a dynamic and complex hospital system (Sobo 2009; Kiefer 2007). Participant observation in particular was an ideal methodology as it revealed both explicit culture and tacit knowledge (Musante 2015:252); I asked people about their experiences and perspectives about advanced cancer, and over time, I also gained an understanding of the less observable aspects of their behaviours, such as knowing what kinds of actions and statements with respect to advanced disease were acceptable and which ones were not. Unstructured interviewing in particular allowed data collection to transpire throughout the different spaces of the hospital that patients regularly passed through (e.g., the blood clinic, the chemotherapy unit, the hospital coffee shop, the rooftop garden) rather than be confined to the consultation room, which is the source of the majority of the qualitative health research in cancer. In fact, often the most interesting things happened outside the consultation rooms, and came up in everyday conversations as I sat with patients for long hours in waiting rooms or in chemotherapy. Participant observation necessitates
consistent, thorough and timely note taking, and thus I took careful notes about everything that I saw.\(^{75}\)

During the busiest times of fieldwork, I was in the clinical sites 4 half days a week, observing the everyday activities of patients and staff, and using the free mornings or afternoons to write up fieldnotes, to call patients at home, to prepare for upcoming interviews, or to visit people in chemotherapy. In order to know when they would be coming to Lady Ann’s, I checked patients’ schedules and then printed off monthly calendars, filling in when they would be coming and what clinic they were attending. Although my preference was always to connect with patients in person when they were already coming to the hospital for scheduled appointments, if they were not coming for a while (a good sign for their cancer), I would call them at home and check in on them.\(^{76}\) Once I had recruited enough patients, increasingly my time in the hospital was spent in the company of at least one of them. Some days, I would be running around the hospital, dropping in on several patients in different locations. For example, my fieldnotes for September 6\(^{th}\), 2011 indicate:

*Time today with:* Elizabeth (10:45-11:45) consult in Gyne clinic; Pam (11:45-3:30 pm) consult in Gyne clinic, waiting in various places (outpatient pharmacy, coffee shop); Paul (1:30-1:40) ran up quickly to see him in palliative care outpatient clinic.

Writing up my fieldnotes for those days was challenging, especially when I spent considerable time with people, as I would try to hold in all the stories I would be hearing and not confuse one person’s details with another. On other days, I would spend most of a morning or afternoon sitting with a patient in chemotherapy. At least half of my time at Lady Ann’s was spent in chemotherapy, because drug regimens often require patients to be there for several hours.\(^{77}\) For patients with ovarian cancer, taking 1\(^{st}\) line chemo was a full day event; they arrived and checked in at 8:30 am and often did not leave until after 5 pm. People on chemo are stuck in place: they can get up and move to the bathroom, taking their IV pole with them, but they cannot leave the unit, making it an ideal place for unstructured interviews.

Patients saw me as someone connected to the hospital, but over time, also as someone aligned with them. Thus, I was seen as both an ‘insider’ and an ‘outsider’ at Lady Ann’s (Hoodfar 1994). My ‘outsider’ status was reinforced by the fact that I could not get patients into the clinic any faster or help them to jump the queue, causing a few of them to comment jokingly to their caregivers, “Alyson has little power.” My ‘insider’ status was reinforced by my hospital I.D. badge, which gave me access to many places that patients could not go. For example, if
patients were sitting in the waiting room and wondering how long it would be before they would be called in, I could go through the clinic door and into the back work area to check how many patient files were ahead of theirs in the roster. This door was not locked, but I seldom observed patients going through this door without being first called in by a nurse or the receptionist. Thus, they respected the boundary between the waiting area and the clinic area. I could also go behind the front reception desk and log in to the computers in order to look up an upcoming appointment or test for a patient and print off their most recent itinerary or make copies for them, if they did not want to bother the busy receptionists.

This dual status – sometimes being aligned with patients, and sometimes being aligned with the research and clinical staff – at times produced challenges. For example, as I could fit in with both populations, what was the appropriate dress code? When I began fieldwork, since I was spending a large amount of time in the clinical areas, I dressed in professional attire in order to fit in with the doctors and nurses. One day, as I waited for a patient outside the medical oncology offices, an older gentleman also waiting and reading off a folder he held in hand, looked up and asked, “Are you one of the residents being interviewed?” I felt myself grow red in the face and replied, “Oh no no no…I'm just waiting for someone here.” On another occasion, I ran into a colleague in the elevator who knew I was conducting ethnographic fieldwork, and she exclaimed “Oh, you look just like one of the fellows!” Both these offhand comments caused me to take pause, as I certainly did not want patients or families to confuse me with a doctor. So I revisited my wardrobe choices, taking note of how patients dressed, for which there was a wide range. When Jennifer was on chemo, she hated the way she looked and she hid herself in layers upon layers of loose, baggy clothing and always wore hats to cover up her bald head. But other patients dressed casually, and some, like Melody, seemed to even “dress up” when they came to Lady Ann’s. One day after I had begun dressing a bit more casually, I was reproached in a playful manner by one of my longitudinal patients for not looking “professional” enough. That experience in tandem with the previous two remarks helped me to see how my choice of dress did matter to some extent. From that point on I tried to dress somewhere between the doctors and patients, wearing dress pants or skirts with sweaters, but not jeans and not collared shirts and blazers.

Additionally, I spent many hours observing the everyday activities of medical staff in each tumour site. I used ongoing verbal consent for the various staff members I encountered in each site, because staff composition changed from week to week, with new trainees (e.g., fellows,
residents, students) who were sometimes there one week, and gone the next. Individual staff experiences were not the focus of my research, but observing their clinical work contributed greatly to my understanding of the culture of advanced disease at Lady Ann’s. Due to different recruitment rates in each site and some other factors specific to each clinic, I spent approximately two months in the Lung site, attending two half-day clinics per week (one for new patients; one for follow-up) and approximately 6 months in the Gyne site, attending two half-day clinics per week (each clinic saw both new and follow-up patients). I paid particular attention to conversations about patients facing advanced disease, organizational dynamics, as well as spatial arrangements and the physical environment. Initially, my questions for the nurses concerned whether I had accidentally mis-recruited anyone, because I found it very hard to believe that the patients I spoke with, who all looked physically very well to me, had metastatic disease. As I recruited patients into the study, and became more accustomed to the work of the clinic, we had more engaged conversations about how patients were doing, and about the nature of their work. My data from the clinical sites is compromised of these informal and unstructured interviews and general observations made while sitting in the work areas of both clinics, where I waited for potential patients to check in for their appointments. The work areas of both clinic sites turned out to be an excellent place to make observations about the daily life of the clinic, as I could observe the activities of the teams as they went about their work (e.g., seeing patients, reviewing files and charts, discussing patients, making phone calls, printing documents). Here is a fieldnote from my second week of fieldwork, which I like to think of as my first ‘lesson’ of clinic culture (Jo and Annie are the nurses; Louise is the receptionist):

February 8/11: So many interesting things happened in clinic today! I made the mistake of remarking, early on – maybe 10-ish that it was “kind of quiet -- not too crazy a day” to which Jo freaked out. She said, “You can never say the ‘q’ word!” She knocked on wood and said that you should never say that in clinic because it’s a curse – just when the shit hits the fan. She told Annie that I owed everyone lunch because I had said it. And the funny part was – she was so right! Shortly after I made that remark and was scolded for it, Louise called from the front and said that there was a patient with shortness of breath in the waiting room and Annie rushed out, followed shortly by Jo, wheeling the vital sign cart.

The physical geography of the space in Gyne facilitated my observations. The Gyne tumour site is actually shaped like an L: two long hallways, connected at a central point, and leading at either end to a waiting room (Figure 1.0). This means that the staff can wander from the south clinic to the north clinic or vice versa. Patients, however, are brought down the hallway from either waiting area, and leave the way they entered, never making it past the central staff
workroom. The oncologist I was working with, Dr. Girard, used the bottom end of the south hallway and she did her charting and computer work in this central room. On my first day in the field, I showed up at around 8:45 am and nervously took a seat at a large worktable within this room. There seemed to be another research staff person there and I did not want to sit around the outer wall, where all the computers and phones were located, presuming they would be for the doctors and nurses. But after the clinic got underway, perhaps noting my discomfort or not wanting me to observe the work of the other clinic, Dr. Girard said, “Alyson, come out here” and took me out into the hallway, where her nurses each had a standing workstation against the wall in the long hallway. Dr. Girard’s clinic used four consult rooms and I noticed that the nurses’ stations were located right about in the middle. Right across from their stations was a little hallway leading to a closed door, and I was able to get a rolling stool and wedge myself into this little T-spot. From that vantage point I could see everything that happened up and down the hallway, but I was out of the flow of traffic. My little ‘perch’ became an ideal spot to make observations in Gyne because I overheard and observed all of the interactions that went on as nurses brought patients in and out of rooms, as doctors and nurses chatted about the status of patients, and as nurses chatted with each other about upcoming meetings, patients, or life in general.

Figure 1.1. Layout of the Gyne clinic

Having two tumour sites proved to be very useful in terms of comparative purposes of the different ‘cultures’ that existed in each site. I was able to see how doctors and nurses were “talking their culture” (Durranti 1993:215). In lung cancer, the diagnosis was almost always the
same, therefore the ‘script’ of interaction hardly varied. After sitting in on 5 or 6 interactions, I had reached saturation. In gynaecological cancer, the possibilities for metastatic disease in different sites of the female reproductive organs (e.g., ovaries, endometrium, cervix) created the potential for many different kinds of conversations.

Although both sites dealt with metastatic patients, a surgical oncologist ran the Gynaecology clinic, while a medical oncologist ran the Lung clinic. As a surgical clinic, the Gyne site saw patients pre- and post-operation, which meant that there were often internal exams (for which patients had to undress and don a gown), examination of surgical scars, and sometimes dressing of wounds. Conversely, in the Lung clinic, physical exams involved often only the torso of the body and in general seemed to be much more rare in frequency.\textsuperscript{84} So while in Gynaecology, the body was often touched, prodded, and considered in detail, bringing the sick body to the foreground of interactions, in lung cancer, the focus often remained on the medicines and what could or could not be offered in terms of treatment.

In addition to moving around the hospital with patients and observing in the clinical sites, I participated actively in the research culture at Lady Ann’s, giving research rounds to various multidisciplinary research groups (e.g., palliative and end-of-life care; behavioural sciences) within the hospital. Outside the hospital, I attended local cancer conferences, sitting in on sessions designed for clinicians, as well as the sessions designed for public education, noting the differences in discourse. Audience members at ‘public’ talks asked what seemed to me very basic questions, revealing of the knowledge gap that existed between what cancer clinicians know about the disease and what patients know. Many questions were personal in nature, focusing on an individual experience or problem, which suggested to me that they had few resources to turn to find answers. Audience members at ‘clinician’ talks asked very specific questions related to treatment regimes.

For example, as my ethics approval was underway, I attended a case-based presentation that focused on one woman’s history of breast cancer, and an expert panel of three clinicians (a radiation oncologist, a medical oncologist, and a surgical oncologist) each took turns discussing how they would approach the woman’s treatment plan. This case was interesting for three reasons: 1) it demonstrated the reverence for Lady Ann’s in cancer care, as the audience members, who seemed to be other oncologists from across the country, asked the ‘experts’ many questions about their recommended treatment plans and rationales, demonstrating that the session was an edifying process for them; 2) it revealed the very clear distinctions between
different professions even within oncology, as the panel members frequently pointed to these differences, e.g., one surgeon joked that medical oncologists are known to make surgical decisions, and another panel member remarked, somewhat tongue-in-cheek, “I never make decisions without consulting my esteemed colleagues,” pointing to the very real challenges in getting the surgical, chemical, and radiation treatment plans to line up, which I later observed in the clinic; 3) it introduced me to the new language of the culture I was entering, as the clinicians were speaking in ‘code,’ using acronyms to describe genetic predispositions to cancer and complicated drug trial name abbreviations to describe the different drug regimens they would consider, and I hardly understood one word that was said. I still recall the sinking feeling I experienced during that session, and how it was my first introduction to the ‘foreign’ culture of oncology I would soon enter.

In addition to conferences, I also attended as a spectator and participated in runs and other ‘thons’ organized in the name of fundraising for cancer, hosted by Lady Ann’s and cancer organizations (e.g., Ovarian Cancer Canada). For all of these events I attended external to the hospital, I kept fieldnotes and jottings on conference napkins and programs; these fieldnotes and experiences form the basis of my discussion of cancer culture in the Introduction.

**Interviews**

Three types of interviews (informal, unstructured and semi-structured) (Bernard 2002) helped me to come to understand the culture of advanced disease at Lady Ann’s. Person-centred interviewing, which is central to the method of ethnography, provides two roles for the interviewee: 1) informant, where the interviewee serves as a knowledgeable person who can share information about the culture or behaviour in a particular place; and 2) respondent, where the interviewee serves as an object of the study itself, and can relay information about his or her own experience (Levy and Hollan 2015:316). In interviews with patients and staff, they often alternated between these two roles, even within the same conversation. For example, an interview with a nurse might begin by asking, “What does it mean to say that ovarian cancer has a “history of recurrence”?” but end by asking, “How do you find working with so many patients with serious disease?” Similarly for patients, I might ask, “How would you describe the atmosphere (or culture) at Lady Ann’s?” and then follow up with, “Do you have any strategies that you can describe about how you approach your time spent here?”
Informal interviews with patients and staff went on continuously whenever I was present at Lady Ann’s. The nurses in particular were instrumental in answering my questions and queries, as I tried to gain an understanding of what was going on. They exhibited a great deal of patience with me and were kind and generous in their willingness to help me recruit, to teach me about ovarian cancer (“here’s the ‘moose’” as Annie said to me one day, presenting me with the very basic view of the female reproductive organs that is photocopied and available in the consult rooms for explanations), and to share their experiences of what it was like working with a large number of very sick patients. As I sat in on consultations where nurses were teaching patients about chemotherapy and side effects of upcoming treatment, I was also learning, and the nurses kindly answered any questions I had out in the hallway after we had left the patient. With patients, both informal and unstructured interviews took place during the numerous hours of sitting and waiting for appointments at Lady Ann’s.

Informal and unstructured interviews with patients were particularly instructive in helping me to see patients’ lived experiences of advanced disease. As Bernard argues, “when you want to get at the lived experience of fellow human beings…you just can’t beat unstructured interviewing” (2002:204). Due to the numerous hours patients spent waiting for appointments and receiving treatments in chemotherapy, there were many opportunities to debrief about recent consultations or to plan for upcoming ones. Many times, patients and their loved ones would emerge from sessions not quite sure of what had just transpired. Because I had been there as well, we could ‘compare notes’ – each person would fill in what she had understood from the doctor’s words. These conversations were very useful in helping me to see how patients and loved ones differently interpret messages, and sometimes actually hear different things from the same conversation.

I was always conscious that asking patients for a formal interview was asking them to schedule one more thing into an already busy calendar. When patients were on treatment, their calendars were largely determined by treatment, follow-up, and testing appointments. Compared to a consult with their medical team, the interview with me had no bearing on their medical care. With the longitudinal patients, I conducted semi-structured interviews whenever it was convenient for them, with most of them choosing to wait until they had completed their first round of chemotherapy. Once they had completed the first round of chemotherapy, patients’ time would free up to a large extent because they were often given a “break” from the hospital for 2-3 months in order to rest and recuperate, and to allow the treatments to take effect. For example,
Deo, a man with lung cancer, spoke frequently with me about when we would “book” the formal interview. But he seemed to delay it for two reasons: 1) treatment was his entire focus, and until his first round of chemo was over, he did not seem to be able to consider adding more to his schedule; 2) it seemed he did not want to speak ‘too soon’ – he was nervous about the treatment and wanted to see how he did on it before committing his words to a recorded interaction. I always offered to travel to their homes for the interviews, so that they need not travel to Lady Ann’s, but only a few patients took me up on this offer.\(^{85}\)

When I did conduct more formal, semi-structured interviews with patients, we often began the interview with a mutual understanding of the circumstances patients were facing. As communication has long been a recognized problem in oncology, much of the qualitative research on cancer patients employs individual, semi-structured interviews in order to find out patient perceptions of their oncologists’ communication skills (e.g., Thorne et al. 2013). Thus, the researcher learns about what was communicated in consultations from the perspective of the patient, and has no other comparison because she was not present for the original conversation. In contrast, in this research, semi-structured interviews with longitudinal patients presented an opportunity to discuss and reflect on events that I had witnessed as well.\(^{86}\) Normally, a researcher might ask, “Are there any aspects of communication with your oncologist that you find helpful or frustrating?” Whereas I could ask, “Remember that time, when Dr. Lawson said […], do you recall how you felt when you heard that?” Or I could say, “I remember that you seemed a bit at a loss for words” and wait to see if they could take themselves back to that day. For example, in Chapter 4, you will read about the “timed arsenal” approach to treatment, and Dario’s reaction to being told that his cancer needed to get worse again before he would be given more treatment. I had been present when the oncologist patiently explained the reasoning behind this approach. Although her explanation was logical, its implication was troubling; this was the first time I had heard about this treatment strategy and I also found it surprising. When we sat down for a semi-structured interview several months later, Dario and I could speak about the consultation from a common level of experience since we had both been there for the original conversation.

In general, I found that the time spent with patients, familiarizing me with their history and their experience, proved to be very beneficial, when we finally did find time for a more formal interview. I also conducted a few interviews with patients I did not know very well, and these experiences offered an important contrast to my work with the longitudinal patients.\(^{87}\) Being familiar with longitudinal patients’ stories and experiences, the interview allowed us to have a
more in-depth conversation about issues that might have come up in the clinic or in chemotherapy. They also allowed me to “fact-check” my data and to confirm that what I had recorded in my fieldnotes was accurate, i.e., had I gotten it right? Second interviews would often begin with a recap of where we had left off the last time, and what had happened since then. These subsequent interviews offered patients an opportunity to reflect on past circumstances in light of present ones, and sometimes to take a different perspective on an issue previously discussed. However, at times familiarity in the interview would prevent me from asking particular questions or pursuing lines of inquiry that I knew would make them uncomfortable.

Semi-structured interviews proved to be very enlightening with some patients, and not very useful with others. To my surprise, I found that the male longitudinal participants were the best interviewees, as they seemed to take the format very seriously, and often mentioned that they had thought about what they wanted to talk about before the interview began. This variability confirms what other ethnographers have also found. For example, in his fieldwork with working class men in Ontario, Dunk (1991) found that the interview was not a helpful methodology, and that formal interviews produced formal answers. Bernard (2002:204) also argues that structured interviewing can “feel somehow unnatural” once you have built personal rapport with close informants. Briggs (1986) has criticized the interview for only gaining access to elements most readily available to the conscious mind, which is why having a combination of unstructured and structured interviews was invaluable for this research. Although some scholars argue that the “forced introspection” of an interview is not necessarily therapeutic (Miller 2000:102), in general there is a recognized benefit for the participant in being able to share their experiences, if for nothing else but to have a sympathetic, interested, and non-judgmental ear (Levy and Hollan 2015:319). I interviewed Norma, a woman with ovarian cancer, just after she completed her first round of chemotherapy and then did not see her again for several months because she was on follow-up care only. When I did see her next, running into her one day in the Gyne waiting room, she told me excitedly, “There were some things I forgot to tell you!” She proceeded to outline a few points that had come to mind once she had gone home on the day of the interview. Even though significant time had passed, she easily jumped right back into the interview, which suggested to me that the interview had kick-started a reflective process about her cancer and Lady Ann’s that had some benefit to her.
Positionality: Being and Having “a Person”

The empathy an anthropologist feels is part of his or her desire to be in a real human relationship with some informants – one that will outlast fieldwork. It is a celebration of a genuine mutual understanding between anthropologists and the people they come to know, based on the anthropologist’s struggles to grasp what informants really mean in their own terms (Lorimer 2010:106).

At the time of research, I was in my early 30s, single and living alone in a big city. The research brought me into contact with two groups of people: married couples (mostly in Lung) and single women (mostly in Gynecology). I do not think it was a coincidence that I felt the strongest ties with the single women with gynecological cancers, given that at the time I was also single and living alone. Their situations gave me cause for concern; I often wondered what I would do if I were faced with a similar diagnosis and who I would turn to for help. As Jennifer pointed out to me early in my fieldwork, most people coming to the hospital have “a person” or companion – be it spouse, family member, friend – who is their designated person to come to appointments with them for support. She made this observation because as someone who did not have “a person,” she was acutely aware of her own deficiency and spent time observing other women and their support people in the Gynecology waiting room.89

Her words have stayed in my mind, as I consider how the research allowed me to become “a person” for some patients who came alone, as well as some who came with a caregiver. Before I began this research, a colleague in psychosocial oncology asked how I would keep my distance, and hypothesized that I would take on a kind of caregiver role for some patients. One day in late January of 2012, I sat through Melody’s chemotherapy, along with her friend Victoria who always accompanied Melody whenever she came to the hospital. Melody had confided in me how grateful she was for Victoria’s constant companionship at Lady Ann’s – calling Victoria her “angel” who made the long days at Lady Ann’s more tolerable. I was surprised to find that over time, their very close friendship expanded to make room for an extra person: the anthropologist who followed them around, shadowing their every move at the hospital. On that day in January, Melody finished her first round of a third chemo for ovarian cancer. She had been very apprehensive about it, because the last time she was on chemotherapy she had had a toxic reaction that could have been fatal, had the nurses not quickly intervened. At the end of chemo, Melody thanked us both for being there, and gave us each long, warm hugs. Her
appreciation for our companionship on this day in particular was palpable, and brought me close to tears.

“Being a person” for patients meant being there as an anthropologist, but also sometimes as a confidant, a support person, or a friend. I became a special kind of “companion” to patients – a person who they met under very particular circumstances, to whom they could talk about their fears or anxieties, without worrying how it would impact me because cancer was the reason that we had met in the first place. Unlike some of their friends and family members, I wanted to hear all the sordid and unpleasant details of their daily challenges in living with cancer, because their experiences (whether positive or negative) were the subject of my thesis. I have had a close relationship with Melody now for close to five years, and know that she has no shortage of friends all over the world with whom she keeps in contact. I have even met some of them myself. But she has told me, “I don’t talk to other people the way I talk to you.” Unlike when she speaks to her children, and has to parse her words for fear of upsetting them by talking too much about how “sick mom is,” she does not have to worry about upsetting me in this way. Unlike when she speaks to her friends, and feels pressured to show them how cancer hardly slows her down, and she is still the “Energizer Bunny” who will not be kept from the social events and parties she has always attended, she does not have to put on that face for me. Sometimes she and I talk about cancer, and how much pain she is in and how she is “not ready to go yet,” and sometimes we talk about fashion, or politics, or relationships. I was present on one memorable day when she had a conversation with another patient in the Gyne waiting room, when the woman shared with Melody that she had been told there was “nothing left they could do.” She told me later that that woman “haunts” her, as the conversation upended all fears of what will happen if her own treatment options run out. That conversation continues to haunt Melody – she has only to say to me, “Remember that woman?” and I know that we are going back to that day in the clinic and to the topic of Melody’s own tenuous treatment future. Becoming close to female patients like Melody, so that I knew their shorthands and the issues they had a hard time coping with, was facilitated by our shared identification as women who lived alone, and did not have partners or spouses on whom we could rely.

In Dickson-Swift and colleagues’ (2007:335) research on qualitative researchers who study difficult topics, participants report the importance of “responding to the participants as human beings” and showing human connection by “touching, offering support and showing emotion” (Dickson-Swift et al. 2007:336). For example, one researcher remarks, “information was given
to me as a human being and I responded as a human being” (Dickson-Swift et al. 2007:336) pointing to the close feeling that developed between herself and the participant during an interview. Similarly, I found that many times throughout the research, responding to patients with just an honest expression showing that I cared was meaningful. While the researchers in Dickson-Swift et al.’s (2007) study refer to interviews as their primary method of data collection, I spent a much greater amount of time with patients than a normal qualitative interview allows. Researchers note the importance of demonstrating respect for the participant as a person embedded in a life context, which was accomplished by showing up early for the interview and sticking around after it was done for some brief social time (Dickson-Swift et al. 2007:332).

Responding to participants in a “human” way takes on a different form in ethnographic research, where relationships with participants span many visits to the hospital. For example, I often sat with patients before, during, and after consultations. Preceding an appointment, a patient might confide in the outcome she was hoping for that day. Minutes later, sitting across from her in the consultation room, I would watch as this hopeful outcome was dismantled in front of her eyes. As I got to know patients over time, we would sometimes share an intense look from across the room. Getting up to leave the consultation, we could continue to talk about what had just happened as we made our way to the next appointment. So while interviews afford researchers a unique opportunity to hear patients’ stories, ethnography allowed me to hear those stories, but also to watch them unfold. It is not the same experience to hold a patient’s hand while she tells you about a difficult conversation with her doctor and you hear it for the first time, as it is to hold her hand and do not ask about the conversation, because you are fully aware of its immense disappointments for her. This shared experience creates a different kind of bond between researcher and informant.

Patients especially valued that unlike almost everyone else in the hospital, as the anthropologist, I had lots of time to give to them. In an interview with Elizabeth, when I asked her if she had found anyone in the hospital – for example staff, volunteers – especially helpful, to my surprise she answered, “You”:

It’s nice to have someone who’s just sitting there and chatting. I mean you’ve been to all the appointments so you know what’s been going on – somebody that will come and have a chat, so I’ve been able to talk with you about everything so I would definitely say you’ve been a big help in all of that.

For Elizabeth, it mattered that she could count on me to “come and have a chat,” as it helped to pass the long hours she spent in chemo. Additionally, it mattered that I had been to all of her
appointments with her, because I knew “what’s been going on.” This meant that she did not have to start her story from the beginning, and relive all the bad moments that had passed, but could just talk to me freely about whatever was on her mind. I spent many hours with Elizabeth in chemo, sitting with her and her mother, who always accompanied her.

Furthermore, the embodied experiences provided by my fieldwork – grasping someone’s hand, holding back tears when I saw people crying, sharing an intense look from across the room, sitting with patients who felt unwell – were instrumental in allowing me to connect meaningfully with some patients. Clifford writes that participant observation “obliges its practitioners to experience at a bodily as well as at an intellectual level the vicissitudes of translation” (1983:119). I was not only present for bad news consultations, but also for much more frequent mundane consultations, where patients’ sick bodies were foregrounded. I observed patients submitting themselves to uncomfortable procedures, like paracentesis, where the ascites fluid that accumulates in the belly from ovarian cancer, is drained into glass jars, litre by litre. I was present while patients discussed in detail with their medical team the physical unpleasantries that are the side-effects of cancer treatments: changes to urination patterns, uncontrollable diarrhoea or painful constipation, ugly and agonizing skin rashes, the sudden appearance of bruises, and of course the complete loss of body hair (not only from the head, but also eyelashes, eyebrows, and nose hairs). I held purses and coats, as people took CTs or ran for the washroom for fear of vomiting or diarrhoea. Thus, the research allowed me to gain an understanding of patients’ experiences phenomenologically – using both my mind and my body (Livingston 2012). In order to try and grasp what daily life was like for participants, I could not turn away from these unpleasant physical realities of living with cancer.

In considering why patients allowed me to observe their lives in such intimate detail, I am drawn to Couser, who in reflecting on Middlebrook’s memoir of cancer, notes that “what she craves – rather than sympathy, much less admiration – is sheer interest, curiosity; she longs to be asked simply, “What’s it like?”” (1995:135 in Couser 1997:74). Ethnographic fieldwork is predicated on the effort to understand daily life from the point of view of its participants. In talking to patients, I was explicit that they were my primary focus – not their disease, not their bodies, not the side effects of their treatments. Unlike most of the people they came into contact with at the hospital, I offered no medical service or care, save the ability to witness their experience and to try to capture it as adequately as I could. Several incidents with patients led me to this insight. One day I dropped in on Isabelle while she was waiting for a clinical trial
appointment in the Gyne clinic. I had not seen her in a little while, and I was nervous that she might be annoyed with my showing up unannounced.93 On the contrary, she seemed very pleased, remarking that I was like “a ray of sunshine.” After our visit, I thought about her choice of words as I walked back to my office. How could such a banal activity – dropping by to ask how she was doing – count as bringing “sunshine”? Upon reflection, I believe it was because unlike the doctor or nurse she was waiting to see, I was not associated with the potential of more ‘bad news.’ For patients, every visit to Lady Ann’s held the potential of life-changing news (Mattingly 2009:262). But nothing I could ever say held this frightening potential, because I was only the observer, not the care provider. So perhaps my brief visit that day gave Isabelle a brief distraction from her feelings of anxiety, as she waited to find out if her trial drug was working.

A conversation with Dr. Girard after I dropped by the Gyne clinic one morning, on my way out of the hospital, hinted that perhaps at times I also served as a witness to what clinical staff regularly had to deal with. We were talking about something that had happened the week before with Jennifer. She started by saying, “I didn’t get a chance to chat with you last week, but what I wanted to tell you was this: she is all wrapped up in her mental disease. What is this? What is this about?” Without expanding much further, I knew what Dr. Girard was trying to communicate about the previous week’s consultation. She had a long history with Jennifer, and a solid relationship with her. She could see that even though Jennifer was finishing treatment, she was unable to step out of the “sick role” and seemed incapable of moving forward in her life, and she was worried about her. Later, as I was writing up notes on the conversation, I reflected that I had been witness to Dr. Girard’s experience – her confusion and frustration in trying to figure out how best to help Jennifer. She could “debrief” about the consultation with me, because I too knew Jennifer, and had been witness to the same consultation.

Responding to patients as a fellow human being, rather than as a doctor, or nurse, or someone who is responsible for providing care to them, is perhaps one crucial aspect of the hospital experience that is missing today. Research on a volunteer program that aimed to connect patients with volunteers trained in empathic listening, demonstrated how the presence of volunteers helped to “humanize or normalize what could otherwise be an intimidating clinical environment” (Nissim et al. 2009a:805). Perhaps having someone respond to their experiences as a fellow human being or witness, rather than as a patient or a researcher, is also missing from staff experiences of the hospital system. Oncologists are often subjected to polarized views – given high praise, and portrayed as “Gods,” or the subject of high critique, portrayed as
“Villains” – but they are rarely just seen as fallible human beings, often doing the best that they can in situations that are intensely difficult.

The Emotional Self in Fieldwork

January 12/12. I go behind the front desk and say hi to Louise, the PFC. I sit down next to her for a minute and ask if it’s ok if I sit here and she says yes. I look over her shoulder and see that Melody hasn’t checked in yet. After a few minutes, I decide to go and check if she is in the blood lab. I leave the desk, and go out through the clinic door into the waiting room. As I go through the door, I hold it open for a woman who is leaving the clinic. She starts to walk faster and as she comes towards me I say, “Don’t rush, it’s ok!” and smile. I am smiling as I turn around into the waiting room. I don’t realize that I must be sounding ‘cheery’ (though admittedly that’s what I felt for a minute) and sitting right across from me is a man who is looking at me with a grim expression on his face. As I head toward the elevators I realize what that look meant – it seemed like a look that said, ‘How can you be happy’? He certainly didn’t look happy himself. By the time I get to the doorway, leading toward the elevators, I am coming down from that feeling of lightness. (I have written ‘light’ into my notebook, reminding myself that this was what I used to feel like when I volunteered once a week). And I realize the hospital isn’t that to me anymore – it is so much different. The heaviness of what it represents and everyone’s experiences while they are here comes back to me and takes up its regular spot. I walk quickly through the blood lab, not seeing Melody and return back to the Gyne waiting room.

This fieldnote, recorded as I re-entered the field after Christmas holidays, demonstrates well the transition I underwent to move from ‘normal life’ back into ‘life at Lady Ann’s.’ The transition was mirrored by staff and by patients, who all looked forward to breaks from having to come to Lady Ann’s everyday. The terms “heaviness” and “lightness” are powerful here, as they denote the feeling of entering back into a place where the atmosphere is often weighed down with apprehension and fear, represented in the man’s facial expression. Being close to cancer through daily fieldwork caused me to experience a kind of emotional flood: all kinds of feelings washed over me, all the time. My daytime hours were taken up at the hospital, but even at night, I had vivid dreams and nightmares about patients, about the doctors, and about the hospital. I re-read almost every novel I owned during the course of fieldwork, with the express goal of taking my mind into a world of fiction before I went to sleep, but it rarely worked. And despite my project’s explicit focus on incurable disease, I still found it very difficult and surprising when some people declined and died as rapidly as they did.

Being close to cancer means that when you hear that someone has advanced disease, you know too well what will happen next and what is in store for that person. Bluebond-Langner (1978:253) who worked with children with cancer, writes that there is a “tacit assumption that to
do a study of the terminally ill is to be constantly concerned and involved with death.”
Conversely, in her research she found that “the difficulties and hard times came not when the children are dying, but when they are alive and you know what is ahead” (Bluebond-Langner 1978:253). Grace, a palliative care nurse I worked with at Lady Ann’s, confirmed this. She told me that with certain kinds of cancer, it is not the end (i.e., death) that is scary: it is knowing what people will have to endure before they get there.

Although many scholars have recently recognized the importance of talking about the emotional challenges of fieldwork (Davies and Spencer 2010; Coffey 1999; Dickson-Swift et al. 2007; Johnson and Clarke 2003) this was not a literature I was aware of prior to entering the field. As Amanda Coffey (1999:5) points out, even though popular methods texts often now include a section that touches on personal and identity challenges when conducting fieldwork, the emotions of fieldwork are “discussed in relatively unemotional ways.” Post-fieldwork, I sought out this literature to try to help me come to terms with the emotional challenges I had encountered in the field, which continued into the writing phase. I felt many parallels with Mukherjee’s (2010:4) account of his immersive training fellowship in oncology at Dana Farber Cancer Institute in Boston, where “cancer was an all-consuming presence” in his life. With respect to his program’s goals of “immersion” in oncology, Mukherjee writes, “by immersion, they really mean drowning” (Mukherjee 2010:5); I could relate to his feeling of sinking. I recall reciting to myself over and over again throughout fieldwork, “Cancer, cancer everywhere” – a play on words of the old sailor’s poem on water. Mukherjee was told at the beginning of his fellowship that it was important for him to have a life outside the hospital, so that he did not get “swallowed” by his work, but found that there was a “dense, insistent gravitational tug that pulls everything and everyone into the orbit of cancer” (2010:4). My experience was very similar. Only three weeks into fieldwork, I told a close friend, “I feel like it’s taking over.” It was a provincial holiday, and I had used it as excuse to stay home and catch up on fieldnotes. Although it had only been several weeks since I started fieldwork, I wrote in my notebook, “I have little desire to go to the hospital today.” The heavy, emotional nature of the material and of people’s stories had already begun to weigh on me. Seven months later, after getting off the phone with Paul’s wife, Sue, I turned to my office mate at the hospital and said, “Every time I get off the phone I want to cry.” My colleague asked if things were not going well, and I replied that things were actually going okay at that moment for Paul. But I was coming to realize how much both he
and Sue as well as my other participants were dealing with, and I was feeling somewhat helpless to do anything about it except listen to it and write it down.

Mukherjee recounts that after 10 months, he was at his “lowest point,” “slowly becoming inured to the deaths and the desolation – vaccinated against constant emotional brunt” (2010:4). This sentiment describes very accurately the feeling of numbness I sometimes experienced during fieldwork, especially after particularly trying days. Reading his book after fieldwork, I reflected back on the fellows I had observed in the lung clinic, who regularly had to tell patients that they had stage IV disease, a diagnosis with limited treatment possibilities and no curative hopes. Compared to their burden of disclosing bad news, my duties of observing and recording experiences were in theory much less demanding. But in practice, because I spent a great amount of time with patients, their emotions and their struggles impacted me significantly. I found myself worrying about patients the night before and the morning of their appointments, going over what news they would be receiving, and hoping – willing – for things to be okay. In this way, my experience was similar to Bluebond-Langner’s (1978), who found herself behaving like the doctors and parents of sick children, by mentally reviewing the children’s cases, noting differences in medical histories, and thinking about the progress in cancer research. She admits that in doing so, she would “push contradictory evidence out of [her] mind” (Bluebond-Langner’s 1978:253). Similarly, I tried to find ways to maintain hope that people might live.

I also tended to try to hold onto all the difficult experiences I witnessed and was not sure how to get them out. Writing fieldnotes sometimes helped. But I often had to persuade myself to do it, as it normally required that I relive the experience to a certain extent. In the novel Music and Silence (Tremain 1999), the character Countess O’Fingal writes in her diary about her husband’s ultimate demise and consumption in trying to write down the music that he dreamt about. Powerfully, she says, “to recount these things is to make them live again. I see that my writing has become wild and very sloping on the page” (Tremain 1999:44). Once, when I was speaking to a non-anthropology colleague about writing fieldnotes, she said, “That’s so much work – spending time with people and then having to go through it again writing it up.” I realized that she had managed to put my fears into words. I did not want to experience the difficult events of the day again in the evening. But, given the importance of writing fieldnotes for anthropological fieldwork, it was a task I had to complete.

Because I lived alone, I often avoided going home, where the thoughts of the day would easily take over. I recall one evening when I wandered the basement of a large department store,
and sat down to rest on an outdoor patio display that had been set up far too early in the season. I sat there trying to stop my mind from going back to Lady Ann’s. I recall many days like this of feeling completely numb – feeling like I could not feel anymore, or tried to prevent myself from feeling anything, because it came with such pain. I did not behave like this around patients. In their presence, I tried to give as much of myself as I could, and we shared many emotional moments (e.g., dismay, happiness, sadness, fear) over the course of even one day in the hospital. But away from them, I would experience the “emotional brunt” (Mukherjee 2010:4) – the effect of carrying around so many patients’ stories in my head, and not knowing what to do with them at the end of the day. Writing them down did often help. But unless I wanted to work on fieldnotes at the office, which I sometimes did, it meant that I took cancer ‘home’ with me, so not only had it taken up my whole day, it then occupied my evening as well.

Although I was conducting research in my home community (Gupta and Ferguson 1997; Altorki and El-Sohl 1988), and was able to access peers, support services, and my supervisors as needed, I hardly ever did. I still went to the library, went to the office, but I spent a great deal of time at the hospital and learned if I went to the library after the hospital every day to work on notes I would not get home until 10 pm. And I could not afford to leave the house at 7:30 or 8 am and get home after 10 pm – it was too long, with too much suffering, and too much cancer. So I experienced a different kind of isolation than one that perhaps I would have experienced going to another country. I was around people I loved and in familiar settings, yet I felt very alone.

Recently, I was looking at an initial draft of my research proposal where I wrote, “I struggle with my own authenticity as an anthropologist who will not experience physical hardships or personal suffering as a result of being away from home and family for the 12 month period of fieldwork.” Upon reading this now, I cringe at my own naïveté. The irony is that I did not need to go anywhere, but still experienced isolation. My isolation was produced by the realization that the people I was working closely with were slowly dying off, and there was nothing I could do to stop it.

In hospitals, people are generally scared of emotional outbursts, and this fear encourages people to try to contain them, and reserve displays of emotion to private moments. But as I show in Chapter 2, containing cancer and the emotions it produces is hard work. Olivia, a young woman with metastatic ovarian cancer, summarized the challenge of trying to find a balance between sharing emotions and keeping them to herself:
I tell pretty much everybody that I have cancer….The reality is that doctor’s appointments and chemo is part of my life right now…and I feel like I need to let people know because they’ll easily find out anyway, whether I tell them or not and, this is also a bit of a control issue on my part too. So, ‘Yeah, I have cancer, I’m used to this, I’ve done this a few times now, I’m used to this.’

So I’m good at it. I can say things like, ‘I feel devastated,’ without breaking down and sobbing, so it’s weird. I can say my feelings without having to wear my feelings….it’s exhausting to hide it and it’s exhausting to show it.

As Olivia indicates, it requires a great amount of work to try to hide from the world what she is dealing with, so she shares her illness with whomever she meets; she can “say [her] feelings without having to wear [her] feelings,” which reveals a kind of personal management strategy for dealing with her emotions. She has succeeded in separating the experience from the emotion. She displayed a mastery over her emotions that came from having had to deal with cancer in her life for over 10 years.

At times, my presence may have given patients permission to express all of the emotions they were trying to hold in. Seated in a small room with patients hearing news they did not want to hear was far from an innocuous experience. The doctor or nurse often did not (and likely could not) react to the news; they often went from room to room to room, relaying grim news more than once over the course of one morning. But I could react. If I stayed in the room after the doctor left, which I did often with patients who were not accompanied by anyone else, I could say or do something to relay my acknowledgement that something significant had just transpired. Reacting seemed to have an impact. Sometimes patients cried, even though they had shown very little reaction while the doctor was in the room. At first, I worried that by holding a hand, sharing a sympathetic look from across the room, or saying something brief like, “Are you okay?” I was causing an emotional ‘break’ that might not have happened if I had done nothing, and had just sat there silently. But I came to realize over time that perhaps having someone there to share the weight of the news – the real burden of it – was not a bad thing, especially for those patients who would have otherwise been alone in the room, waiting for the doctor or nurse to come back.

My intuition that it was valuable to let patients express their feelings was confirmed in September 2013, when I was pleasantly surprised to find out that a patient had nominated me for an award at the hospital, meant to recognize staff and volunteers who have demonstrated compassionate care. In her nomination letter she wrote,

Alyson, was often the only person with me at an appointment. The first time the doctor said they had to put my chemo on hold I was OK. The 2nd time I was
devastated. I am not an emotional person, but Alyson was there and held my hand and let me shed a tear and it meant so much to have someone there who truly cared about me and my circumstance at that moment. She genuinely has an empathy for the patients she comes in to contact with.

Her words were very touching to me. What I found most rewarding about her letter was that I also remembered that day very clearly, and always thought that it had marked the day our relationship had become closer. On that day, she allowed me to see a side of her she had not yet shown to me – her emotional side – and in being there, and just letting her express her feelings, I think she had learned to trust me. But we had never spoken about it. So to hear her reflect on that day over two years later and to confirm what I had felt had happened was significant beyond words.

Knowing that I had taken on a specific role for patients, as a companion or a witness, made it especially hard when it came time to leave the field. For example, as I was preparing to leave the field, I wrote about a typical day in the clinic, accompanying Elizabeth and her mom:

June 5/12. I go and meet Elizabeth and her mom around 8:50. Elizabeth jokes that I am late today. I complain about the subway (as usual). We don’t wait long. A nurse calls us in, and takes Elizabeth’s weight. I get up and take her bag, her mom takes her own coat and bag. We have a ‘routine’ now and I am part of that routine. I have asked permission to be here and now I have to try to get out without having an effect – but of course it will be different.

It is obvious from my notes that I am nervous about leaving the field. As Fabian notes, during the writing phase “the observer has moved on, usually to another place as well as to another time” (1983:138). Doing research in my home community meant that there were no clearly defined points of entry and exit to the fieldsite (Gupta and Ferguson 1997:12). I had no plane to catch, or tickets booked that would signal the official end to the fieldwork. Hoodfar (1994) reported that doing research at home resulted in feeling pressured to maintain relationships developed during research at the same level of intensity, which was personally exhausting, and taxing on her own non-research friendships. While every anthropologist has difficulty leaving the field, what made it particularly challenging for me was to think about the possibility that patients might not be alive once I tried to contact them again. Contrary to some anthropologists who have had decades-long relationships with informants and particular places (e.g. Lee [1979] 2002, 2006), my fieldsite and research topic did not afford these possibilities. Due to the nature of advanced disease, I could not imagine my relationships with informants going on indefinitely. So saying goodbye in the field was also in a way saying goodbye for good, which was very difficult. Given that patients have reported feeling sometimes abandoned by their
doctors and caregivers when they are dying (Back et al. 2009), I feared my leaving would feel
the same.

Writing about patients who have died also proved to be a very difficult task. Janet Hoskins,
reflecting on her experience working with the Kodi of Indonesia and dealing with the death of
several of her informants, confesses “the loss of these people, sudden and unpredictable because
many were so young, haunted me during my writing and analysis” (1993:11). For me, sometimes
the anticipation of having to experience some hard event again – going back to how difficult it
was for a patient to hear about a negative turn of events or progressing disease, would make me
not want to write at all. Listening to recorded interviews of deceased patients was also hard; I
found I could not do this when their deaths were new. It took many months after fieldwork, and
many miles of distance between the hospital and me, before I could really begin to write patients’
stories.

Conclusion

Becoming close to cancer and watching people ride up and down the tides of illness made
this project exemplary of an “anthropology that breaks your heart” (Behar 1996). In this chapter,
I have described my preparations for fieldwork, my experiences of the field, and the impact that
fieldwork had on me as an anthropologist, and as a person. I often questioned in my research if I
had become too close to some participants, and whether erecting firmer boundaries between us, I
could have prevented some of the challenges I later faced. But the work that would have resulted
from such strict boundaries and such unnatural reactions to human pain and suffering ultimately
would be very different. I believe that people let me into their lives because I always tried to
make clear that I was interested in their experiences as people, and not just as patients at Lady
Ann’s.

As such, this thesis offers perhaps an important contribution to the qualitative literature
on cancer research, especially what is published in health services journals, where patients are
often stripped of their identities and identified by a series of “characteristics” or
“demographics.” I have identified some of those qualities in a few brief paragraphs above, in
order to satisfy the curiosity of those who would like to know these more quantitative details
about patients. I will not return to these ‘numbers’ details in the thesis, as the overarching focus
on these kinds of quantitative details about patients in the cancer literature run counter to my
aims. These details are often separated from the quotes to which they are attached, and thus they
alone could never be combined to produce a person – a real, living, complicated person, struggling with an uncertain diagnosis. For example, when she has diagnosed with breast cancer, Barbara Ehrenreich recounts how the surgeon said to her, “Unfortunately, there is a cancer.” She writes, “the most heinous thing about that sentence was not the presence of cancer but the absence of me – for I, Barbara, did not enter into it even as a location, a geographical reference point” (2008:18). In the thesis, I work to ‘reappear’ the stories of people whose lives and complexities of care have been disappeared through the hegemonic focus on quantitative research in health care, and on qualitative research that looks much like quantitative research (Thomas 2008).

Notes
51 Here, I am using Bernard’s (2002:203-205) terms, where he situates interviewing on a spectrum based on how much control the researcher tries to exercise over the participant’s responses. At one end of the continuum, is “informal interviewing,” where the researcher gathers information indirectly, by paying attention to conversations that pertain to her interests and by keeping detailed fieldnotes over the course of a day. Participants may or may not be aware that data collection is going on. The next form is “unstructured interviewing” (also known as ethnographic interviewing), which “goes on all the time,” (Bernard 2002:203) is an open-ended activity, and takes place in the middle of other activities, such as sitting in waiting rooms, hanging out in chemotherapy, or chatting over coffee. Both the researcher and participant are aware of the interview, but the researcher is not trying to control responses. Conversely, a “semi-structured” interview is a scheduled activity, where the researcher follows an interview guide and thus shapes the direction of the conversation according to particular thematic interests.
52 This experience was foretelling, as it mirrored what I would come to observe four years later, when I began sitting in on oncology consultations for my own study. Thus, the patients’ records did reflect what actually happened in practice, with death often being quickly acknowledged, and quickly left behind.
53 As I was not yet conducting research, these notes contained no names or personal information about patients, and focused on my own experience at Lady Ann’s.
54 We all wore maroon vests, as well as I.D. badges, so patients and staff could easily pick us out. Although the program was fairly new in 2008, by 2011, people did recognize the “talking volunteers” (as the staff called us) and saw the program as very beneficial.
55 Talking to these patients in the waiting room, I found out that they had often never been involved in a clinical trial at Lady Ann’s before and were unsure of what they entailed. A Phase I study is in its earliest stage of approval; it is the first time a drug is tested on human beings, and its intention is to determine appropriate dosage levels and watch out for levels of toxicity. For patients to go to that clinic, they have to have exhausted all other treatment possibilities. Otherwise, no one would willingly try a drug for which they really are the “guinea pigs” or “one step up from the animals” as the palliative care nurse I worked with called this clinic. Over the course of several years, I met some patients who had short-term success on these trials, but eventually, as with other treatments, their effects ran out. Many times I overheard the doctors from the Phase I clinic complaining about the patients that had been sent their way, as they were
often too sick to qualify for the studies, and now these doctors were charged with the tough job of being the ones to convey that this “last ditch” attempt at treatment was not going to pan out. Similar to my experience being asked to explain what palliative care was, it seemed like someone along the line had “passed the buck” and had not done their due diligence in explaining the seriousness of the diagnosis. But this was far too simplistic an explanation, which disregarded that many actors and dynamics contributed to the pervasive treatment culture that characterized advanced disease at Lady Ann’s.

I remember feeling so overwhelmed at the prospect of having to start again – to write essentially a 2nd proposal, now referred to as a research “protocol” in line with the language of biomedical sciences and clinical drug trials. For the first few months, I did not accomplish much on this task, except for attending a few training sessions on ethics at the hospital and at the University of Toronto. In the meantime, I continued my volunteer work, and my part-time research assistant work at Lady Ann’s, and worked as a teaching assistant. In the spring of 2009, I met with a senior research staff at the hospital, who aided me greatly in providing an overview of all the documents I would have to submit, in order to satisfy the very specific requirements of Lady Ann’s REB. I then began working on the application in earnest. But it still took a very long time from my initial forays into writing the protocol to the finished product.

The REB board at Lady Ann’s reviewed all protocols that involved oncology patients. Therefore this form, the LAREB, was required whether the study was an RCT for a new drug or a qualitative interview study.

The REB submission represented a colossal amount of work. In addition to the LAREB form, the final submission contained 11 appendices (numbers in brackets represent the number of versions): Study Protocol; Consent Forms (5); Interview Guides (3); Study Introduction (mailed); Study Introduction (in-clinic); Study Notice (general information); Recruitment Posters (2); Demographic Input Sheets (2); Data Tracking Sheets (2); Budget; Email Confirmation of Support for Study (6); University of Toronto Social Sciences and Humanities REB – Guidelines for Ethical Conduct in Participant Observation.

I had been told that approval at the University would not be difficult to obtain, since the agreement between the teaching hospitals and the university was that any research undertaken in the hospitals had to receive approval there first, and thus the University’s approval was essentially a ‘rubber stamp.’ This proved to be true in my experience.

One of these two women has written about the challenges she experienced while undertaking her fieldwork on gender re-assignment surgery. Gotlib Conn’s (2005; 2008) experience demonstrated a particular reluctance on the part of physicians to sign official forms demarcating their participation in her project.

In addition to the trainings I had already attended as a volunteer and part-time staff, I counted at least 4 other trainings/modules I completed in preparation for fieldwork: 1) good clinical research practice, a half-day course that upon successful completion, I received a certificate that was to be kept on record with my ethics documents; 2) training on how to enter patient information into the clinical research record; 3) training and approval to access the patient record system (I had read-only access); 4) training and approval to access the patient scheduling system, so that I could keep track of when patients were coming to the hospital.

Although my period of full-time fieldwork in the hospital ended in June 2012, I have kept in touch with a small number of longitudinal patients from that period to the present day.

In choosing to focus on the activities of only a small number of patients, I was guided by previous research by The et al. (2000) who also used ethnography to examine a group of 18
patients with small cell lung cancer in the Netherlands. They found that it was not possible to keep intensive contact with more than 15 patients and their families.

Relative survival ratio (RSR) is the ratio of the observed survival for a group of cancer patients in five years to the survival that would be expected for people in the same general population (e.g., with the same main factors affecting survival such as sex, age and area of residence). For example, a patient diagnosed with lung cancer that has an RSR of 3.8%, has a 3.8% chance of living for 5 years after diagnosis compared to similar people in the general population. As the CCS points out, an RSR provides a useful “average” indicator of survival, but does not reflect any one individual’s prognosis (2015:60). I discuss the challenge of moving from survival statistics like RSRs to individual prognoses in Chapter 5, in reference to Jain’s work on “living in prognosis” (2007).

Statistics available on the Canadian Cancer society website cite 1% as the RSR for stage IV disease, but the statistics may be drawn from multiple sources and are not specific to Canada. For most patients, the first line treatment for lung cancer was a combination of Gemcitabine and Cisplatin.

Chemotherapy is given in “rounds.” Each treatment within a round is referred to as a “cycle,” and normally one round of chemotherapy consists of 6-8 cycles of treatment. Treatment schedules are dependent on the drugs being given, but most patients in the study received one treatment (composed of 1-2 drugs, and any additional add-ons such as blood transfusions, Magnesium infusions, platelet infusions) once every 3 or 4 weeks. When doctors and nurses ask at follow-up appointments how patients did at their “last cycle” they are referring to the treatment itself and any ensuing symptoms and side effects they experienced post-treatment.

No statistics are available on the CCS website for the RSR for endometrial carcinoma or its various stages.

For most patients, first line treatment for ovarian cancer consisted of a combination of Carboplatin and Paclitaxel.

For simplicity, I will include the patient’s age when I first met them in 2011 (i.e., they will not ‘age’ throughout the thesis, even though I have known some of them for several birthdays).

In order to assist the reader, the two primary oncologists have been given pseudonyms that correspond with their tumour sites, e.g., Dr. Girard is from the Gyne site, and Dr. Lawson is from the Lung site.

For example, Becker et al.’s introduction begins, “For medicine is man’s work. It is also woman’s work, and there is no theme of human history more interesting than the changes in the respective roles of man and woman in looking after those who are sick or in labour. But in this country, although an increasing proportion of the people who have a part in the medical system are women, the medical profession itself remains overwhelmingly male. In this book, we shall talk mainly of boys becoming medical men” (1961:3).

Many small to medium hospitals in Canada may have only a few internists who specialize in oncology, and as a result they see all the cancer patients, regardless of tumour type. This means they must have excellent generalist knowledge, but are less likely to see the same tumour type over and over again, since they are treating a wide range of tumours in daily practice.

Although the research was at least in part contained by the boundaries of the institution of Lady Ann’s, this is not an institutional ethnography per se (Smith 2006), as my intent was not to uncover relations of power and to track how the most vulnerable are at risk.

All fieldnotes were recorded in small, non-descript journals. I did not often write notes when patients were present, except when I was in the consultation room. I added details to these upon leaving the consultation room before I would forget what had happened. Similar to other
ethnographers (Jackson 1990; Dunk 1991), I found that having my notebook out when we were engaging in regular conversation to be distracting for me and for patients, and learned to abstain from writing so as not to disrupt the natural flow of conversation or events. However, I would jot down quotes and comments in free moments, like when patients went to the washroom. Some of these fieldnotes were not written in my notebooks, but were typed straight into the computer as soon as I returned to my office. Neither the handwritten notes nor the typed notes contain personal identifiers.

Calling very sick people at home, when I did not know what had recently transpired for them, was always slightly nerve-wracking. One patient in particular declined very rapidly after diagnosis and I had missed her several times she had been in hospital. I was able to read her clinical notes and I knew she was very sick, which made calling her to check in for the purpose of my study seem very insignificant. I never called early in the morning or late at night, but people with cancer who are off work and at home may sleep at various points of the day, so there is never really a good time to call. Speaking over the phone did work well with some patients; for example, I have had innumerable conversations with Melody that have helped me to come to understand her experience. But with other patients, the phone call mostly functioned as a means of checking in with them and confirming a time when we could next meet.

In fact, I spent so much time in chemotherapy that I was able to pass on some information I heard from the nurses or the patients to other patients on the study. For example, Paul recounted to me in detail the day a nurse helped him to realize that after the initial needle finding the vein is inserted, the needle is withdrawn and what remains taped to the arm is just a plastic catheter. He was very scared of needles and prior to this conversation, thought (logically) that what remained in his arm for the entirety of the chemo session was the sharp needle. This thought caused him to be very wary of bending his arm in any way, lest he push the needle further or injure himself. But one day, he had a nurse who said he “had to look” and “had to know this” and she showed him how the needle is taken out and only the plastic tubing remains. This made a huge difference in his experience of chemotherapy – he could do the very normal things he wanted to such as eat lunch or go to the washroom without fear of hurting himself. After he told me this story, I passed it on to a few other patients, who similarly were bothered by the needles. They too, seemed grateful for the knowledge.

Marzano (2007) conducted research with the terminally ill in Italy and wore the doctor’s white coat as a “disguise,” so that he could conduct research without the patients being aware.

I had dropped by to see Deo and his family in chemo. I happened to be wearing jeans that day, as I knew I was not attending any clinics. This must have bothered Deo because he managed to work a critique about my clothes into our conversation, by talking about how “success breeds success.” He said, “For example, if you show up to work in jeans and riding boots” (what I was wearing that day) “then you will not be as successful as if you were Dr. [Lawson] and wear a blazer and white shirt…people will take you more seriously.” I joked that I was sorry to be wearing jeans, and now that I know he notices, I would be more careful. Thus, Deo saw my role as that of a professional, requiring professional attire. I still think of this conversation and laugh, as his daughter who was closer to my age, was so embarrassed that he had brought it up, saying, “Oh Dad…”, and rolling her eyes.

Recruitment of participants in the Lung site was very much facilitated by Eve, the primary nurse. She left her position in the Lung clinic about 2 months after I began fieldwork, which meant I would need to establish rapport with the new nurse taking her place. I realized that I already had 4 follow-up patients, and 6 one-time observations and had reached saturation in terms of seeing the same kinds of conversations with few surprises, so I stopped attending that
clinic for recruitment purposes. However, I did continue to visit the Lung site throughout my fieldwork, in the company of the longitudinal patients. In contrast, in the Gyne site, recruitment was a bit slower, so my presence in the clinic extended over 6 months, during which I had the opportunity to observe extensively the everyday life of the clinic.

The Lung site had been recently renovated and everyone worked in one central room. On busy clinic days, all 16 seats and computer terminals could be full. So while I could see and hear everything that was going on, I was often at a loss for where to position myself. I did not want to take up a seat in front of a computer, since I was in no need of the computer itself. I sometimes tried to tuck myself into a desk next to Dr. Lawson where there was no computer, but it felt awkward sitting so close to her. Other times, I stood against the wall with my back to the door leading out to the waiting room, trying to make sure I was not blocking the whiteboard on the wall where the nurses kept track of what room each patient was put into.

There were of course, some exceptions to this. Some patients would leave their consultation room and head the wrong way down the long hallway, and out into the waiting room only to find that they were not where they had started (which might be evidenced by the absence of family members they had left in the waiting room).

In fact, my little perch became somewhat of a running joke with a nurse from another clinic. One day, three weeks into my fieldwork, she was bringing a patient down the hallway, and after she introduced herself and her role in the clinic, she said, “This is Alyson, our little hall sitter.” In response, I laughed and said hello. On the off day I was standing or leaning against the wall, she would joke, “What – no chair? What did you do wrong?” insinuating I was being punished. I interpreted her comments as evidence that I was gradually being accepted into the atmosphere of the clinic.

Physical exams often began before I could excuse myself from the room. I was highly cognizant of patients’ rights to privacy and since I was not a person that needed to be there for any edifying purposes, I often tried to leave if I could. In the Lung clinic, I was sometimes present while men removed their shirts and sat bare-chested on examination beds, while doctors listened to their chests. In the Gyne clinic, patients needing an internal exam would first need to change, so I was sometimes able to leave the room first. But if patients had already changed, and the doctor was leaving the exam to the end of the consultation, I was often sitting in the corner of the room, making notes on the consultation when suddenly it came time for the physical exam. After being instructed the first few times to, “Just go behind the curtain Alyson” (there was a curtain that could be drawn around most of the room, including the exam table), I would end up standing awkwardly in the tiny space left between the curtain and the closed door, trying to scribble down notes on the conversation that regularly continued during the examination. It always felt surreptitious and somewhat like I was ‘hiding’ behind the curtain. And in fact, that became the running joke with some of the longitudinal patients, for whom I sat in on several exams, with them calling out to me “You can come out now, Alyson!” as the exam finished up and they were fixing their clothes back in place. My presence during physical exams demonstrated that in many ways, I was treated just like a training student or fellow in the hospital, an extra person who could be privy to these interactions. It is very likely that my gender and the fact that the doctor and patient were female also mattered.

In Chapter 2, I discuss patients’ efforts to “contain” cancer by keeping everything associated with their cancer experience reserved to the times they were physically present at Lady Ann’s. Even though I grew close to many patients, I was still very much connected to Lady Ann’s. Thus, it is possible they did not want me going into their homes, bringing everything associated with the hospital with me.
All semi-structured interviews were audio-recorded and transcribed by me. I also took notes to help prompt questions that arose from their comments. I began each interview by making it clear that it was open-ended. I developed general interview guides that outlined questions for particular themes I wanted to touch on, and used these to a greater or lesser extent depending on the interviewee. For example, in one of my first interviews, I asked one question and the patient spoke for over 2 hours. In others, I found having some pre-defined questions from the interview guide very helpful in moving the interview from topic to topic. Most interviews ranged between 1-2 hours in length.

One of these interviews was with a one-time observation patient, so I had met her on the day I had observed her consultation but had not spent any significant time with her. Another interview was conducted with a patient I met at a hospital event, who I chatted with briefly after the event. Our conversation was so productive that I asked if she might consider doing a formal interview. For example, I knew that any questions related to fertility or children were very sensitive issues for Elizabeth, so I never introduced that topic into formal interviews, but only picked up on it if she introduced it into the conversation.

Jennifer’s lack of “a person” was made explicit one day when I received a text from her, as I was working in the University library, telling me that she had a “recurrence.” I immediately called to see how she was doing. She had just got the news, and was leaving the hospital when I called. She said she wasn’t sure “who to tell” so she had contacted me.

Dickson-swift et al. (2007) interviewed 30 qualitative researchers whose research focused on topics such as cancer, homelessness, violence, death and suicide.

If you have ever had someone in your family become seriously ill, you will know that his caregiver tires very quickly of giving “the update.” Family and friends are rightfully concerned, and want to be kept abreast of what is happening and they show their concern by calling or emailing or dropping by to get this information. I have watched this unfold in my own family; each new appointment or piece of ‘news’ sets off a series of phone calls. Similarly, Deo told me that the week following his first chemotherapy, his wife screened his calls. He said, “Everyone is calling and they want to know everything – Did you vomit? Were you sick?” He said he knew people were well intentioned, but he had no desire to talk to them all. Thus, if you are the sick person, or the caregiver of the sick person, providing this ‘update’ grows old very quickly because if things had not gone as well as you had hoped, you are repeating the story over and over again to each new person. This means you are constantly reliving the bad news.

In Livingston’s (2012) recent ethnography on cancer in Botswana, she justifies writing in the first person as a way to engage the reader phenomenologically: “For example, it is one thing to say that Botswana is a very small place and that at times staff in the ward will find themselves unexpectedly treating friends, relatives, or acquaintances who are cancer patients. It is another to experience, as I did on a few occasions, the sinking feeling one has on looking up from one’s task to see a friend unexpectedly walk into the clinic as a newly diagnosed cancer patient, even while one tries to ensure that feeling is not conveyed on one’s face. It is one thing to read that cancer wounds can be necrotic, and quite another to make sure to chat with a patient while holding the plastic bag into which his or her dead tissue is being deposited” (2012:27).

I had stopped going into consultations with her some months previously, after her condition had worsened and she had been referred to a different doctor than Dr. Girard for a clinical trial. Since I did not recruit patients from that doctor’s clinic, I would go to see Isabelle when she was in the waiting room, or in chemo, or admitted as an inpatient.

Mukherjee (2012:4) similarly notes that at the end of his days, he sat in his car for hours, compulsively reviewing his cases for the day and letting the decisions he had made “haunt” him.
This was similar to my experience, where I needed to spend time in a sort of transitional space before I could go home.
Chapter 2
The Hospital as Permeable Institution:
Holding in and Holding off Advanced Cancer

The modern, technological hospital figures prominently in our cultural imagination. In North America, it is a place with which we are all familiar; many of us were probably born in a hospital and many of us, despite an increasing desire to meet the end-of-life at home, will probably die there (CIHI 2007). When someone says, “I’m going to the hospital,” the listener automatically know two things about that person: 1) that he or she is going to a physical place – an institution or structure – that is charged with providing health care, however that may be defined in that particular setting; and 2) he or she or someone close to that person is sick. It requires no elaboration or specificity because it often does not matter which hospital the person is going to: although they may range in size and services, a hospital is a hospital is a hospital. Or at least most of the time anyway.

A cancer hospital, like Lady Ann’s, is a slightly different place. It is a specialized centre, which means that people cannot walk off the street and receive treatment there. In order to receive care at Lady Ann’s, patients need to be referred from somewhere else. Therefore, every patient comes from ‘away’ – from community hospitals, from general practitioners, from specialists or from other cancer services – and they are all coming for one reason and one reason only: cancer. So when a person says that he has been referred to Lady Ann’s, people whose lives have been touched by cancer understand the shorthand. They know that cancer is in his present, and may well define his future.

The Rabbit Hole of Advanced Disease

It’s Tuesday morning, at 8:50 am and I am heading towards the Gyne clinic. In order to get there, I enter through one set of front doors, go past a bank of four elevators and through an impressive looking set of green double doors. The size of the doors makes what I see next even more surprising. There is a tiny little hallway, which forces me to go either right or left as soon as I enter it. Its narrowness is demonstrated by the realization that I will need to move single file in order to pass through it. If I take a left and follow it until I can go no further, I end up on Lady Ann’s main thoroughfare, connecting to the blood lab, outpatient pharmacy, central atrium or lobby, restaurant, gift shop, and main bank of elevators. On my way towards this main corridor, I
pass two entrances to gynaecology waiting rooms. If I were a patient with gynaecological cancer, coming to see my oncologist, I would have arrived at my destination.

When I first began research, this was the route I took to the clinic. However, after a few weeks in the clinic, I realized that if I took a right turn in the tiny corridor, I could take a shortcut. A right turn brings me immediately up against a closed door. Opening this door and going through, I end up in a little beige anteroom, facing five closed doors, which are also beige: 2 to my left, 2 straight in front and one to my right. Of these possible entryways only 2 are labeled (I did not notice this at first, but after many subsequent visits): the one to my right is a stairwell, and the one to my immediate left is a utility closet.

Every time I ended up in this anteroom I had the same experience: I felt a moment of brief panic and uncertainty, not knowing which door to choose. The image of Alice, from Alice’s Adventures in Wonderland, stuck in a hallway of closed doors frequently came to my mind. Alice falls down a deep hole in pursuit of an intriguing, talking rabbit. She falls for a long time and, upon landing, finds herself in a long, dimly-lit and low hallway, with doors all around her. On her first tour around the hallway, she finds all the doors are locked and then “walk[s] sadly down the middle, wondering how she was ever to get out again” (Carroll 2007[1865]:15). I felt like Alice, trapped in a hallway of closed doors, wondering: How do I get out of here? Which door do I choose?

I think this experience provides a useful illustration of many patients’ experiences on their first visit to the hospital. Many people have waited a long time to get to Lady Ann’s; as a specialty cancer hospital they must be referred by their G.P.s or by other specialists at other cancer centers or hospitals. People often suspect they have cancer before they are referred, and this first consultation will confirm the diagnosis. Others are coming to Lady Ann’s in hopes of a clinical trial or treatment not available at their last place of care. This means that these first visits are highly anticipated and produce a great amount of anxiety for patients. For example, when I asked Paul, a man in his early 60s diagnosed with stage IV non-small cell lung cancer, what he remembered from his first visit to the hospital, he replied:

My wife and I are showing up in a hospital that we’ve never been to. It’s just a big place with many, many people. It’s just…like it’s close to overwhelming in terms of where do we go, who do we see? Everybody’s running around busy and we’re both fearful.

In reflecting on his first visit to Lady Ann’s, Paul articulates a heightened sense of being lost, as well as fear of what the appointment would hold. Recent Canadian research has demonstrated
that having some sort of hospital orientation service “would have greatly reduced the stress and anxiety that [patients] had experienced, especially prior to their first chemotherapy appointment, when unfamiliarity with both their chemotherapy routine and the hospital environment had been overwhelming” (Nissim et al. 2009a). Little and colleagues similarly found that patients are confused upon entering a hospital; one of their participants remarked, “there’s nurses coming at you left, right and centre, and they’re using all these big words and you are lost, you are absolutely lost” (1998:1487).

The patients that I spoke with had various experiences with learning to navigate the hospital; some, like Paul, spoke of “being lost” and not knowing where to go and whom to see, and others, like Isabelle, said the hospital was easy to navigate if you just “follow the signs.” They often recalled waiting a long time to see the doctor and then not remembering what was said to them when they finally had the long-awaited consultation. Although most patients could not recall in any detail what was said to them during their first consultation at Lady Ann’s, what they could recall were the small acts of kindness they received: being walked to their next appointment by the doctor, for example, or having a volunteer come by and support them during the first chemo, distracting them from what was happening. Thus, first visits to the hospital leave their emotional mark.

These patients not only had to deal with this physical initiation to the hospital, but a parallel experiential initiation to life as a patient with advanced cancer. Patients with metastatic or incurable disease fit into a cancer hospital in unique ways. They go through the same motions as patients with isolated or more curable cancers, focusing first on treatments and actions that can reverse or stave off the disease. And yet at some point, their distinction as patients with advanced cancer – as having cancers that respond less well to treatment or ones that keep coming back – is made clear. This may happen when they must begin treatment for the second or third time, or when the tumour recurs or progresses following a period of being stable. In a place like Lady Ann’s, which is fully committed to fighting cancer, and curing it where possible, these experiences make the journeys of patients with advanced cancer quite unique, but often in ways that are not explicitly acknowledged.

And so, I came to think about this little anteroom as symbolic of patients’ special positioning at Lady Ann’s. Like Alice, they fall “down, down, down” (Carroll 2007:14) into a different reality, but this time, not into a wonderful adventure filled with talking animals and grandiose queens, but into the world of advanced cancer. They end up in an unfamiliar place, but
unlike Alice, they find no clue or key that points them in the next direction. In this sense, patients are ‘lost’ both physically, in terms of the spaces of the hospital and its indeterminable corridors, as well as experientially, in terms of knowing what will come next for them in their cancer care. They hope to one day climb out of this place and leave it behind, and go back to their regular life before it was touched by cancer. But the rabbit hole of advanced disease does not often provide a ladder back to life before cancer.

**Containing Advanced Cancer**

This chapter explores the micro-world of a cancer hospital and the role the hospital itself plays in patients’ experiences with advanced cancer. I argue that Lady Ann’s tries to contain cancer in both a structural and an experiential sense, by drawing firm borders around different units in the hospital and between different roles for patients and staff. In practice, these boundaries tend to fall away, as patients must navigate multiple sites and practitioners within the hospital and their trajectories on any given day may not be linear or even logical. From a seemingly contained and physically enclosed place, emerges a site of many overlapping spaces lacking clear distinctions between clinics and roles.

Although a hospital is a familiar institution in North American culture, the public has only limited insight into how hospitals work, and there is a great divide between “clinicians who know what goes on in their services and the lay population that knows next to nothing” (Finkler et al. 2008:248). I show the hospital from the perspective of patients and their families, who are outside the world of oncology and only admitted because they themselves or someone they care about is sick, and therefore are not coming to Lady Ann’s under ideal circumstances. People regularly report that Lady Ann’s provides “excellent care,” and that they have heard it is the “best place to be if you have cancer,” but of course everyone wishes they did not have to be there at all. So on the one hand, they are “extremely grateful” that such a place exists and is able to provide them with first-rate care. On the other hand, it is the site where they undergo what are often difficult treatments and receive news that literally changes the course of their lives.

By taking them in when they are in need, the cancer hospital emerges as a central figure in the provision of their care. Lady Ann’s thus becomes a powerful metonym for everything associated with their cancer experience, including getting treatment and follow-up care. For example, Deo, a man in his early 60s diagnosed with stage IV, non-small cell lung cancer, tells
me how his son-in-law reacted to his diagnosis. “He said, “You are going to get through this, this is nothing for you. You are going to walk away from [Lady Ann’s] and then we can just give a donation or something.” Deo recounts this story to me as evidence of his son-in-law’s belief that he will get better. In this statement, the son-in-law envisions Deo walking away not only from the physical structure of Lady Ann’s, but more importantly from the whole experience of cancer itself and one day being able to leave it behind.

Following human geographers and their attention to the distinction between space and place, I reveal Lady Ann’s as both a space and a place that works to contain cancer. In general, geographers tend to distinguish between place as bounded and grounded in a specific location, and space as a more abstract and continuous notion (Andrews 2008; Gieseking et al. 2014). Thus, I examine Lady Ann’s as both a physical place, an institution that reflects and is implicated in contemporary discourses about cancer, and which condenses social practices and affective experiences, as well as a composite of many, overlapping spaces made meaningful by the different actors that cross paths within its confines. The Oxford English Dictionary (2006) outlines two meanings for the verb “to contain” that are particularly relevant here: “1) have or hold within; 2) control or restrain; prevent (a problem) from becoming worse.” As a physical building in which all diagnostic, treatment and follow-up care is provided, Lady Ann’s ‘holds in’ people’s experiences with cancer, allowing them at times to try to separate real or normal life from life they experience when they are physically present at the hospital. As a place that is highly charged with meaning, and a site of refuge, Lady Ann’s also ‘holds off’ advanced cancer in terms of preventing further disease progression. By containing the hopes of patients, families and staff who traverse its spaces daily, Lady Ann’s serves as a container for “social progress, development, and modernity” and emerges as a space of hope that anticipates a better future (Street and Coleman 2012:10).

Containment also occurs at a more experiential level. People want to contain the messiness of disease, how frightening it is, and the consequences it has for their lives and the lives of their families and children. Within the institution, people contain their emotions and their behaviours so that they comply with the expectations of being ‘good’ patients – i.e., no loud outbursts, no crying. Sitting in the waiting rooms of Lady Ann’s, you notice this exercise in self-containment that is happening. For example, a patient’s caregiver, looking out over the blood lab one day, said to me “It’s like a faceless society.” When I asked her to elaborate, she said that the room was filled with “so much apprehension.” She had been through her own cancer experience and
was now accompanying her friend through hers. She knew what apprehension looked like – and the feeling of not wanting to say anything for fear that you might burst open.

The theme of containment permeates the work of anthropologists, who are often fascinated by borders and boundaries, and social life on the periphery. Anthropological works have examined containment in quite literal ways, such as attention to the physical containment of people in institutions or prisons, often drawing on Foucault’s panopticon as described in *Discipline and Punish* (1995[1975]) or on Goffman’s *Asylums* (1961). For example, Crabtree (2003) provides an ethnographic account of a psychiatric institution in Malaysia where all patients are physically enclosed, but Chinese patients suffer an extra kind of “moral containment” due to professional staff’s negative attitudes towards them. Physical containment can also contribute to spiritual containment, such as the *Ama* shrines constructed in Dogon villages in Mali, which enclose and provide “ontological security” by protecting against evil spirits and invaders (Douny 2011). Sandra Bamford’s (1998) work among the Kamea of Papua New Guinea examines how boys are seen to be “contained” by their mothers’ bodies, causing both mothers and boys to avoid certain foods lest they harm one another. It is only through rites of initiation that boys become “decontained” and these taboos can be dropped (Bamford 1998).

Containment has also been shown to occur through less explicit means, such as through language in the media (Page 1997) or through discriminatory policies. For example, Gay Becker’s (2007) work on American uninsured minorities demonstrates how they get “contained” by Medicare; the public service is their only available source of care, but it is of such low quality and provides such poor service that people choose not to access it at all, and in doing so, become more ill.

Here, I take up the theme of containment in order to argue that experiences of cancer become physically and symbolically enclosed within Lady Ann’s, yet the boundaries between Lady Ann’s and “normal life” are more permeable than they might seem. The anthropological literature on hospitals has highlighted the contrast between the hospital as an “island,” a closed institution functioning independently of real life, and as a “mainland,” representing biomedicine’s foremost institution and a place where its core values and beliefs are made visible (Van der Geest and Finkler 2004). In the island argument, the modern hospital is perceived as having its own unique dynamic, separating the medical world from the non-medical world; people who become institutionalized there are removed from the world at large, likened to life on an island. This perspective was advanced by early sociological studies of the inner life of the ward, when patients were contained in separate units and spent a great amount of time there
(Coser 1962; Zussman 1993). In the mainland argument, hospitals are seen as institutions that are interpreted and influenced by the local culture, thus they are perceived as microcosms of larger society. Proponents of this view suggest that it is more appropriate to view the hospital not as an island, but as an important part (possibly even the capital) of the mainland (Van der Geest and Finkler 2004).

Recently, Street and Coleman revisited this idea in a special issue of *Space and Culture*, where they introduce a series of articles that work to reveal that hospitals can be “simultaneously bounded and permeable, both sites of social control and spaces where alternative and transgressive social orders emerge and are contested” (2012:5) and that this seemingly “paradoxical” status of a hospital is “crucial to its constitution” (2012:7). Thus, rather than view hospitals as either bounded as separate islands or permeable as mainlands, the articles demonstrate that they are both at the same time. Street and Coleman argue,

Hospital spaces are often regulated, standardized, and ordered according to biomedical and bureaucratic knowledges in order to align disparate doctors, nurses, relatives, patients, technologies, and spaces in the diagnosis and treatment of diseased bodies. At the same time, the hospital is necessarily open and permeable because these technical-spatial arrangements do not act on isolated microbes that have been primed for laboratory analysis but on disease as it is found in the “real” world; and the unpredictability and the complexity of that world enters the hospital with disease (2012:8).

I develop Street and Coleman’s key argument that there is “intrinsic ambiguity in the relationship between the hospital and everyday social space” (2012:5) in demonstrating how this kind of dual permeability and boundedness takes shape in one cancer hospital in Eastern Canada. Their volume aims to demonstrate the hospital’s permeability by showing other forms of “spatial ordering processes” that take place in addition to the powerful force of biomedical ordering; for example, Brown’s (2012) work in a Kenyan hospital illustrates how a domestic space is “remade” within the space of the hospital, with domestic practices, such as relatives feeding, cleaning and caring for loved ones, taking place alongside biomedical ones, such as doctors and nurses giving needles, diagnostic testing, and treatments. I illustrate how Lady Ann’s boundaries are made permeable both inside and outside the hospital. For example, as a large and efficient bureaucracy, the place of Lady Ann’s is separated into many distinct spaces and roles that serve to accomplish its various clinical tasks; but in everyday practice, the boundaries drawn between different services and roles within the hospital tend to fall away, as patients must often bridge the borders between services in order to receive care. Lady Ann’s is also permeable to everyday life.
outside the hospital, because it is a place where patients, families and staff, are always coming to and going from – bringing contemporary ideas about cancer in with them and taking out experiences of cancer into the “non-hospital” world afterwards. Lastly, Lady Ann’s is also a type of “global assemblage” that is “constituted and made meaningful through [its] relationship with places elsewhere” (Street and Coleman 2012:12). As a major centre for research and teaching on cancer, Lady Ann’s is connected to other similar cancer institutions around the world and works to define itself in relation to its peer institutions such as M.D. Anderson in Texas or the Dana Farber Cancer Institute in Boston.

By examining how borders are maintained or transgressed in everyday life at Lady Ann’s, I aim to draw attention to how spaces are created through social and material practices. These interests tend to fall under the domain of science and technology studies (STS). For example, Mesman’s work (2012) demonstrates that patient safety in a neonatal intensive care unit (NICU) is a spatial accomplishment, requiring coordination of both people and things that exist together in the NICU. The space itself becomes deemed “safe” as a direct result of the collaboration of workers and parents, who follow carefully designed protocols that produce a “clean” space. Importantly, Street and Coleman (2012) argue that STS scholarship sometimes privileges material practices to the detriment of the imaginative and emotional qualities of space. I follow their lead in order to show how Lady Ann’s space is not only defined through its repetitive biomedical practices, but also through the emotional and imaginative qualities that patients especially bring to its spaces. As the “best place to be if you have cancer,” Lady Ann’s is invested with patients’ hopes for a cancer-free future. Thus, it contains not only the hopes of patients and families for a cancer-free future and the triumphs of appointments where the cancer is reduced in size or at least stable, but also the difficulties and inevitable downfalls of cancer treatment and care, as well as the disappointments of appointments where cancer progresses or recurs.

Lastly, I show that there is a direct consequence on the lives of patients with advanced disease that results from Lady Ann’s status as a bounded place with permeable borders. Care for solid tumour cancers is provided at Lady Ann’s on an outpatient basis, which means that patients come and go regularly from the hospital for treatment and follow-up care. Thus, patients are always switching between “hospital life” and “non-hospital” or normal life. I argue that the nature of ambulatory cancer care mystifies how well patients are doing, and gives the illusion that things are better than they seem. In other words, because they are always in transit between
“sick life” and “non-sick” life, and are not “contained” in hospital for the duration of their illness as they would have been less than 100 years ago, patients are led to believe that they are doing better than they are.

In the following sections, I demonstrate both the bounded and permeable aspects of Lady Ann’s. I begin by briefly introducing the context of care, since everyday life in a cancer hospital is not the same as everyday life in a general hospital, thus what happens there must be understood through the particular context of cancer care more generally. I then briefly review the historical development of the specialist cancer hospital. Historically, patients with life-threatening illnesses were regularly excluded from general hospitals because of their negative impact on hospital mortality statistics (Murphy 1989). Had these patients lived in the late 1880s, when general hospitals were being developed in Ontario, they would have been put into what were then called “Hospitals for the Incurables” (Allan 1934). To consider Lady Ann’s in light of a history of shunting patients with incurable cancers into their own specialized hospitals reveals that the contemporary cancer hospital has become a more ‘permeable’ institution (Quirk et al. 2006) than its predecessors. Yet, as I show, this lack of physical enclosure may actually contribute to the contradictions patients with advanced disease experience, precisely because they are now treated side-by-side with patients who have curable, localized disease.

After reviewing the history and context of cancer care, I move into a discussion showcasing how Lady Ann’s tries to contain cancer, both in a structural sense and an experiential one, yet it has difficulty doing so. I demonstrate how Lady Ann’s spaces are clearly laid out, and roles are defined in order to meet the needs of a large volume of sick patients. Containment at the structural level in terms of divisions of clinics and staff roles and responsibilities is mirrored by containment at the individual level in terms of the management of emotions and delineation of the cancer experience to when patients are actually physically present at Lady Ann’s. I then address what threatens both structural and personal containment: doctors’ clinics that move from day to day, requiring patients and staff to move as well; a scheduling system that cannot produce “patient-centred” appointments; patient and staff role transgressions; imperceptible distinctions between medical staff resulting in patient confusion; news that comes as a surprise in the consultation room and causes an emotional break; and the reality that being a patient takes over the monthly calendar, resulting in daily life being oriented around cancer, rather than delimited to the time spent at Lady Ann’s. In practice, boundaries or efforts to contain cancer tend to fall away.
Lady Ann’s 101

Lady Ann’s is a world-renowned cancer facility, seeing close to 1000 patients per day. It has an international reputation for cancer care and research, and is positioned at the forefront of innovative research about the treatment of cancer and the psychosocial aspects of living with a cancer diagnosis. Its reputation is built on years of treating patients with some of the most difficult cancers in Canada. Over the course of one year, it will provide care to over 200 000 patients and their families, in the form of diagnosis, treatment and follow-up care, totalling over 400 000 patient visits per year. It is primarily an outpatient hospital, which means that it functions mostly on a 9 am-5 pm schedule, during which patients come to the hospital for clinical and treatment appointments. It is a large, impressive building, with 18 floors above ground, as well as 2 floors below ground level. The hospital’s main floor and arteries feature a central atrium, two coffee shops, a patient and family library, a multi-faith space, an outpatient pharmacy, the blood lab, a gift shop, and hospital security. There are 130 inpatient beds, mostly serving patients with non solid-tumour cancers and palliative care patients. The palliative care unit provides pain and symptom management, as well as respite care so that tired caregivers may be given a break. Its primary focus is for short stays; just fewer than 50% of patients die on the unit, while the rest are stabilized and discharged home when possible or to another community palliative care unit. My research took place mostly in the outpatient clinics, with patients who had solid tumours of lung and gynaecological origin.

In contrast to Julie Livingston’s recent award-winning ethnography (2012), which examines the only cancer ward in Botswana, where a lack of drugs and technology means that cancer is often left untreated and people languish until they die, a condition she astutely summarizes as “cancer without oncology,” doing research at Lady Ann’s meant that I was allowed to observe cancer with the greatest amount of oncology possible. As a large, specialized cancer centre in Canada, Lady Ann’s is similar in reputation to other North American heavy-hitters in the cancer field including M.D. Anderson in Texas, Memorial Sloan-Kettering in New York, and the Dana Farber Cancer Institute in Boston. Similar to those institutions, Lady Ann’s is not only a place that provides care, but a research hub; its location nearby the campus of a large university, as well as other hospitals and centres that commercialize the research emerging from the universities, helps to facilitate this. It is a teaching hospital for physicians, nurses, social
workers and other professions in oncology. It also serves as a training site for international fellows from all over the world, who come and complete 1-3 year terms, in order to gain the expertise necessary to run clinics in similar cancer centres around the world. Lady Ann’s research culture is exhibited by the fact that a minority of the 18 floors in the building are reserved for clinics or inpatient beds; the rest are devoted to research labs. Its devotion to research is carried through in each of its departments – from psychosocial oncology, conducting studies on therapeutic approaches to helping patients come to terms with cancer, to bench science, conducting laboratory experimentation on cancer genetics, to the oncology outpatient clinics, enrolling patients in clinical trials. Patients only tend to come into contact with the latter manifestation of research culture; the possibility of being enrolled on a drug not yet approved by Health Canada is the reason some of them are referred to Lady Ann’s. The visible presence of clinical trials in the outpatient clinics exhibits what Keating and Cambrosio (2011) have called a “new style of practice;” they argue that despite the fairly recent development of oncology as a separate sub-field in the 1970s, its science and practice are now completely dependent upon the existence of clinical trials.

Lady Ann’s is centrally located in the downtown core of a large, urban city in Eastern Canada. In addition to Lady Ann’s, there are four other hospitals located in very close proximity, making the north part of the street a kind of ‘hospital alley.’ Many patients come from out of the city – from nearby towns and smaller cities – and so they drive themselves in. Parking costs are normally atrocious. In 2011, when I was conducting research, a full day parking pass cost $27. The lots are located behind the building. There are no ‘come and go’ allowances and no discounts for being a patient (although there is a discount for arriving before 9 am). Some patients on radiation have to come to the hospital every day, and if they are driving or coming with a caregiver who is driving and will need to park, one can imagine how expensive it gets. Patients may also take advantage of a free transportation service operated by the Canadian Cancer Society.

The hospital is also accessible by subway, and many patients who did not drive chose that form of transportation, with some caveats. Lady Ann’s is only a short 5-minute walk from the nearest subway stop, but that subway stop has four possible exits, on four different corners. I stopped many times and tried to assist confused looking people who were in search of either Lady Ann’s or one of the other hospitals located in this hospital-dense area. The stairs or escalator exiting the subway station and 5-minute walk are very manageable for a person who is
feeling well, but many people on chemotherapy or radiation can find even those small exertions exhausting. Public transportation also may be avoided due to its association with germs and with close proximity to others. One patient told me she had never taken the subway when she was on chemo precisely because the chemo pamphlets they had given her at Lady Ann’s told her to avoid high traffic zones. People also sometimes avoided the subway if their appointment time at Lady Ann’s required that they travel during the morning or afternoon rush hours, making getting a seat much less likely. Lastly, the front entrance to the hospital has no accessibility ramp and requires that patients climb a short flight of eight stairs, so a person in a wheelchair or using a mobility device cannot enter that way. The back entrance is accessible, but is on a small side street, and is thus not visible to those coming out of the subway exits. Patients coming to Lady Ann’s for the first time will not know to go around the building. Therefore, feeling weak or tired, worrying about germs, rush hour, or having to climb stairs all at times may preclude patients from taking public transportation to get to Lady Ann’s.

The Context of Care

In mid-April of 2011, I was observing in the Lung clinic and witnessed a consultation where in the space of several minutes a patient went from his worst fear to a far better scenario. Ralph, a 65-year old gentleman, smoker of 18 pack-years (equivalent to smoking 20 cigarettes per day over an 18 year period), had kindly consented to me observing his consultation. Dressed in a dusty work-shirt and jeans, he chatted with me in a friendly manner throughout the consent process, as we waited for the doctor to enter the room. Dr. Johnson, a fellow working under Dr. Lawson, entered the room and asked the patient what he knew about why he was there. Ralph replied that he had been discharged from the ER and was told that he could have cancer, and that if so, he would have three options – radiation, surgery, or chemotherapy. Dr. Johnson interrupted his story to confirm that it was cancer.

Dr. Johnson: “As far as we can tell it is at an early stage, at a stage which can be operated on – if disease is not anywhere else. If it is only on the lower portion of the lung, then the approach would be surgical – no lymph nodes, no other organs…If it is the best case scenario, 2/3 chance of being cured or better.”

Ralph, looking happy, replies that this news is “Excellent. I was hoping I wouldn’t have to come for radiation for 2 years.”
Dr. Johnson says there might be a role for chemotherapy if they find that the lymph nodes are involved at the time of surgery. Ralph again reiterates that he is fine with the operation and that it doesn’t faze him “because it’s over and done with – not coming here for 2 years.”

Dr. Johnson proceeds with a physical exam and speaks to Ralph about the importance of quitting smoking. He then leaves the room, and I follow, smiling at Ralph as I leave. As we are leaving the room, Dr. Johnson comments to me, “It’s kind of nice – we don’t see many early stage cases here.”

During the case presentation to Dr. Lawson, she seems annoyed and confused as to what this patient is doing here, asking “Why am I seeing him?” She asks to see the referral sheet and noting that Ralph has “no evidence of mets [metastases]” says, “This patient got to me by mistake.”

When we go back in the room, accompanied by both Dr. Johnson and now a 2nd fellow, Dr. Lawson begins by saying, “I don’t think I’m the doctor you need to see.” She then talks to him about disease and says the prognosis “is excellent and hopefully operated on for cure.” She says, “You should consider all this good news.”

They have a short discussion about smoking where she reiterates the importance of quitting in order for the lung to be healthy for surgery. Then she says, “I’m not going to say any more, because you don’t want to hear about chemo. If you don’t need to see me that’s a very good thing.”

I note that Ralph seems very jubilant in his reply, “It’s not that I don’t like you, but I hope to never see you again.”

Dr. Lawson replies, mirroring his enthusiasm, “This is a red letter day for me, I don’t usually get to send patients away with such good news.”

Ralph says, “God Bless you.”

We leave the room in a flurry of happiness and laughter. I notice that the fellows are joking with each other, remarking again how “it’s quite nice to see patients like this.” As we walk back into the workroom, there is an air of celebration and lightness in everyone’s step. Everyone who was in the room seems momentarily ‘lifted up’ by this brief consultation.

What is interesting about this interaction is the discernible change it brought about to the team and to the atmosphere in the clinic for a few moments. Note that at no time does Dr. Lawson tell the patient he does not have cancer. In fact, she confirmed that he had cancer and would need surgery in order to remove it. But this lessening of the blow of cancer, this ability to be a bearer of somewhat ‘better’ news (deemed “excellent” by the oncologist herself), must be understood within the context of everyday life of Lady Ann’s, and particularly the context provided by a lung clinic aimed exclusively at advanced stage patients. I recorded this
observation in my second month in Dr. Lawson’s clinic, and almost all the conversations I had witnessed previously stood in stark contrast to this one. The heaviness of an advanced stage lung cancer had already begun to weigh on me, and I hardly spent any time in the clinic compared to the oncologists, nurses, and fellows who regularly saw between 20 and 30 patients in a morning or an afternoon clinic, which happened several times a week. Their work really did involve the worst cases – stage IV lung cancer – a diagnosis with a 3.8% relative survival ratio of surviving 5 years (SEER Cancer Statistics 2011). This is the context in which they regularly worked, day in and day out, seeing new patient after new patient, all of whom were likely to die from their disease in on average less than two years, as I heard Dr. Lawson verbalize on the rare occasion a patient was brave enough to ask for the specifics about prognosis. The temporary ‘lightness’ in the air provided by this one consultation exemplifies the context of care at Lady Ann’s, where goals and values are specific to cancer; although cure or cancer-free status is always hoped for, people will often be satisfied with much less. Only within a cancer hospital that regularly sees patients who are much, much sicker than Ralph, can a conversation that still ends with him having cancer be portrayed as “excellent news.”

The Cancer Hospital in Historical Perspective

While general hospitals have extended the treatment they offer to cancer patients, the role of the special cancer hospital has in some important respects come full circle – from terminal care to aggressive treatment and back to terminal care – in the course of a century. (Murphy 1989:238)

The contemporary cancer hospital is a particular kind of place, situated in a particular time in our history. In this section, I consider what it means to be a specialized cancer hospital early in the 21st century in North America, a time when cancer is highly present and visible in our culture, due to the growth and more obvious presence of activities in support of cancer research and to the increased visibility of the survivorship community. According to Murphy, in the late 1800s, cancer was “malign, painful, evil-smelling, and deadly” and it was understood that a diagnosis of cancer meant “certain and painful death” (1989:223). Compare this to our current climate, exemplified in the cheery atmosphere of the fundraising activities for cancer research (King 2006). For the patients that I followed, the diagnosis of advanced cancer is still a threat to mortality, yet they live in a contemporary culture that in some ways has shifted its perception about cancer.
Hospitals throughout history have often been associated with places of refuge, taking in people that society could not otherwise care for, such as the poor, the indigent, and the mentally and chronically ill (Duffin 2010). As houses for the poor and the homeless, they were places that people tended to avoid at all costs if they had the means to do so. They were founded as places of charity, often religious in nature, and had little to offer in the way of treatment based in science until about the mid-1800s, with the discovery of antisepsis, followed by germ theory in the late 1800s (Duffin 2010). These discoveries launched the beginning of a new period in hospitals, where they began to be linked with scientific discovery and medical research (Henderson et al. 2007). As Duffin recounts about the ushering in of this new era for hospitals, “no longer places to be shunned, hospitals were centres for science and cure” (2010:238). With new treatments and technologies, such as the use of radium to treat cancer developed after the First World War, people had to be admitted to hospitals for access to diagnostic tests and technologies that were housed there (Duffin 2010). Historians generally see the period that followed the late 19th century as the ‘modern’ period of hospital development, seeing them as places of “scientific investigation and cure, furnished with expensive equipment and essential to rich and poor alike” (Duffin 2010:240).

Recently, hospital historians Henderson, Horden and Pastore (2007) have challenged this ‘modernist’ teleological framework for examining the history of hospitals. Their volume, which examines the development of hospitals from 300 AD to 2000, aims to remove the lens of modernity and medicalization they argue is often applied to the history of the hospital. This lens presumes that there “has been a great ‘before’ and ‘after’ in hospital history; some pivotal period in which charity gives way to medicine, care to cure, stigma to pride, the mortuary to the recovery room, the poor to the middle classes” (Henderson et al. 2007:32). They say that this lens tends to eclipse what might better be viewed as continuities in the history of hospitals; for instance, many features of the ‘modern’ hospital, such as centralization, care by physicians, and an attached pharmacy were actually present in hospitals in 15th and 16th century Florence (Henderson et al. 2007:22). Thus, continuities in cancer care, examined in the Introduction (Patterson 1989), have parallels in the history of specialized cancer hospitals. This privileging of continuity rather than the scientific or the modern seems particularly apt in turning to examine the development of specialized cancer hospitals. Michel Foucault (1979) famously called hospitals “les machines à guérir.” But if a hospital is a “curing machine,” how do we make sense
of a place like Lady Ann’s, where many people, despite the best efforts of oncologists and the most ‘modern’ of medicines, will not be cured of their disease?

The emergence of the specialized cancer hospital

The historian Caroline C. S. Murphy (1989) provides an excellent history of specialist cancer hospitals in the U.K., pointing to their early beginnings in the middle of the 19th century. These hospitals had a ‘hospice’ orientation when they opened, in that they were meant to take in patients with incurable cancers who were not being accepted in other general hospitals. At that time, there was little to offer cancer patients in the form of treatment except for surgery. One way to keep hospital mortality statistics in the ‘black’, was to exclude patients who had ‘inoperable’ cancers, which meant that patients with advanced disease did not have access to professional nursing care unless they had means to pay for it at home.

In 1852, William Marsden opened the London Cancer Hospital, the first hospital dedicated exclusively to cancer, specifically to address this lacuna of care after losing his wife to ovarian cancer. Several cities in the U.K. followed suit, with Manchester and Glasgow not far behind. Murphy (1989) notes that the treatments at the London Cancer Hospital, including leeches, blisters and caustics, were far from advanced; they did not lend the London Cancer Hospital and those modeled after it very good public reputations. In the late 1880s, as radical surgeries became more popular, these cancer hospitals considered establishing “Friedenheims” – a German word indicating a place in the countryside where patients could go in order to die in peace and comfort. These cancer Friedenheims were to be modeled after similar places developed for patients with TB in Germany. But Friedenheims never came to fruition, because their proposal came in parallel to the rise in popularity of scientific research and the belief in aggressive surgeries for cancer. Scientific research became the beacon of hope for the treatment of cancer, causing money and investments to be diverted away from homes for the dying and towards the establishment of scientific laboratories. For example, the year 1902 saw the establishment of the “Imperial Cancer Research Fund” (ICRF) in the U.K. “in the belief that, given half a million pounds and twenty years, cancer would be cured as a result of the work of scientists in its laboratories” (Murphy 1989:227). One cannot help but be reminded of a similar declaration made by President Nixon 69 years later, when he proclaimed a “war on cancer,” paired with a comparable influx of a large sum of money to the National Institutes of Health.
The end of the First World War saw the discovery of Radium and its potential application in the field of cancer research. Murphy notes that the availability of this treatment for cancer meant that beds in cancer hospitals that normally would have accommodated dying patients were then diverted to patients receiving aggressive surgery or radiation treatments which were aimed at cure (1989:230). Then after World War II, chemotherapeutic agents were developed and those too contributed towards a shift away from caring for dying patients as central to the mission of the specialist cancer hospital; the focus on finding the cure, at the expense of therapies that grew more and more aggressive, persisted throughout the 1960s (Murphy 1989; Baszanger 2012). The National Health Service, when it was developed in the U.K. therefore did not have care of the dying as central to its mandate, but rather saw the dying as “embarrassing evidence of the failure of medicine to make man immortal” (Murphy 1989:234). This abnegation of care of the dying continued until the pioneering work of Cicely Saunders, a nurse and physician, who established St Christopher’s Hospice in 1967, the outcome of research and work on pain control she had undertaken since the late 1950s. As Murphy eloquently recounts, “we live in the remains of our history, just as much in the field of cancer treatment as elsewhere” (1989:237). The research and cure agenda did not succeed at completely obliterating the care of the dying, but it did forestall it for many years, until public outcry and protest pushed that agenda back into the spotlight.

In Canada, the care of incurable patients developed similarly to what happened in the U.K., although about twenty years after the first cancer hospital opened in London. Government of Ontario historian Allan notes that, “early in the history of our general hospitals, it was recognized that the admission and treatment of chronic incurable patients was greatly detrimental to the usefulness of the hospitals” (1934:193). Thus, special homes or hospitals were opened for the patients with incurable disease, and these places were called plainly “Hospitals for Incurables.” The first of these sites opened in Ontario in 1873. Allen notes that immediately after the first “Hospital for Incurables” was opened, the need for such a place was recognized and plans began to increase the number of beds. By the year 1935 there existed seven such institutions in Ontario (Allan 1934). These sites, although similar in function to what had developed in the U.K., were not specific to diagnoses of cancer, but housed patients with many ailments that were incurable at the time. The 1927 annual report of one of such homes lists cancer as the cause of death of one third of all patients, but as only one fifth of all admissions, which also included arthritis, hemiplegia, paralysis agitans, and cardiovascular disease (King 1927:10).
The contemporary cancer hospital, complete with treatment for all types of cancer is thus a very modern invention, given that less than 100 years ago, patients with advanced disease would have been contained in these types of separate institutions. Interestingly, Murphy demonstrates that the early specialized cancer centres founded in the U.K. were not seen as being positioned at the forefront of scientific discovery, but rather as sites of rather questionable, even “quack” treatments (Murphy 1989:225). In the contemporary moment, places like Lady Ann’s, M.D. Anderson in Texas, Memorial Sloan-Kettering in New York, and the Dana Farber Cancer Institute in Boston are all are founded upon their strong links to “science,” evidenced through their research and clinical programs that run in parallel. These institutions all relay a consistent message: “science” (currently being represented by personalized medicine through genomics) will offer up better treatments and the elusive cure.

Viewed in a contemporary light, the idea of a place called “Hospital for Incurables” seems strange or antiquated, as today patients with advanced disease are given treatment and care very much akin to what patients with localized or more curable cancers receive. To think about casting them out to a place whose name is indicative of hopelessness seems unduly cruel and stigmatizing. Yet such sites do exist in contemporary society – their modern incarnation is likely the hospice. But patients newly diagnosed with advanced disease do not go to hospice. Rather, they begin treatment just like other cancer patients, whether its intent is curative or palliative. Contrary to the “total institution” that Goffman (1971) described, Lady Ann’s is a “permeable institution” (Quirk et al. 2006) where no bars or physical boundaries are used to separate patients with incurable disease from those with curable disease. Perhaps Lady Ann’s serves as a beacon of hope precisely because it makes no demarcations. By containing all of these diverse experiences of cancer – ranging from early stage, and curable to late stage, and incurable – Lady Ann’s represents the “Hospital for Incurables” and “Hospital for Curables” merged into one place. In this sense, it hides patients’ liminality. Whereas the “Hospital for Incurables” made the category of the person facing advanced illness explicit, the contemporary cancer hospital makes it seem like all patients are the same. But make no mistake, the patients who in 1927 would have been housed within a different place still exist – “science” has not succeeded in making them obsolete – now they are just that much harder to see.
Holding in and Holding off Cancer at Lady Ann’s

Structural containment: translating spatial boundaries

Whereas in the past, a patient would be admitted to hospital, and remain on one ward for a long time (until he was better and could be discharged, or until death) (Zussman 1993), visiting a hospital today often requires navigation of multiple sites or units within the institution. At Lady Ann’s, each of the floors has designated clinical spaces for tumour types; for example, there are separate clinical spaces for GI (gastro-intestinal), gynaecology, breast, lung, head and neck cancers, among others. These names appear outside the clinic doors or above the reception desks. Some of these spaces are more contained than others. For instance, the chemotherapy treatment area is closed off to the general hallway. People wait in a room that has a clear glass wall, but once they have been assigned a chair or a bed, they proceed into an area that is not visible to people walking the hallways. Containment of chemotherapy has dual benefits: it prevents other patients or visitors to the hospital from the daunting sight of a long room of people hooked up to I.V. poles, and it provides some privacy to the patients receiving treatment there, which can often take hours, or even a whole day.

Other sites, like the blood lab and the waiting areas for other tumour sites are wide open. The blood lab is located on the first floor, as part of the same waiting area as the outpatient pharmacy. Both of these spots are heavily trafficked by all staff and visitors to the hospital, as they are within a person’s line of view regardless of whether he enters Lady Ann’s from the front or rear entrance. This large waiting area, often full of patients with bald heads or headscarves, sometimes looking very sick and tired and lounging on chairs as they wait for their numbers to be called, makes it impossible to forget that Lady Ann’s is a cancer hospital. Because this open waiting room spills out into chairs in the hallway, very close to the main bank of elevators, people are often rushing past this space on their way to some other place in the hospital. In the morning hours, the blood lab (7 am-5 pm) side is often busier, as patients must have bloodwork about 1.5 hours before an appointment in order for the lab to have the results by the appointment time. In the afternoon hours, the crowds shift over to the pharmacy side (9 am-5:30 pm), as patients come out of appointments and wait sometimes up to an hour for prescriptions.

Although both the Gyne and Lung clinics where I worked are relatively closed off from the general walkways, in other tumours sites such as Haematology on the 2nd floor, there are no enclosing walls or structures around the waiting room. Thus there is no distinction between the
hallway and the clinic; patients wait in a space that is between the actual clinic and the hallway. People walking up and down the main open staircase in the middle of the building, which runs between the 1st and 5th floors of Lady Ann’s, have a clear vision into this waiting room and the patients (not) contained within. As an observer, walking up or down the stairs en route to someplace else, I always felt I had wrongly trespassed in their territory. Patients are highly visible in these clinics, and it is not only their bodies that are ‘on display’ and not given privacy, but also their anxieties, their I.V. poles, their fatigue, all of which would be contained if they were in a different clinic site, such as Lung or Gyne. The juxtaposition of the open waiting room in Haematology with the closed waiting rooms of Gyne and Lung demonstrate how hospital spaces are both bounded and permeable at the same time (Street and Coleman 2012).

Most often patient appointments occur in clinics that bear the same name as their cancer; however, sometimes patients are seen in clinics that have no relevance to their particular diagnosis. The ‘clinics’ in the sense of the doctors and staff who run them, move around the hospital into whatever physical spaces are available. This happens especially with clinics that are open to patients of all tumour types (e.g., phase I clinical trials, pain, palliative care). So the name on the outside of the clinic is at the same time meaningful and somewhat meaningless. For example, the outpatient palliative care clinic, although it runs 4 days a week, is in effect ‘homeless’ – it has no designated outpatient space (although a very nice inpatient one). The nurses push around a little cart that contains all the forms and materials that they need for the clinic. On more than one occasion, I sat with male lung cancer patients in the breast cancer clinic as they waited to be called in for their palliative care appointments. At least one of them commented to me that this made him slightly uncomfortable. In this example, the clinical site name (i.e., “breast”) was meaningless. No one explains this to the patient – he just has to pick up this knowledge along the way.

Adding to the confusion, the clinics change with day and time. So for example, a patient can see a GI doctor on Monday morning in the GI clinic, but by Monday afternoon, the clinics have all switched over, and palliative care has now taken up some of that space. Patients often come to the reception desk on a day there is no clinic for them scheduled and want to see their doctor. The front desk staff have to explain to them that the entire team, including their doctor, is working somewhere else in the hospital that day. To the staff, it is not a problem. Every day, the front desk staff – who are not called “receptionists” but actually “patient flow coordinators,” abbreviated to “PFCs” – are given a chart detailing how the spaces of the hospital are being used.
for that day. But the patient is not privileged to that same information. A patient new to the hospital might be sitting in a waiting room, worrying that the name on the outside has some significance and that their cancer has progressed and moved somewhere else in his body, but no one has yet told him.

In fact, I witnessed this exact kind of confusion, when I was still volunteering. I was working in the GI clinic, and that afternoon that space was simultaneously being used by an outpatient palliative care clinic, a lung radiation oncology clinic, and a phase I clinical trial clinic. A male patient’s daughter came up to me at the desk and pointed out that the sign on the reception desk listed the doctor her father was seeing – the radiation oncologist – with two palliative care doctors. Each PFC checks in patients for particular clinics, and this PFC had made a sign that listed all three doctors names, under the heading “palliative care.” If you looked closely at the sign, underneath the two palliative doctors names was a little symbol and a space before the radiation oncologist’s name, meant to distinguish the two palliative doctors who were working the clinic that day from the radiation oncologist. But those small details went unnoticed by the concerned family member who said the sign was “misleading,” as she had been sitting there worrying that her father had been referred to palliative care and it had somehow escaped her attention. When I pointed it out to the PFC, she was a bit annoyed and surprised that anyone would read so much into it, noting that it “didn’t mean anything,” but in the end she did change the sign. In this case, something so small as a paper sign provoked anxiety in a family member, who likely already had enough to deal with without having to worry that her father was now considered “palliative.”

Thus, patients and families may read into signs and symbols in the hospital that to the staff are actually irrelevant or meaningless. As Frankenberg (1988:136) outlines, in the space of a hospital, “patients’ uncertainty is reinforced by the certitudes of the physician’s (and to a lesser extent other health workers’) understanding of complicated routines.” So the hospital is like a foreign island to them. It is a large physical space, with clinics, doctors, and staff who do not stay in one place. Moreover, it pulses with biomedical and bureaucratic rationalities that are external to the lived experiences of disease. As Brown observed in her work in a Kenyan hospital, staff generally have much more ease and freedom of movement about and between the various spaces, contrary to patients who “wait obediently on the peripheries of those spaces in order to get things done” (2012:21).
Once patients get the hang of it, they adjust quickly to this new world. But they often need people in the system to “translate” it for them. The PFCs do an incredible amount of this navigational work – as their title suggests, they keep patients moving through the hospital system. But navigational and directional advice is not often dispensed with reasoning or explanation. So patients may know their next action, next destination within the hospital, but the reasons why that action or place is next and not another are seldom made explicit.¹⁰⁹ As a volunteer, I found that I spent much of my time in the hospital explaining how things work – the reasons why other people who arrived later than them were being called in first, the reasons why they had to wait again after coming out of their appointment in order to get their new itinerary, the reasons why the doctor they saw in this space the day before was not there the following day when they dropped by to ask a follow-up question. In doing so, I was trying to make the seemingly very “bounded” institution more permeable for patients and families.

**Structural containment: making the system “work” for patients**

Sometimes patients themselves are required to help the hospital system “work.” For example, I watched one day as Melody, a woman in her early 70s with metastatic ovarian cancer, was told her CT scan appointment was scheduled for 9 o’clock at night at one of the other hospitals in Lady Ann’s network. The time was not uncommon – increasing reliance and demand for tests and a limited number of machines means that the CT and MRI machines are running far beyond the 9-5 hours of Lady Ann’s. Melody lived alone and often relied on public transit to get to the hospital. The other location is not as accessible as Lady Ann’s, as it requires both a subway and a streetcar ride. It is also a bit of a daunting place to go to at night, as it is not in the most desirable neighbourhood and is located on a dark corner.¹¹⁰ So Melody’s age, access to transportation, and general comfort level all stood in the way of this being an appropriate time for her to have a CT scan. But the PFC had not in fact chosen this timeslot with Melody in mind. The PFC does not book the appointment herself, but rather submits a request for an appointment, and a person somewhere else in the hospital gives back the first available timeslot.¹¹¹ So the institution does not have ‘eyes’ to see the individual patient, unless the PFC inserts her into the request, and asks for special accommodation. When patients complained about their timeslots, PFCs would often encourage them to go the CT department themselves, on the 3rd floor, and make a personal appeal. Interestingly, in conveying this advice, they often told patients they
would have “better luck” than if they tried to amend their original requests. Melody did as suggested and was able to obtain a more appropriate timeslot.\textsuperscript{112}

This example demonstrates that although the process of booking a CT scan is clearly laid out, with different workers within the system completing tasks that lead up to a scheduled appointment, in practice, the patient might need to do some “work” in order to get a timeslot that fits with her schedule. While it seems like Melody’s problem could have been avoided if the PFC had made a special request in the first place, in practice, the PFC or the CT department does not have time to take into account every patient’s preferences when it comes to scheduling. PFCs are supreme order multi-taskers; they are not only checking patients into clinic, but must also schedule any follow-up tests or appointments. This is why patients wait again, after their appointment, in order to leave with their updated itinerary in hand. As the ‘faces’ of the clinic staffing the reception desk, they must also deal with any complaints about the long wait, which sometimes build towards an overall feeling of resentment towards them. For example, one day I watched Louise, the Gyne PFC, standing in the back clinical area, quickly devouring a sandwich. It was around 1:15 pm, when the morning clinic should have been done (the afternoon clinic starts at 1:30 pm), but some patients were still waiting to be seen. In response to my questioning look as to why she was choosing to eat in the hallway rather than at her desk, she said, “they’re ganging up on me,” referring to these patients in the waiting room who kept inquiring when they would be called in for their appointments. Thus, there is an emotional kind of labour (Hochschild 2012 [1983]) that Louise must manage, in addition to her many tasks at hand. The PFC does not need another job; she already has too many. From the perspective of the hospital system, it would take a lot more time both for the PFC and the CT scheduler, to accommodate all personal requests. From a time perspective, it would therefore be highly inefficient, and inefficiency is every hospital’s administrator’s greatest enemy. Thus, in order to produce an outcome that was both efficient \textit{and} patient-centred, some of the work must actually be accomplished by the patient herself. Melody needed to cross over these different parts of the system and insert herself, the patient, into the equation in order to get a timeslot that was actually appropriate for a 70-year old woman with advanced disease.

Here is a different type of example, which also demonstrates how patients must do work in order to make the hospital system “work” for them. A typical visit for a patient on treatment will often involve stops at a minimum of 4 locations: the blood lab, the clinic, treatment site (chemotherapy or radiation), and the outpatient pharmacy. If the patient has a port (a direct line
into the vein that stays in throughout treatment), then they must go to the ambulance waiting area (AWA) to get blood drawn. AWA is also the place where they get an electro-cardiogram (ECG), so AWA is also a fairly common stop. One day I followed Pam, a woman in her early 50s with stage III ovarian cancer, on the following route: blood lab → clinic → blood lab → AWA → clinic → outpatient pharmacy. Her patient itinerary that day included only the blood lab and the clinic appointments. But after waiting her turn in the Gyne waiting room, and then being called into a patient room, she was immediately sent back out; first, to bloodwork to get the “correct” vials drawn for the clinical trial she was on, and second, to AWA, to complete an ECG that needed to happen on this visit (as the trial protocol outlined). Although neither of these additional stops was outlined on her itinerary, it seemed to be her responsibility to remember to do them before checking in for her appointment in Gyne. Pam was chastised a bit for this “forgetfulness”; the clinical trials’ nurse seemed a bit annoyed that these tasks had not already been completed. This meant that she would now be behind schedule; she would have to make time to call Pam into clinic again. She sent Pam back out to bloodwork bearing instructions to the blood nurses about what vials of blood were needed for the clinical trial. This is telling; Pam literally needed to bridge the gap between services and between health care workers in order to receive care that day. Pam’s experience demonstrates that patients’ movements through the hospital are rarely straightforward, and that they often must move from service to service (sometimes even in a repetitive pattern). Spending a day in their company, I would observe these circular routes, and wonder if anyone was keeping track of this discrepancy between what was outlined on patients’ itineraries and their actual movements in the hospital.

Another example of the invisible labour of patients occurs when they are asked to retrieve their own hospital cards, which I witnessed when I volunteered in the GI clinic. Patients would arrive for their first visits and upon checking in, would be told they needed to go retrieve their hospital cards, which were being printed at a station elsewhere on the floor. I observed patients and families, who had just managed to find the clinic they were looking for, then be directed out of the clinic and down the hallway, to a station which was not always staffed, to pick up a card that emerged from the printer. I could see them struggle to not lose their tempers, and as the volunteer, I would offer to go and get it for them, wondering on my walk to the carding station how patients new to the hospital would be expected to find this desk. If the station was unstaffed, as it sometimes was, retrieving the card required that they lean over the desk and riffle through the other cards being printed from other clinics on that floor. This practice itself seemed to cross
all sorts of boundaries regarding patient confidentiality. Yet, I doubted that it was intentionally conceived, but rather an unintended consequence of a large, bureaucratic hospital system. In other words, since there are carding stations spread out throughout the hospital, and not enough for one in each clinic, and the PFCs are stuck behind the reception desks and cannot get up to go for a 5 minute walk every time they need a new card, they ended up asking patients to do it.

The work completed by patients here – in retrieving cards, in carrying messages from other clinic sites, in scheduling appointment times that are ‘patient-centred’ – is very important work that is likely hidden within the system. As Robert Murphy notes, “the hospital has all the features of a bureaucracy, and, like bureaucracies everywhere, it both breeds and feeds on impersonality” (1990:20). Each of the examples demonstrates that the hospital is set up like a machine or a system that can run on its own and produce particular outcomes. But as Georgopoulos and Mann (1962:23) point out, there is an important distinction to be kept in mind between machines and human systems: “unlike industrial and other large scale organizations, the hospital relies very heavily on the skills, motivations and behaviours of its members for the attainment and maintenance of adequate co-ordination.” As they describe,

Fundamentally, then, the hospital is a human rather than a machine system. Even though it may possess elaborate and impressive looking equipment, or a great variety of physical and material facilities, it has no integrated mechanical-physical systems for the handling and processing of its work. The patient is not a chunk of raw material that passively goes through an ordered progression of machines and assembly-line operators (Georgopoulos and Mann 1962:23).

Thus, the “work” that patients accomplish can be interpreted as the result of a human system, which depends on human intervention. It is doubtful that hospital policy documents about correct procedures and protocols plan for or anticipate this kind of patient labour, but it takes place in the everyday life of Lady Ann’s. Mesman demonstrates the “mobility work” required of nurses working together to create a safe and sterile NICU (2012). She uses the term to refer to “the spatial aspects of the cooperative work” (2012:37) that goes on in the NICU when a team gets the unit ready for a new baby. The cases I have described above demonstrate a lack of coordination in the system – an unplanned, haphazard activity – revealing an absence of coordination between the spaces of cooperative work. Because there is a shortfall in the system, someone has to make up the extra work required to connect its disparate elements. Patients literally bridge the spatial gaps between services. In doing so, they make the “human system” function in a more patient-centred way. It is worth remembering that as the primary users of the
hospital system, and also the people in the system who have the least amount of power, it is patients who bear the brunt of system malfunctioning.

Thus, actions and efforts to contain cancer in a structural sense are limited because a hospital is filled with human actors. Actors in the form of patients and staff complete all kinds of work that is within their roles and also outside of them.\textsuperscript{114} For the hospital worker, the hospital’s boundedness is visible through the division of labour and of sites of care; clinics are divided into separate spaces with separate workers who complete particular tasks within the system. For the patient, the hospital’s permeability is visible through the reality that their daily travels require that they visit many different sites throughout the day, and they perform tasks that actually make the hospital system work better. Boundaries are clearly laid out within the hospital and between clinical sites, but in the everyday life of the hospital, patients cross over these boundaries and bridge different sites of care.

**Structural containment: troubling staff and patient categories**

The sense of borders and boundaries also pertains to people’s roles within the hospital. There is a strong sense of actions that are appropriate for patients, and actions that are strictly reserved for staff. These implicit rules of order are just as important as the rules of order that are made explicit; for example, the directive to sanitize your hands when you enter the building is symbolized by the sanitation station set up just inside any building entrance. Both implicit and explicit rules of order are generally followed, resulting in “pliant bodies” (Casper and Moore 2009:7). But sometimes rules are broken, as the following example from my fieldnotes indicates:

*March 15/12: A woman has just pushed herself out of ultrasound. I hear her say, “Porter who is here went on break. I have had enough – I’ll push my bed back to my own unit.” At first I don’t understand: is she a patient or a staff member? She is dressed in a hospital gown, as a patient would be, but performing the role of a staff person. What is also incredible is that no one gets up to stop her. Every one of us in the waiting room looks up and notes the discrepancy – like an event – but no one gets up to help her, or to stop her. I look at the woman who is behind the reception desk and she seems to be on the phone calling a porter but not trying to stop her either. The patient is temporarily stumped once she gets into the waiting room, asking, “Can I get out here?” She is looking at a door marked ‘Allied health’ which she can’t get through. She then pushes herself out the main public exit of the unit.*

I was sitting in the waiting room of the ultrasound area, waiting for a patient, when I made this observation. This event constituted a clear boundary transgression on two levels: 1) the woman troubles the categories of patient and staff member by performing the role of a staff while
dressed as a patient; 2) the woman breaks the hospital rule that she had to wait for a porter to take her back to her room and decided to push her own bed back.115

This event stands out in my memory because it was so rare to see a patient explicitly disobey what was expected of her, break the rules, and step out of her patient role. Patients often waited interminable lengths of time for various things in the hospital, and in this sense, waiting for a porter was just one more kind of waiting. For example, patients wait hours for appointments, sitting quietly in the clinic after checking in and waiting patiently for their names to be called. New patients are easy to spot – their energy is different and they sit a bit more restlessly as they wait. Many times I sat with longitudinal patients in waiting rooms, and they would point out to me other patients who were “newbies” – the difference in demeanours was also obvious to them. New patients would often approach the PFCs and ask how much longer the wait would be; the patients I followed would just smile knowingly and lift their eyebrows. They knew that learning to wait was part of learning to be a patient.

On another occasion, I myself transgressed an invisible boundary, sitting in the waiting area of the mammography clinic. I was waiting for Jennifer, a 41-year old woman with endometrial cancer, who was being tested. This was the first and only time I accompanied a patient to the mammography clinic, and I was unsure of the clinic’s layout. There seemed to be two waiting rooms – one designated the “women’s waiting area” located inside the unit, and one on the periphery of the clinic that seemed to be the actual “waiting room” for family and friends. Because I was sitting and chatting with Jennifer before she went in, I had proceeded to the “women’s waiting area” with her, and waited as she went into a change room and put on a gown.116 There were two rows of five or six seats, facing one another other in the middle of the space, and several closed doors around the periphery. After Jennifer was called into a testing room, I remained there, taking a moment to jot down in my notebook some of the things we had been chatting about. Initially, I did not really pay attention to my surroundings. But as women began emerging from the testing rooms, and others on the seats beside me were called in, I became acutely aware that this was perhaps not the most appropriate place to catch up on my fieldnotes. A woman would emerge from the testing room, and be asked to sit and wait for a few minutes. I found out that what they were waiting for was the ‘okay’ to leave – after a few minutes, the nurse would come back and say “You’re good to go” or “You’re all done here today.” I noticed that there was a palpable sense of community, as each woman got the good news she was hoping for. For example, one woman said to the other, “We're both fine I know it –
it’s a lucky machine,” wishing and hoping it to be true. In all cases for the 20 minutes I sat there it was true. As they each got up to leave, they would smile at the others and wish them well. I felt a bit uncomfortable, sitting there in my normal clothes, wearing my hospital I.D. badge, and hearing all these women’s results. This general feeling of uneasiness was solidified when one woman looked over at me, and asked with a smile, “Are you on break or having a mammogram?” It was a very simple comment and not said in a malicious tone. I babbled something in response about waiting for a patient on a study, as my face grew red. In my notes afterwards, I wrote, *Patients have noticed that I am not gowned – I’m not in this temporary purgatory they find themselves in.* The smiling woman had rightfully pointed out my own border transgression, implying that if I was not getting a mammogram and in fact just taking a break, I had chosen a highly inappropriate place to take it. In doing so, she reinforced the boundary between staff and patient roles.117

**Structural containment: doctors “coming through the ceiling”**

When I asked Deo, a 62-year-old man with lung cancer, what he remembered about his first time at the hospital, he responded immediately with one word: “Overwhelming.” This interview took place eight months after his initial visit, so it required that he reflect back many months into the past year, which had been very, very busy, as he had just completed six rounds of chemotherapy. Yet my question produced no hesitation. In the next several minutes of the interview, the adjective “overwhelming” came up five more times, in addition the words “aggressive” and “bombardment.” Deo attributed the overwhelming nature of the first day to the fact that there were “several, several people coming into the room“ and “[he] was looking at everyone that came in and was wondering which one is [his] doctor.” This may seem like an odd comment, given that he had been given a referral to Lady Ann’s to have an appointment with a specific doctor, and had just checked in for that doctor’s clinic with the reception desk. The “several people” he refers to were related to different research studies. Because Lady Ann’s is a teaching hospital, patients are regularly asked to participate in research studies, and this may begin even on the first day. He continued,

Yeah, they were coming from like – let us say like through the ceiling. If I may use that term, but it was overwhelming. Because – I don’t mind, I mean I’m a willing candidate to give up my body if it comes to that or give parts of my body or of my blood or whatever for research, to get to the bottom of what this disease is all about. I have no question, queries or qualms about that. But, the overwhelming way that as a first timer, anxious and everything else, I was not sat down and reassured or spoken
to in a reassuring way. I just was bombarded more or less, in terms of what was my initial experience.

As the visiting anthropologist, I had been one of those “several people” who had “come through the ceiling” that first day. Research ethics for all patients required that someone in the patient’s ‘circle of care’ first introduce me to the patient – usually the doctor or nurse. In the lung clinic, I was observing first time consultations, so it meant that the introduction and consent had to take place prior to the consultation starting. I realized that I had been guilty of this during the course of the interview, and brought it to his attention. Deo said, “I remembered my daughter was in your shoes once, and so I didn’t have much trouble with that.” (His daughter was also a researcher, so he had been sympathetic to me). Yet it does not change the fact that I too had entered the room before he had had a chance to speak to his doctor. His choice of wording (“coming through the ceiling”) provides a powerful image of hospital staff almost ‘descending’ upon him – akin to an alien invasion. From his perspective, these various people who kept coming in were an invasion, as he and his wife and daughter waited anxiously for the main person he had come to see. His orientational metaphor indicates the disruption, and showcases how from his perspective, the boundaries enclosing his consultation room had become permeable, allowing people to enter not only through the normal route (i.e., the door) but also through the ceiling. In discussing the “overwhelming” nature of the first day with him, it seemed to be the timing of the entries of various research personnel that bothered him.

But in retrospect now, a lot of what they did perhaps were not timed in the right way, in the right manner. I would have gone through all of that, I would not have made these statements to you as I am doing now, if it was put in a different…not perspective, but if it was timed differently. And now, for example, I would have rather my oncologist to sit with me first and foremost. And told me ‘Well, listen Mr. [Deo], here’s where we’re at.’ She did that eventually, but after I’ve spoken to like at least five or six people.

Together, we tried to recreate the original scene to figure out who those “five or six” people had been. First was the nurse, Eve, who had called him in to the room and who had chatted to him a bit. She had introduced me, the visiting anthropologist. I went in and did the consent procedure and then left while they waited for the doctor to come in the room. Deo remembered that a fellow had come in first, and he said she had been accompanied by an “associate.” Interestingly, I did not have a record of this second person in my notes, so whether or not this was my mistake or his is unknown. He remembered that this first doctor was a “Fellow,” (in fact, she was a resident, but this difference escaped for me for many months as
well). He could not remember the first doctor’s name or affiliation, but he remembered that she took his history. Next, “there was this lady that was going to take my blood,” who I told him was from the blood bank; these researchers approached most patients in this clinic, although normally after the oncologist had come in. He remembered that the fellow had left the room and then come back to do a physical exam. When she came in a third time, she was in the company of his oncologist, Dr. Lawson, the person whose name was on his referral sheet.

From Deo’s point of view, everyone was of course a stranger – he had no idea who to look to for counsel or who would be providing him with the news he had come to receive. Doctors and nurses in this clinic sometimes wear white lab coats, but most often not; they are dressed professionally and wear their hospital I.D. badges pinned to their clothing or on a lanyard. This means that in terms of dress, there are no clues to distinguish between the different people entering the room. In the interview, he admitted that at one point he thought that the nurse was the doctor. I found this interesting and asked him why. He responded in a kind of matter-of-fact way, “Well, she was doing a lot of talking.” As each person came in the room and said his or her name, he was mentally checking off the “not my doctor” box in his head, but how was he to keep track of all of these different visitors? He did not have to wait for Dr. Lawson to get the negative part of the news – the incurable nature of his disease was stressed by the resident the first time she came in. But he did have to wait for Dr. Lawson to get his plan – what they were going to do about the cancer. Once she arrived in the room, she reiterated the incurable nature of the diagnosis, and very efficiently explained the next steps in terms of his treatment and the limits of what that treatment could do. So the news he had been waiting for – yes, he had cancer, and yes, they would treat him here for it – was finally delivered. But not before he went through half a dozen hospital research staff in order to talk to the person he had come to see.

Deo’s experience of not being able to tell who the different people were who entered his room was not the only account I heard about this. When I first began volunteering, I could tell the difference between the doctors and the nurses, since their roles are made kind of explicit, but I was baffled by all of the different types of doctors. It took me two years as a volunteer to figure out the difference between fellows and staff physicians. It took the first few months of research and lots of questions to figure out the difference between residents, fellows, staff physicians, “floor doctors,” and medical students. With the exception of the students, all of those people could at one point in time enter the room and introduce themselves as “Dr. so and so.” Often a
The staff physicians are the ones whose names appear on patients’ itineraries; they each have clinics and carry caseloads. They are often clinicians and researchers at the same time, and as permanent staff of the hospital are reserved the highest title. There is another set of doctors who run “the floors” – they work on the inpatient wards at Lady Ann’s, and sometimes they work in some of the clinics as well. Since I did not conduct research in the inpatient wards, I seldom came into contact with this group of doctors. Then there are the more transient people: the fellows and the residents. The fellows are similar to post-doctoral fellows (as one fellow finally explained to me using an academic comparison that I could relate to); they have completed oncology training elsewhere and want to be able to obtain the kinds of positions that the staff physicians have in terms of running their own clinics in a specialized cancer setting. So they come to Lady Ann’s, a renowned cancer centre and train under the ‘best.’ Fellowships tend to be at least one year and sometimes two or three, so some patients develop very strong relationships with the fellows and think of them like their doctor even though their name will never appear on their itinerary (although of course their names do appear on other important documents – they can write prescriptions, sign letters required by insurance companies, and complete many other tasks regularly asked of doctors).

Dario, a man in his 50s with non-small cell lung cancer, consistently referred to the fellows that he saw as “the flunkies.” I corrected him the first time, thinking he had misunderstood their name, but he just smiled and continued to use that term. For him, seeing a “flunkie” (i.e., fellow) meant that he was not seeing his oncologist (i.e., the person listed on his sheet), which he found highly frustrating. His use of “flunkie” suggested he was seeing a doctor who was sub-par, who had failed out of his or her intended profession. Given that fellows are actually selected to train at Lady Ann’s from all over the world, “flunkie” is a misnomer. I am sure they would certainly not appreciate the name, given that they spend much of their time running the clinics for the physicians they work under. I once overheard a staff oncologist refer to her fellows and residents as her “sous-chefs,” which seemed like a very apt metaphor. There can only be one head chef, but there are many people working extremely hard to hold that one person up.

The residents and medical students are even more transient. Residents are still completing training in whatever area they have chosen to specialize in, and that training involves a stint of work in numerous different clinics across the city, working under various doctors in their clinics.
and seeing their patients. From what I observed, this seems to be a challenging position, as they are working in several hospitals at the same time, seeing patients with difficult problems they may not see again, trying to do a good job but without enough time to develop a great amount of rapport with individual patients or health care teams. For example, I once overhead Fiona, a veteran nurse in Gyne, calling down the hall to a resident she wanted to go into a room to see a patient. Another person interrupted to try to tell Fiona the male resident’s name, and she replied, “I don’t care what his name is, I just want him to go in.” Although they are working hard and putting in long hours, they are rarely there long enough to fit into the culture of the clinic. Lastly, there are medical students, who as their title suggests are not yet doctors. I only saw these students in the Gyne clinic, never in lung cancer, perhaps because Gyne is also a surgical clinic. The students often get called on to do the patient histories and then they discuss the history with the supervising physician.

I found Deo’s misunderstanding of the nurse as his doctor interesting, because that was one distinction that always seemed clear to me. The nurses always introduce themselves by first name, and often have the most contact with the patients (e.g., they bring patients in the rooms, check in to see how things are going, explain how chemotherapy works and what it will look like, call patients back to answer questions or concerns). From what I observed, nurses are the backbones of each clinic site: they run the clinics, keep doctors on time, check in with patients about symptoms and side effects of treatments, and often give the doctor a little update on how the patient is doing before she goes in the room. Nurses actually seem to have more power than the various kinds of doctors underneath the staff physicians because they are the consistent force in the clinic. They tell the other doctors in the clinic where to go and what patients to see if the staff physician is not available to do so.

So, five different kinds of ‘doctors’ might enter the room, but no one says, “I’m a fellow, that means…” or “I’m a resident, that means…” Patients may never see this particular doctor again and could possibly see a different fellow or resident the next time they come. The various roles within the hospital seem to be clearly bounded, but from the patient’s point of view, health care providers’ roles blend into one another. Patients are nervous and anxious, and all they know by looking at the physician’s hospital ID badge is: ‘You’re not the person I’m supposed to be seeing. You’re not the person on my sheet.’
Personal containment: holding in emotions

As a cancer hospital, Lady Ann’s features particular sights and sounds, and these features that are specific to cancer contribute to its ability to be seen as an “island.” For example, shiny bald heads or heads covered in scarves, hats, or wigs, and facial and other bodily deformities fit in here; bodies with missing parts are normally not so visible in life on the “mainland.”

Similarly, Lady Ann’s also features particular sounds: in the chemo area, the I.V. monitors and the chemotherapy bell ring out regularly, and provide background noise. Lady Ann’s is a busy place and like any hub, it bustles and hums in its core areas – the sandwich shop, the atrium, the blood lab. But other sounds are notable for their absence. For example, clinic waiting rooms are often fairly quiet. The sounds of pain and anguish are also surprisingly absent. Crying is so exceptionally rare that people take note when it happens. A fellow researcher recounted a time he had witnessed a woman crying very openly – sobbing, really – in the clinic and no one reacted to it. Because it was an anomalous event in the clinic, he was unsure how to react and noted that other patients were ignoring her.

For frequent visitors to Lady Ann’s, these sights and sounds soon become the norm and they no longer draw attention. But that does not mean they are ignored, or forgotten. Some scenes continue to disturb. One afternoon, sitting with Elizabeth, a 37-year old woman with ovarian cancer who was waiting to be called into chemo, we sat across from another patient whose appearance provoked fear.

May 2012. The woman across from us is kind of frightening to look at. She looks very thin, and like the skin on her face barely stretches over her skull, so you can actually see the contours of her skull through her skin. She has grey hair, and large white teeth. Something about her face is ‘gruesome’ in a way – Grim Reaper-ish – like she is warning of what is to come. Even when she smiles, which she does often, sitting with what appears to be a family member, it looks twisted, like a grimace, and the effect is scary and frightening.

I believe that Elizabeth also noted this woman’s presence, but we did not speak about her. Rather, we sat there trying to ignore her, since she was such a visible sign of what happens when cancer consumes the body.

This woman stood out to me because she changed the experience of the chemo waiting room that day. While it is common to see sick patients, it is less common to see patients quite so sick – or skeletal. Waiting between appointments one day, Jennifer told me that Lady Ann’s felt “dressed up.” She said that at the hospital, you were always “surrounded by nice things,” which she interpreted as intending to “cheer [patients] up.” But she saw a darker purpose to these
decorative features, such as the outdoor garden. In her view, the level of detail given to the built environment was a concerted effort on the part of the hospital to conceal the reality that up on the floors “people are dying.” She remarked that you would never know this, because Lady Ann’s is “not all doom and gloom.” But in her view, it seemed like “the patients that are really sick are really hidden.”

Thus, the woman Elizabeth and I saw in chemo that day represented what Jennifer rarely saw: the reality that cancer will likely cause death. In Jennifer’s view, it is possible to “dress up” the hospital with nice decorations and a beautiful environment, but these efforts cannot ultimately change the meaning of a place like Lady Ann’s. In this sense, the environment of Lady Ann’s encourages patients to “hold in” the typical emotions we associate with cancer – fear, despair, hopelessness – and to try and replace them with more hopeful, optimistic feelings. But the reality of the skeletal woman unsettles the optimism in cancer treatment and progress. As such, her presence threatens attempts to keep these emotions contained.

In August of 2011, I witnessed first hand all the strength it takes to hold these emotions inside. I was sitting in on a regular follow-up appointment, pre-chemo with Pam, which was going fine until the end of the appointment. The patient seemed all set for chemo the following day, but the doctor, who was just then looking at the bloodwork, said, “Your blood is… (pause)… not good. (pause) So you can’t get chemo tomorrow.” I was sitting in the corner of the room with my head down, writing, but I could hear Pam shift in her seat and adjust to the news. After the doctor leaves the room, we are kind of quiet. When I look at Pam I see that she looks like she might burst. I can’t remember now what I said – something like “It’s ok to be upset Pam” – something about being sorry that she has to wait because I know how much she wanted to get it over with. She said, “If I could sleep until it was over…but that’s just not possible,” and started to cry a bit. I got up and got her a tissue. I manage to say something to make her laugh at some point, something like, ‘Well I’m sorry you are not going to get chemo because you were expecting it, though I’m not sure it is something you really look forward to given that it’s a kind of ‘beating’ on the body.” She laughed and this broke the tension for a bit. But then got serious again. I touched her arm – I wasn’t sure if that was helpful or if she was a touchy person, but then just sat with her. I tried not to stare look at her – I noticed she was averting her eyes. Maybe when I got up to get her the Kleenex she noticed that I was close to crying as well. I said that what she was dealing with was a lot.

In this case, Pam’s attempt to hold in her emotions and her reaction to her chemo being delayed was even more palpable than if she had just started crying – the enormous effort it required of her was visible in both the expressions on her face and in her body language. In that sense, the efforts people are making towards personal containment of emotions and reactions
within the hospital are highly palpable, if you look for them. After witnessing an emotional outburst in the lobby one day, Jennifer remarked, “That’s the first emotion I’ve seen in this hospital.” She described Lady Ann’s as a “weird atmosphere” and somewhat “artificial.” Similarly, she found that even when she was struggling with her emotions, she had to hide those feelings – “you’re not allowed…you don’t show it.”

Both Pam and Jennifer’s experiences demonstrate how a biomedical space such as Lady Ann’s may discourage emotional outbursts or showing your feelings. From their perspective, biomedical practices trump emotional experiences, which must be hidden from view or expressed only once the doctor has left the room. I have seen myself that when an emotional outburst does happen – such as anger, tears, or fear – people react uncomfortably, often ignoring the instigator as if his or her expression of what they might be feeling threatens their own attempts at a contained composure. But these efforts at self-containment cost patients; it takes a great amount of work to “hold in” all the disappointments and dejections until they have left the building. And so sometimes these feelings escape and reveal themselves. Going back on a visit post-fieldwork, I had been thinking about this idea of containment and how you rarely see people crying in the hospital. But as I pushed through the glass circular doors into the atrium, I came face to face with two women, one with the arm around the other, red-faced, with a scarf on her head, visibly crying as they walked towards the door. And there it was: so obviously plain and visible, if you were willing to see it.

**Personal containment: carrying “place” around**

Coming to and leaving a place like Lady Ann’s involves a kind psychological transition. People want to leave their cancer experience behind when they leave Lady Ann’s each day, but in practice, that proves to be very challenging. As Elizabeth, a teacher, tells me,

> When have I forgotten? At what moment in my life have I forgotten since I was told that I actually have cancer? Right? Never. It’s always right there (pointing to her forehead). Even if I’m in the middle of teaching a math lesson – still, it’s right there.

An ex-patient of the hospital once who told me that he changed his entire way of getting to work (which was closely located to Lady Ann’s) after he stopped receiving treatment because he could not stomach revisiting that route again. He associated that subway stop with going to the hospital, and so he altered his route so that it no longer included that stop. Similarly, at M.D.
Anderson, a nurse working in advanced breast cancer reports “I have patients who say, ‘I just see a hospital gown and I feel nauseated’” (Kolata 2009). When Deo finished his treatment and had to come back to the hospital for his first follow-up appointment, he told me that his wife got up that morning and was in a cranky mood. He told her that he could go the appointment alone. She replied, “It’s fine, it’s just that well… I just don’t want to go back there.” The association to the life of the hospital, even post-treatment, does not easily subside. Similarly, in her research on four-year-old Keisha, who has cancer, Mattingly reminds the reader: “The hospital has been a source of great pain for her, a place she generally dreads…. It is not a casual place. It demands vigilance” (1998:262). Both Keisha and the patients I worked with knew too well that every time they entered and left the building, things could potentially change for them – sometimes for the better, and sometimes for the worse. Even when they were not physically present at Lady Ann’s, they still carried those connotations and experiences around with them.

The Permeable Institution and Concealed Liminality

Much of the ethnographic research that has focused on long-term and serious illness has taken place on a closed ward (Coser 1962; Germain 1979; Bluebond-Langner 1978). These studies focused on ward dynamics and relationships, which was made possible because all patients were contained in one place (Zussman 1993). Up until very recently, hospital admission was meaningful; people were admitted when they were not well, and they stayed until they were well enough to be discharged or they died. One does not have to read far into Solzhenitsyn’s classic Cancer Ward (1971) to see just what happens when patients are stuck together on a ward: they fight over trivial things, develop friendships, eat, sleep, and recover from treatment in the same space, among other things. There is the potential for camaraderie or even communitas (Turner 1967). Most importantly, inpatients share the knowledge that they are all sick. If a person were not sick, he would have no place there. Thus, institutions where patients are enclosed on wards make the categories of the sick and the non-sick explicit – sick people stay inside, non-sick people stay outside.

Outpatient cancer care relaxes the boundaries of the hospital, resulting in a more “permeable” institution, where lives are contained by diagnosis, not by bars or locks and keys. Quirk and colleagues (2006) name the modern psychiatric unit a “permeable institution” in comparison to the “total institution” described by Goffman (1971). They provide three pieces of
evidence for permeability: ward membership is temporary and always changing; patients maintain contact with the outside world while inside the unit; and boundaries are blurred between patients and staff (Quirk et al. 2006:2105). Although Lady Ann’s is not a psychiatric unit, it does seem to be a particular kind of permeable institution. Its patients are only “temporary” visitors as well; in fact, they are even more temporary than the settings Quirk and colleagues (2006) describe, because outpatient cancer care at Lady Ann’s means that no patients “stay.” Treatment follow up regimes require that patients go to and from the hospital, and thus they spend some of their days in the spaces of Lady Ann’s, but they do not spend all of their time there. Since they are always moving between life at home and life at the hospital, the “outside” world is their world for the majority of their time.

One positive aspect of having an institution that does not confine people for long periods of time is that patients are able to “maintain pre-admission identities” which helps to “reduce the impact of discharge” (Quirk 2006:2114). Outpatient cancer care means that a patient is admitted and discharged from the hospital on every visit. This goes against how we think about the hospital as a place where the admission or the discharge is meaningful. Van Gennep (1960) demonstrated that changes in social identity are normally marked by “territorial passage,” such as moving through a doorway or under an archway (e.g., newlyweds passing under an arch to signify the newly-formed bond). So entrances and exits are normally portentous, but not in the case of daily admission and discharge from Lady Ann’s. While retaining personhood is normally seen as beneficial, in this context it might actually produce a negative effect for patients with advanced disease, because people around them may fail to see their liminal status. In other words, because they are constantly shifting between normal life and life at Lady Ann’s, their friends and family might believe they are doing better than they are. For if they were really, truly sick, would they not be confined to a hospital bed? This means that people around them might not see just how sick they are, or they themselves may get caught up in the notion that they are getting better, when in reality they are remaining stable or declining.

Where the “Hospital for Incurables” used to distinguish patients with incurable illness by containing them in a separate place, now they gain admission to the same place that can provide deliverance for patients with more localized, curable disease, but is unlikely to provide that same outcome for them. Now that all patients are treated together within the same institution, it is no longer “place” that distinguishes patient groups from each other, but rather the experience of cancer itself. This represents an important shift from an external, visible, and culturally
recognized difference to an internal, invisible, and individual difference. Paradoxically then, the conflation of different cancer experiences housed within the same building may actually increase the isolation of patients with advanced disease.

**Conclusion**

A place like Lady Ann’s offers patients both the hope for salvation and the likelihood of suffering, demonstrating what Byron Good (1994:86) has called the “soteriological” aspects of modern biomedicine. People come to Lady Ann’s hoping that it will contain their disease in the sense of controlling it – to shape it into a form that is controllable or at least manageable. In this way, they are hoping that Lady Ann’s will help them to define some borders around its messy associations with death. In some ways it fulfills that function. It offers first-rate care and the concerted efforts of a group of cancer experts – clinicians and researchers – unparalleled anywhere else in the country, and the most “technical efficacy of medicine” (Good 1994:86) is certainly on display there. But where it may at times serve as a beacon of hope, taking patients in and offering care when they are in need, it may at other times disappoint, when there are no more treatments to be offered and death becomes imminent. Like the Great and Powerful Oz, Lady Ann’s is not in practice, as powerful as it may seem. For some patients, it cannot offer a cure and a return to a cancer-free life, which is what patients most greatly desire. Lady Ann’s ‘holds in’ all of these diverse experiences of cancer, but at some point, patients with advanced disease come to the realization that theirs is a cancer that will not be ‘held off.’ They must then adjust to the reality that their situations are not like the others. Within the rabbit hole of advanced disease, the ladder leading back to ‘normal life’ is not available.

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**Notes**

95 There are of course, a few notable exceptions to this. In Canada, most births happen in hospitals, and that is regularly regarded as a joyous activity when the baby and the mother are healthy. The point I am trying to make is that most times, the expression “going to hospital” indicates past, present or future illness.

96 When I was doing fieldwork and a friend texted to ask, “What are you up to?” I would reply, “I’m at the hospital,” trying to communicate, “I’m at my office” or “I’m working.” People who did not know my shorthand would invariably respond, “Are you ok?” Once my response triggered a rapid succession of texts from a friend I had not seen in a while – “Are you okay? Can I do anything? Do you want me to come there?” – before I could even reply to clarify. These experiences helped me to think about what hospitals represent in society, and how laypeople who may not regularly visit hospitals tend to associate them with negative connotations.
Although patients may start their treatment at Lady Ann’s, their cancer ‘journey’ may have actually started a long time before they first step foot in the hospital. Many patients that I spoke with had spent months caught in the health care system, working up to a cancer diagnosis and then waiting to be referred to Lady Ann’s. Once referred, patients often did not have to wait long to see a doctor, which was seen as very positive.

People could clearly remember the feeling of being a new patient to the hospital. The feelings of being fearful and overwhelmed spread over their faces as they recounted first days to me. Yet when I asked what the doctor said, specifically inquiring about what they were told about their illness, they often had very little recollection. I found this interesting, as there seemed to be a distinction between the feeling of that first day, which was easily recalled, from its content, which was not.

The reality that the hospital really does shut down after 5 pm was made clear to me every time I left chemotherapy after 5 pm in the company of a patient. As I walked a patient towards the atrium doors, I would observe the evening cleaning staff all sprawled in the chairs near the doors, seeming like they were waiting to begin their shifts. During daytime hours (i.e., between 9-5 pm), patients or their family and friends always be occupied these chairs – never staff.

In the elevators, this difference between “researchers” and “clinicians” is at times very obvious; the researchers tend to more casually dressed, they often leave together for lunch or coffee, and they also engaged in conversation more frequently. Since the elevators also potentially contain patients, clinical staff were perhaps more cautious about engaging in conversations.

Two or three of my participants took advantage of this service. Rides are coordinated through local Cancer society offices, with the volunteer drivers being drawn from that community. Patients travel to and from the hospital alongside other patients who also have medical or treatment appointments that day, and who live in proximity to them. People who used the service seemed to appreciate it greatly, although there were some challenges with it: it was unclear whether or not caregivers were welcome as well; you had to wait for the rest of the people in the car before you could leave (this meant if your appointment finished at 2 pm, but another passenger’s not until 4 pm, you waited around the hospital until 4 pm); and you had to give them generally at least four days notice, so if an appointment suddenly came up or was rescheduled, and you relied on this service for transportation, you might be forced to find another, more-costly alternative. In 2014, the CCS announced that it would be making changes to this service by imposing a fee for service, but that it would be based on ability to pay. They argued that no one would be turned down based on lack of income. This change prompted many critiques in the media, and the CCS defended its position, arguing that it was the only feasible option. Since my fieldwork ended in June of 2012, I have no observations of the consequences of this change on the lives of patients. However, given the obstacles that were already in place, it seemed that introducing yet another bureaucratic requirement (i.e., proving you were of low income to access the service for free) could potentially discourage users from accessing the service.

There is a hand railing, but in the winter the steps get very slippery. I saw enough older and unwell persons going slowly up and down those stairs to see them as a barrier, even if you are able to walk. If they can get to the top, the glass door they must pull on to enter is heavy and somewhat of a hindrance. As one patient commented, “Is there something wrong with that door? You feel like if you don’t catch it you are going to get batted down the stairs.”

The “pack year” calculation was regularly performed in the lung clinic to get a number representing a person’s history of smoking, by taking the number of cigarettes smoked per day...
and multiplying it by the number of years of smoking. One pack year is equal to 20 cigarettes per day over a one-year period.

104 “Hospice” did not have significance as a specialized service in the mid 1800s. Hospice care would not emerge as a specific kind of medicine until the pioneering work of Dame Cicely Saunders in the 1960s (Murphy 1989).

105 The rise in popularity of “scientific medicine” was due to some recent success in controlling infectious diseases (Murphy 1989).

106 The early sociological studies of the hospital were greatly facilitated by the fact that patients were “contained” within one unit or ward. For example, Glaser and Strauss’ now classic ethnography Awareness of Dying (1965), examining how “aware” patients and staff were of approaching death, hinged upon being able to study the same group of patients over time (see also Coser 1962).

107 Unlike what you see depicted on American TV shows and films, where doctors sit across from patients in nicely furnished offices, showcasing their various degrees and accreditations, patients do not regularly visit doctors’ private offices at Lady Ann’s. Many of the medical oncology offices are located on the 5th floor, which is not a floor where patients regularly go. There is one central door that provides access to a long list of doctors, posted outside. A patient may enter the door, but is stopped immediately at reception. There is a printed list of doctors, and the corresponding list of their personal secretary’s numbers available on the desk, next to a telephone. A patient or family member can use this phone to call the receptionist, who will then come to the front desk to retrieve them. I very seldom went into this office as it definitely gave the impression of crossing a boundary, and would wait outside for a patient’s family member who had gone in. Thus, the clinic space becomes heightened in importance, because it is the main space through which patients will access their doctors and their health care team.

108 Palliative care has a particular meaning in a cancer hospital, because of its traditional associations with end-of-life care. Even though its meaning has changed profoundly in the last 20 years, and it is now recommended that patients with advanced disease are referred as early in the disease as possible in order to improve symptom control and quality of life (Zimmermann et al. 2008), this change in practice has not been translated well to the patient population, who may still see a referral to palliative care as a sign that the oncologist is giving up hope.

109 For example, in describing a “mother of all mammograms” that lasted 1.5 hours, Barbara Ehrenreich (2008:16) recounts that the endless shifting and repositioning of her body seemed “without purpose” as no one ever explained to her what was going on. It seemed to her that “the X-ray was successful but apparently alarming to the invisible radiologist, off in some remote office, who called the shots and never had the courtesy to show her face with an apology or an explanation” (Ehrenreich 2008:16). The “invisible radiologist” who remained hidden, far away from the patient, demonstrates yet another boundary within the hospital system, which impeded Ehrenreich’s comprehension of what was going on.

110 I once heard Dr. Girard recount to a patient why she did not like going to this other hospital at night. She said she found it very “creepy”. As a doctor she had to enter through a special entrance, and hated the time in which she stood outside in the dark, waiting for someone to let her in.

111 I will use the female pronoun exclusively when referring to PFCs, because I only ever encountered women in this job position. At the end my fieldwork, I heard a rumour that a male PFC had been hired, but I never came across him in my time at Lady Ann’s.

112 As a volunteer and a researcher, I accompanied patients several times to the CT department exactly for this purpose. There were two booths that normally were open, and when staff were
not on the phone or responding to requests on their computers, they would invite the patient to sit down and search for another timeslot. They never seemed particularly disturbed or enthused by this practice. It just seemed as though it was the reality of their work that people would be unsatisfied with their given appointment times and thus they would need to be rebooked.

Lung cancer patients always also had to have a chest x-ray before their visits. CTs and MRIs are usually scheduled on days when the patient does not have a clinical appointment; they obtain the results at their next follow-up consultation. These tests are normally at particular time points in a treatment schedule, e.g., at the halfway mark, after 3 treatment cycles have been completed.

Here, I have concentrated on the “invisible work” of patients, but there were many times when I observed the invisible labour of staff, especially clinical nurses.

Both the woman’s gown, and the fact that she arrived for an ultrasound in a bed, suggest she was an inpatient.

Jennifer told me that the last time she had come, a male friend had accompanied her, and he was made to wait in the “waiting room” because he was a man.

Although every other woman had been dismissed with good news, Jennifer’s news was more ambivalent. She was told they wanted to do ultrasounds on both breasts, which she found concerning.

The sound of I.V. monitors ringing out (e.g., as I.V. bags are emptied, or lines are blocked) was such a regular feature of chemotherapy, that I became highly disturbed when, during a brief period in the middle of my fieldwork, the I.V. monitors were replaced with a different model. The new model made a lower tonal sound than the previous ones. It struck me then how accustomed I had become to the previous sound, and had found it oddly comforting after a time, whereas the “new” sound seemed unpleasant and disturbing. Staff also remarked on the lower sound emitted by the new monitors because it was harder for them to hear. But the change was short-lived; the old monitors soon reappeared and the older, higher-pitched ringing was re-established as the norm.

Patients with cancer are by no means the only population that is increasingly receiving care as outpatients. An insufficient number of hospital beds all over Canada and rising costs of hospitalization result in patients being discharged and sent home often before they are really ‘well’ enough to be there.
Chapter 3
Communication vs. Emploiment in Oncology:
Story-telling a way back to life

It is mid-March in 2011. I am observing in the lung site today, and arrive shortly after 9 am. The primary nurse, Eve, tells me there is a patient (Mary, a 54 year-old woman) who might be good for me. Her exact words are, “I think communication would be important to her.” I write interesting into my notebook, along with, isn’t it important to everyone? The fellow (Dr. Johnson) has already gone in to conduct the patient history, so Eve will ask if I can observe the presentation, when the team goes back in with Dr. Lawson, the staff oncologist.

Dr. Johnson emerges from the room and proceeds with the case presentation to Dr. Lawson. I notice I am being included in this, so I turn my chair around so I can see her screen. Dr. Johnson starts by saying that Mary “isn’t crazy” and doesn’t know how she got this reputation. (I am unsure where this comment comes from since this is her first time here; perhaps she has been calling ahead requesting information prior to the appointment?). He said Mary asked if they could cure it and he said “No.” Dr. Lawson seems a bit distracted throughout the presentation; she is looking through a bunch of scans, which she keeps loading up on her computer screen. She seems to be deciding which ones to keep. She asks some follow-up questions about Mary’s smoking history. In the middle of the presentation on family history, Dr. Johnson mentions that Mary is the mother of 4 boys. Dr. Lawson interrupts his presentation at this point to joke that Mary and her husband were probably “trying for a girl.” She tells a story about how she went to someone’s house, a parent of 4 girls, and there was a picture on the fridge of a big sow with udders hanging out and a sign that said Take your Birth Control. Then Dr. Johnson tells a story of an ad on YouTube that has a baby crying, then a frantic father and then the Use Trojan slogan appears at the bottom of the screen. Both stories generate lots of laughs and joking around. As that subsides, Dr. Johnson gets back into the presentation.

Dr. Lawson asks, “What’s your plan?” He says first radiation, then chemo. She asks what was available to Mary, and he mentions a few studies for her cell type. One study in particular Dr. Lawson seems to like, so she gets on the phone and pages the clinical trials’ nurse to come down in 15 minutes. She asks the nurse some details about the study while she has her on the phone, like, “Does everyone get it or randomized?” We hear “Good, good” on her end, so she seems happy with the response. She asks the nurse, “How long to wait post-rad?” [i.e., before the chemo can begin] and finds out 3 weeks.

We all get up and go into the consultation room. Mary and her husband, Robert, are sitting beside each other against one wall with the desk in between them. Dr. Lawson sits across from them, Dr. Johnson on the bed, and Eve on the stool. I crouch between the door and the sink, as there are no other seats left. Before we all went in, Eve had gone in alone and asked Mary if it was okay to have a “graduate student” observe, and she had said yes. As we all settle into our seats, she says something to me about how she thinks “it is great” that someone is interested in communication and the hospital system, and if it could help other patients, she is supportive of it.

Dr. Lawson: Tell me what you know about your diagnosis in your own words.

Mary: I plan on putting cancer behind me. (Dr. Lawson looks slightly confused). ‘I know it’s stage IV, and I know it’s an ugly fight and it got uglier the day it metastasized.’
And no disrespect to [another hospital], but… (she says something about how it might have been handled differently).

(Dr. Lawson still looks confused, but is listening, and allowing Mary to talk.)

Aside from this cancer, I am healthy and want to be aggressive in approach. I know we have to do chemo and radiation.

Dr. Lawson: I think we are here to be realistic that we are not going to make it go away forever. The goal will be to put it into remission, and improve your symptoms, but survival is not going to be in decades. Not going to live until you are 95. (Mary says something here I miss – I think makes a joke about living to 95). How long will depend, but ‘hopefully in years (emphasizing the ‘s’), good chance it could be in years.’ ‘We have to have realistic goals for both of us – for your family and for the team here – we can’t work with too much unrealism.’

(Mary says something about understanding.)

First thing is to have you seen by the radiation team here, so first radiation, then chemo. When it comes to chemo, we can give the standard or there is a clinical trial. ‘Nothing to lose by going on trial and everything to gain’ – you have to delay chemo 3 weeks post-rad, but if standard, need to delay 2 weeks anyway. I think it would be great to go on the study. It’s a new drug and added drug. Everyone gets the standard treatment, which is my favourite, but we don’t use it [new drug] in 1st line because of government regulations (she is explaining this very clearly to patient). On trial, you get 2/3 of chance of getting the extra [drug]. It delays treatment one week but one week in the long term is not a big deal.

Chemo is ‘not as ugly as stories would make you think’, it goes in an IV. Do you have private drug coverage?

They have a short discussion about the drugs that are going to be given, with Dr. Lawson outlining that “everything that goes in the vein is covered, but anything that goes in your mouth is not covered.” Of those oral drugs, she tells Mary that they “usually give 5-8 drugs for nausea.” Mary says if she can get a list, she can call her company and check. Eve and Dr. Lawson say that anti-nauseates are always covered.

Dr. Lawson: ‘You are not going to lose your hair, so that’s good on or off trial.’

Mary: Not an issue anyway

Dr. Lawson says that she lists all the side effects of chemo to some patients with no response, and then if she says they will lose their hair, they are suddenly upset. “But,” she says, “we recognize it’s an emotional issue even if it’s not a physical one. A reflection in the mirror of just what’s going on all the time.’

Mary then tells a story about how last week, last minute she, Robert and their kids – says something about having 4 boys – but Dr. Lawson interrupts and makes a joke about ‘trying for a
girl’ (the same joke she made in the workroom). Mary says no, she is very happy, very lucky. They went to the Caribbean for 4 days, knew her appointment was today. She said it wasn’t until she had some pain on the weekend and was sitting in a wheelchair that she could, “see it on my son’s faces – accepting that mom was sick.”

Dr. Lawson: Let me get to pain

Mary: I’m taking 4-6 T3s [Tylenol 3s] daily

Dr. Lawson: What is going on with bowels?

Mary: Prune juice

Dr. Lawson: Works ok? You do need something a little more than prune juice.

They have a short discussion about the pros of trying a different stool softener. Dr. Lawson says that she will give Mary a pamphlet on ‘managing your bowels’ while on treatment. She adds that prune juice will not be enough when she is taking that much narcotic.

Dr. Lawson: Taking 1 or 2 [T3s] at a time?

Mary: 1

Dr. Lawson: You could take more T3s or we could give you Percocet. (She discusses the slow release version). ‘If we thought you would be on narcotics forever we would put you on slow release.’ She asks Mary when was last time she took her pain meds?

Mary: Last night

Both Dr. Lawson and Eve look surprised. They ask Mary, ‘Are you in you in pain now?’

Mary: I wasn’t sure if you wanted to examine me and wasn’t sure if I could say where the pain was if had taken drugs.

Dr. Lawson: ‘There are no gold stars for suffering through pain’. If we have to do it with druggies, then we do it. Don’t want you to worry about becoming an addict – not going to happen.

She tells Mary to take 2 every 6 hours so will be pain free. Eve adds that she should take it on time to get ahead of the pain. Then discuss her PET scan briefly, saying they could not access it, then move on to discussing the chemo drugs. They tell her what the standard drugs would be (Gemcitabine and Cisplatin) and what the trial drugs would be (Pemetrex and Cisplatin).

Mary: (very sincere) Doctor, I totally trust you and your direction.

Dr. Lawson: Well, my direction would be to do the trial because I love that regimen. Today we will do chest x-ray, x-ray to hip, study nurse – blood and trial. We are going to send in a ‘slew’ of research nurses.
Dr. Lawson, Eve, and Dr. Johnson all leave the room. Robert looks at me and says, “You got left behind.” I tell them I stayed to tell them about the study, but that I will let all the medical people do their stuff first, and will come back when they are done. I see that the clinical trials’ nurse is waiting outside the room, so I leave and she goes in.

I go back and wait in the workroom. Eve tells me that Mary will be sent to PROP that afternoon. I ask what PROP stands for, and she tells me Palliative Radiation Oncology Program; they just do single doses of radiation for palliative purposes only. I wonder to myself if they use the acronym to disguise the palliative part? The clinical trials’ nurse is in there for a long time. So long in fact, that Dr. Lawson sends Eve to go in and pull her out of there. Eve comes back into the workroom and says she gave her ‘the look’ – she makes a kind of serious, pointed face. When the clinical trials’ nurse comes out she suggests that Mary was crying, by making motions with her hands around her eyes. I note to myself that it was interesting that Mary seemed so calm and brave with Dr. Lawson and then not with this nurse. Thinking, I guess the emotions have to come out somewhere, with someone – even if not with the doctor?

When I go back into the consultation room, Mary is filling out one of the questionnaires for the blood draw. Looking at my consent form, she says, “see Alyson? There is always a positive in things.” I’m not sure what she means. We get up and I walk them out of the consult room. As we are rounding the corner of the lung site, she says, “I’m hoping to see the other side of this.”

I walk them out of the clinic and ask if it is their first time at the hospital? They reply yes, and that it had been a long wait to get here. She says that her diagnosis was mid-January, and she knows that it’s not that long really, but it had seemed like a long time because they wanted everything to happen so fast. I explain about parking and drop-off. She is looking pained as she walks, so I tell her about the wheelchairs downstairs and offer to get one, which she accepts. I take them up to the CT area and help them check in there and wait with Mary so her husband can use the washroom. I inquire about her leg because she is wincing in pain and she says it is new, she was in the grocery store and realized she never had pain there before. I ask, is that what took you to the doctor? She says no, it was a cough that wouldn’t go away. As I say goodbye, I tell her I will give her a call next week. She says that’s fine – she will be around as there are “not many more trips to the Caribbean.”

This chapter examines the conversations and communications about advanced disease that occur between patients and medical staff. I use Mary’s story here to introduce many of the themes that will be discussed, including: 1) the harsh reality of a diagnosis of incurable disease; 2) the ‘realist’ narrative of oncology, which specifies that patients may live with incurable cancer but not outlive it, introduced by Dr. Lawson to counter the ‘unrealist’ narrative that Mary introduces; 3) the kind of ‘business as usual’ conversations that take place everyday in an oncology clinic; 4) even though the content of their work is quite heavy, co-workers in the clinic still have normal co-worker interactions, such as sharing jokes and stories with each other; 5) how little Mary actually speaks or is given opportunity to speak; 6) points where Mary expresses
feelings, such as “mom was sick,” are not picked up on or responded to with empathy, inviting
her to elaborate on her emotions; 7) although incurability is addressed, the focus remains on
treatment and on treatment side-effects (e.g., drug coverage, pain killers, bowel issues resulting
from taking narcotics); 8) lastly, even in the face of grim news, Mary is optimistic and setting
herself on a different plan, or narrative, for her future than the one Dr. Lawson envisions for her.

Significantly, before Dr. Lawson can even begin, Mary jumps the gun and outlines the
‘plotline’ she has scripted for herself – one where she lives through this disease and “puts
[cancer] behind [her].” Dr. Lawson outlines a different kind of ‘plotline’ for Mary – one in
which she will get treatment, but it will be limited in its effects. Mary’s own plotline seems to
suggest that she did not hear what the doctor said. But she had heard quite clearly (recall that Dr.
Johnson had already answered the question of curability his first time in the room). Regardless of
this message, Mary is intent on letting her doctor know that she plans on surviving; in doing so,
she rejects the reality that Dr. Lawson proposes in favour of a different outcome. It is worth
noting that on this day, when Mary comments, “aside from this cancer, I am healthy,” she was
using a cane because the cancer had already gone to her bones and was causing her incredible
pain. But none of these obvious and presenting factors (e.g., significant pain, her recent need for
a cane, seriousness of diagnosis) were going to get in the way of communicating to Dr. Lawson
her conviction that she would get better.

In the chapter I analyze clinical interactions, such as that between Mary and Dr. Lawson, in
order to address a tension between doctors’ need to convey information about advanced,
incurable cancer and patients’ need to build narratives that will provide them with the necessary
hope for living with a fatal diagnosis. The chapter is not only concerned with the words people
use when they talk about incurable disease, but also with non-verbal forms of communication,
and with talk that takes place outside the closed doors of the consultation room. Thus, I grant
communication a wide berth, examining how it spreads out over time and space, and manifests
itself in the narratives patients tell themselves about their illness. Although first consultations
generally involve the communication of the incurable or metastatic nature of the diagnosis,
in subsequent appointments the focus quickly shifts to the progress of treatment. In most cases,
teams do explain, in very clear terms, what the patients are faced with. The words are duly noted,
written down by the observing anthropologist and recorded in the patient’s chart. But the actions
that follow this disclosure may contribute to muddying what seemed like a clear message.
Patients and doctors sometimes seem to have conflicting stories about what the outcomes of treatment will be.

The medical literature has conceptualized this issue primarily as a problem of “communication.” Thus, there have been innumerable studies focusing on the process of communication for patients diagnosed with cancer (Rodin et al. 2009; Hagerty et al. 2005) and specifically, with advanced cancer (Nelson et al. 2011; Grunfeld et al. 2008; Ugalde et al. 2012). A recent, large systematic review concluded that despite numerous studies devoted to this topic, there is “no definitive evidence” that supports one method of communication over all the others (Rodin et al. 2009:627). I briefly review some of this literature in order to provide the reader with a sense of how ‘bad news’ – discussions focusing on a cancer diagnosis, cancer progression, or end-of-life – is conceptualized as a piece of information that needs to be transmitted (often from the doctor → the patient). In contrast, my analysis is more informed by the theories of narrative and of therapeutic emplotment innovated by Cheryl Mattingly (1994, 1998, 2009). Mattingly’s concept of therapeutic emplotment posits that “therapists and patients not only tell stories, sometimes they create story-like structures through their interactions” (Mattingly 1998:2). Importantly, this crafting of stories that can be shared and worked on together produces a kind of “healing power” or therapeutic potential (Mattingly 1998:2). Mattingly conducted ethnographic research amongst occupational therapists working with patients who had suffered serious, debilitating injuries (e.g., spinal cord injuries) when she devised this theory. She argues that therapists play a crucial role in recruiting patients to particular narratives, and in assisting them in a kind of narrative labour about their clinical predicaments (Mattingly 1998). Therapists are “in quest of dramatic plots that will transform the painfulness, irrelevance or sheer tedium of therapeutic activities into important events, ones that figure for the patient as critical episodes in their healing experience” (Mattingly 1998:6). Although the patient population these occupational therapists were working with would never again be “well” or returned to their “pre-morbid state,” the therapists helped them to come to accept their condition and to learn to live with disability (Mattingly 1998:163). Conversely, in my research, patients were not facing the possibility of a life lived with impairment or disability, but a life that would be cut short from a cancer that could not be cured.

Thus, I build on Mattingly’s work by examining how the imperative to confront the proximity of death – the end of the narrative, as it were – creates different storylines or “clinical plots” than the kind Mattingly analyzes. Applying these ideas to oncology discourses, here I
examine each consultation as a small piece of a bigger story that patients are telling themselves about the possibilities for their future. I argue that the incurable diagnosis makes it much more difficult to create a healing drama in the consultation room, and that other factors, outside the consultation, affect how well a dramatic version will hold. Whereas occupational therapy is a profession founded upon the potential of rehabilitation, where healing is a possibility even if a person might be healed to a life that is not ideal, oncology is a profession dedicated to treating and curing (where possible) cancer, an often fatal illness. Oncology’s most obvious associations, then, are with the potential of death. Mattingly’s therapists work to try to align patients with plots that can help them to become stronger, able to live “a life of maximum independence” (1998:168). Conversely, here I demonstrate that in oncology consultations, patients with incurable cancers often feel that they are fighting to hold onto a ‘hopeful’ plot, while their oncologists narrate a more ‘realist’ plot.

In addition to Mattingly, I draw theoretically on the research of Annemarie Mol (2002, 2008) and her argument that health care ought to be motivated from a “logic of care” rather than the “logic of choice” that has risen in popularity in line with the decline of medical paternalism. Mol (2008) argues that although “patient choice” is a powerful rhetorical tool, it results in less than ideal care for patients, who have nowhere near the medical knowledge that their care providers do. Although in recent years, the medical system has tended towards conceptualizing the patient as a consumer, privileging choice and autonomy, this mentality relegates health care professionals to a very limited role: to lay out the facts for the patient to consider and to implement the chosen course of action (Mol 2008:48). Thus, in health care motivated by a logic of choice, the purpose of the consultation is for the doctor to transfer information to the patient, or consumer. Conversely, in health care motivated by a logic of care, the purpose of the consultation is for doctor and patient together to craft a plan for what is actually possible for each patient (Mol 2008). Mol’s ideas are drawn primarily from her ethnographic research with patients suffering from artherosclerosis (2002) and diabetes (2008). For example, Mol’s (2002) work on artherosclerosis diagnoses demonstrates that a diagnosis emerges out of practice, and is never just ‘given.’ Thus, Mol is also concerned not with communication ‘ideals’ – i.e., what we could imagine in terms of the best possible conversations about cancer between patient and oncologist – but with what happens in practice, when doctor and patient meet in a consultation room. She argues, “the logic of care is not preoccupied with our will, and with what we may opt for, but concentrates on what we do” (Mol 2008:7).
Thus, Mattingly’s use of therapeutic narrative emplotment (1998) and Mol's logic of care (2008) converge in the idea that a diagnosis is not just a piece of information; it is, rather, a critical juncture in a person's self-narrative, and it is something that is intersubjectively or dialogically produced by both clinician and patient. They both help to showcase how the communications that take place during a consultation become central narratives for patients, and how those conversations drive the plots that patients are able to sustain. While Mattingly’s work is instrumental in understanding the forms of verbal and non-verbal communication taking place within the consultation, Mol’s work helps to situate the consultation within contemporary discourses of health care, and its increasing emphasis on “patient choice.”

In applying their ideas to oncology consultations, I demonstrate that sometimes patients and doctors are not working together to sustain the same story(ies). For example, oncologists are legally required to disclose the nature of the illness to patients in Canada. Based on my observations, they see their job as sustaining a ‘realist plot’ – this is the plot that says that the disease is incurable and will always come back, even if it is temporarily kept at bay by treatment. Patients, conversely, want to sustain a more ‘hopeful plot’ – this is the plot that says that they can beat the cancer and survive. Thus, oncologists speak in an indicative mode (the cancer cannot be cured/the patient will die), and patients speak in a subjunctive mode (there is still hope the cancer will be cured/I will live) (Mattingly 2009; Turner 1986). Mattingly argues that if we look at therapeutic encounters as proto-narratives, or stories-in-the-making, we see that our sense of self is made up by “living subjunctively, living out multiple and even contradictory life plots at the same time” (2009:267). Patients are thus asking their doctors to live in the subjunctive mode with them. Patients do not want to die. They want to live. Thus, they interpret their conversations and interactions with their oncology team in such a way that they forward several, even contradictory plots.

In the chapter, I show that although oncologists generally speak in the indicative mode, forwarding the ‘realist plot,’ and patients speak in the subjunctive mode, forwarding the ‘hopeful plot,’ the dichotomy does not always hold true in daily life at Lady Ann’s. I demonstrate how even within a single consultation, the oncologist and the patient can switch places, with the patient becoming despairing and the oncologist suddenly having a more positive outlook. Furthermore, I outline the kinds of sub-plots that challenge or trouble both the ‘realist’ and ‘hopeful’ plots. For example, the overarching focus on treatment by both patients and oncologists contributes to muddying the message of the ‘realist plot.’ When oncologists continue to offer
treatment to patients with advanced disease with the dogged determination their specialty is known for, patients interpret those actions as contributing to the 'hopeful' plot because there is still something to be done, i.e., they are not just waiting to die. But, often the doctors do not really intend for patients to place so much hope in the treatments; although they do, of course, want them to have enough hope to continue taking them and fighting the disease. Thus, hope itself is a precarious balance, and it is difficult for patients to have what might be called the ‘right amount’ of hope. Another sub-plot that contributes to patients’ ability to hold onto their ‘hopeful’ plot is the ‘care plot,’ which relates to feeling cared for by the people they have entrusted to lead them back to life, and being included as respected members of their own health care teams. When patients feel like someone is “looking after” them, and trust in their health care professionals, that feeling of care permeates all aspects of their hospital experience and results in a more positive outlook towards their illness. Conversely, when they feel that no one is supervising their care or they are being excluded from decisions about how to manage their illness, they struggle on their own to hold onto a ‘hopeful’ plot, because they do not feel any support that contributes to that narrative.

These challenges to the primary plots demonstrate that oncology consultations are full of narrative plot ‘twists’ – sudden changes of events and facts that must be managed and dealt with. Mattingly (1994) distinguishes ‘clinical time,’ which follows a linear progression model, from ‘narrative time,’ which is not so orderly, but rather full of “tricks and reversals.” Mol also speaks to the necessity to see time as something that is experienced, rather than as a discrete variable. She argues that in daily life in the clinic, “time twists and turns” (Mol 2008:62). Although we might imagine that a consultation is an event in which rational actors examine all the “facts” (i.e., the scientific information) and “values” (i.e., what matters to patients), and then make an informed decision, Mol (2008) argues that there is never any one point when all of the facts and values can be known. Rather, patients and physicians work in the moment to make decisions based on the always-limited information that they have. For example, a CT scan reveals that a patient’s cancer is ‘progressing’ (i.e., worsening) even on chemo. This patient must now be taken off that chemo regimen, and perhaps put onto another one, if there is another one for her. This sudden change comes a surprise to both patient and doctor, who both believe her cancer to be shrinking. Thus, in consultations, patients struggle to craft multiple plots out of the values and facts that are available, which are constantly shifting. Each consultation, then, is approached with
anxiety and trepidation, but also with hope, as it presents a new opportunity for patients to cast
themselves onto a more hopeful, or life-affirming plotline.

I bring these analyses of time forward to introduce a conception of time that is less about
seeing it as an external, quantifiable variable, and more as a lived and experienced orientation
towards life. In Chapter 5, I discuss this subject in greater depth. But for the purposes of this
chapter, it is worth noting that narrative time gives greater agency to the patient, or actor, as it
gives him or her a role in the room. Mattingly argues, “in therapeutic context, time is narrative
when the body as lived and experienced, as called upon by the actor, is central to the
intervention” (Mattingly 1998:141). Non-narrative time is when the patient as actor “recedes into
the distance” and the focus of the consultation becomes the “treatment of discrete body parts or
functional skills” (Mattingly 1998:142). When conversations in oncology regularly focus on
treatments and side-effects of treatments, they focus on a kind of “non-narrative” time. By
focusing on the instrumental or technical aspects of their illness, they offer little fodder for
patients to contribute to their ‘hopeful’ plots, and provide few opportunities for oncologists to
demonstrate their support for those plots.

Throughout the chapter, I argue against the idea that communication in oncology is only
about the transfer of information, and work to reframe “communication” as an inherently
relational process. As Mattingly argues, a clinical consultation “requires an interplay between
therapist and patient. Neither can impose an experience on the other single-handedly”
(1998:157). The research methodologies that have been used to study communication (e.g.,
questionnaires, surveys, and analysis of transcripts of recorded interactions) give the impression
that communication is something that takes place for 10-20 minutes behind the closed doors of a
consultation. Conversely, I argue that “communication” is an insufficient trope or concept for
understanding clinical interactions and how patients apprehend and incorporate medical
information. I take a broad lens to imagine communication and introduce two variables to the
consultation: 1) a longer temporal frame and 2) an interactional and experiential quality. I
demonstrate that there are multiple layers to communication, and introduce other contextual
factors to the consultation, such as the life-world of the busy oncology clinic, and the
oncologist’s, patient’s and family’s expectations. Ethnographic methodology allowed me to see
how communication gets processed and was made meaningful by both patients and staff.

In doing so, I build on an important ethnographic study by Anne-Mei The and colleagues
(2000) examining the communication of prognosis for patients with small cell lung cancer in the
The study was aimed at understanding why, with a life expectancy at a maximum of 2 years, many patients seemed to believe they would recover from the cancer. By studying communication over time using the tools of ethnography – observing consultations, interviewing patients, family members and oncologists separately – they were able to demonstrate that it is both patient and provider’s behaviours that contribute to a kind of “false optimism” for patients about their chance of recovery, what they term “collusion in doctor-patient communication” (The et al. 2000). They argue that patients’ optimism cannot be accounted for by a lack of communication by the doctors because it presents the consultation as a one-sided event, and denies that both patient and physician play an active part (The et al. 2000:1377). In particular, they found that patients often get caught up in the “treatment calendar,” and interpret physicians’ activism in treating their cancer as a sign of their future recovery. Eventually, patients were forced to come to terms with their prognosis, but not often as a result of an open conversation with their physicians, but rather through acknowledging their own physical decline or by speaking to other patients in a similar situation. Within the qualitative medical literature, this paper offers the most compelling evidence of the many complexities that characterize communication in oncology.

However, because it is such a short article, limited by the usual length of a medical research article (6 pages), The et al. (2000) do not have room to analyze in-depth how collusion comes about. For example, the authors point to the role of the treatment calendar in contributing to both patient’s and physician’s ignorance of prognosis, and provide a useful vignette summarizing one conversation where this was observed. While the single vignette discloses the physician’s discomfort in not knowing how to turn the conversation from one about treatment, to one about approaching death, it does not reveal, as I do, how the ‘treatment plot’ continues to materialize in each subsequent clinical interaction. Treatment becomes such a focus of consultations that it begins to take over patients’ time, to such an extent that it becomes one of the means by which patients measure the passage of time, as I discuss in Chapter 5. The vignettes accompanying each major summary point are effective for illustrating the kinds of things that are said and their effects, but they do not give the reader any sense of the actual patients who were studied; in fact, because they are designated only by last name initials (e.g., Mr. H. and Mrs. L.), and only 2 vignettes out of 6 are about the same patient, the patients come across almost as ‘stock’ characters, rather than real people who are struggling to incorporate a negative prognosis into their life plans. The et al. (2000) also suggest that patients subscribe to a kind of “recovery
plot” (or what I call the ‘hopeful plot’). But they do not take the analysis further to show how oncologists are involved in their own kind of alternative plotting of their own, or how patients’ “recovery plots” might co-exist with other plots they maintain. Thus, here I build on The et al.’s (2000) research, by showing that it is not only patients who hold onto “plots,” but also oncologists. It is too simple to say that patients have only one plot and that doctors themselves do not harbour their own plots or desires for each patient. I show that both patients and clinicians advance therapeutic plots, and that some actions and conversations may contribute to forwarding plots unintentionally.

I examine ethnographic examples, like Mary’s detailed above, which show how patients interpret the messages that are being shared with them about their progress, and how these messages contribute to the story-making that patients are engaged in about their own lives, illness and possibilities for the future. A longer temporal frame – such as Mattingly’s (1994) notion of clinical plots or narratives – is particularly useful here, as it helps us to understand how people with advanced cancer cope with that information over time. As Rodin and Zimmerman suggest (2008), patients with incurable disease may be able to maintain a kind of “double awareness,” where they are conscious of the proximity of death, but still maintain a will to live in spite of significant emotional and physical suffering. Almost all the follow-up patients I worked with at some point made comments to me that made me fear that they did not understand the incurable nature of their diagnosis. In at least two of those cases, I had been present in the room and knew that the oncologist had clearly conveyed this statement. Had I only interviewed these patients at one time-point and not had many, continuing conversations over a period of several months, I would have walked away with a false impression of what these patients understood about their disease. Because I was fortunate to speak to them on different occasions and in various contexts, I came to realize that the sentiments expressed were more dependent on what was happening to them in-the-moment, and how they were managing to get through that day, rather than any hard and true statement about how ‘informed’ they were. Rather than be reflective of ‘acceptance’ or ‘denial’, these kinds of conversations over time were demonstrative that feelings change – sometimes in a minute and sometimes over several months. These regular, informal conversations, showed me how ‘double awareness’ operates, and revealed how people come to understand their disease and its seriousness in unique ways. Double awareness might also be thought of as ‘living subjunctively’ (Mattingly 2009; Turner 1986) – that is, living as if
more than one outcome, or narrative thread, is entirely possible – rendering both “acceptance” and “denial” of a fatal diagnosis to be entertained simultaneously.

**Living Subjunctively in the Space of Advanced Cancer**

The notion of emplotment offers one way to examine the social construction (and reconstruction) of illness and healing as a fluid, shifting process influenced not only by molecular conditions, institutional structures and cultural meaning but also by the exigencies of the concrete situation (Mattingly 1994:820).

Mattingly’s notion of ‘clinical emplotment’ is particularly instructive to analyze data on oncological consultations because it focuses on the clinical interaction itself, as opposed to second or third-hand accounts of what happened. Thus, she begins from the position that clinical events are meaning-making activities. Mattingly draws on literary theory (e.g., Paul Ricoeur’s work on narrative) and on phenomenology to re-conceptualize the clinical encounter as one where clinicians and patients are building a story together, a story that, constructed carefully, can be therapeutic and do healing work for a patient, what she terms a kind of “healing drama” (1998). Mattingly demonstrates that although the therapist (here, the oncologist) can set about a particular narrative, it is up to the patient to pick up those cues, and he or she can resist and propose a different narrative. So narratives cannot be dictated, although perhaps the therapist may see patterns between one patient’s narratives and another’s (Mattingly 1998:155). In stories-in-the-making, endings are never known but always uncertain (Mattingly 2009).

Although Mattingly’s original theoretical framework was developed to analyze the work of occupational therapists treating patients with incapacitating injuries, it is her more recent work (2009), where she explores the case of a young mother who is dealing with a four-year old daughter with brain cancer, that is applicable for my purposes here. The mother, Aliyah, constructs several possible ‘plots’ for her daughter, Keisha, that would be acceptable: 1) a plot where Keisha is given back life with a stable tumour, so that she might live; and 2) a plot where Keisha has a foreshortened life, but she lives as well as possible, for as long as possible (Mattingly 2009:267). Mattingly demonstrates that for Aliyah, the same encounter with Keisha’s oncologist, Dr. Hansen, can further both these plots at the same time. Importantly, she argues that multiple plots can be contradictory, but they are not experienced as such (Mattingly 2009). Even when Mattingly interviews Aliyah three years after Keisha’s death, she maintains
that Dr. Hansen did care for Keisha and did everything that was possible for her. Thus, despite Keisha’s death, Mattingly (2009) presents the consultation as evident of a “healing drama.”

In the case of my participants, I ask whether it is possible for their consultations to be similarly conceived as “healing dramas,” when the ending that has been mapped out seems so inevitable. In other words, Mattingly’s in-depth analysis of this one session with the oncologist is about how Aliyah, as a mother, forwards and holds onto particular plots. Even though in Keisha’s case too, “the ending is very much in suspense,” (Mattingly 2009:266) the reader cannot hear from Keisha, because she is only 4-years old, and has no insight into her experience. Aliyah feels her daughter was well looked after, but what other perspective might Keisha offer, if she could speak for herself? In the cases I will present here, beginning with the ‘realist’ plot that sets the stage for all patients with advanced cancer at Lady Ann’s, it seems much more difficult for patients to try to forward several plots simultaneously, especially the ‘hopeful’ plot, precisely because the ‘realist plot’ carries so much weight. Can oncology consultations still provide the fodder for healing dramas when ultimately the patients will not be healed?

Importantly, one key difference between occupational therapy and oncology is the level of participation of the patient. Where rehabilitation is founded upon a partnership between therapist and patient, who work together towards the goal of rehabilitating the patient, based on my participants’ comments, they do not always feel that they and their oncologists are “in the same story” (Mattingly 1998:136). Mattingly provides the example of a therapist and a woman who seem to want different things to come out of the time they share together in terms of the specific goals of the therapy (1998:136). As you will see below, some participants feel that they are the only ones in a consultation who are forwarding the ‘hopeful plot,’ and they find that every time they become too hopeful, that plotline becomes quickly replaced by a more ‘realist’ framing about the limits of cancer treatment. In Mattingly’s terms, this encroaching plot might be termed a “threatening plot,” because the “the patient cannot identify with the therapist’s hoped for story and is allowed no room to initiate a different one” (1998:149).

Additionally, patients undergoing physical therapy are actively involved in treatments; often by pushing themselves to exert painful, excruciating exercises and by being committed to getting better is how they make progress in becoming rehabilitated (Murphy et al. 1988). For example, in physical therapy, the “demand for complete obedience goes far beyond hospital insistence on inmate passivity” (Murphy et al. 1988:240). Similarly, the cancer patient is exhorted to have the ‘right’ attitude and to be compliant with his care. But, frustratingly, there is
very little he can do to make himself better. Patients are constantly reminded of this during oncology consultations, when they inquire hopefully about the potential utility of a drug they have researched on the Internet, or whether an alternative treatment, such as an immune-booster, is likely to help. Oncologists at Lady Ann’s often did not give much weight to alternative treatments; they constantly reassured patients that the treatment regimens they were on were the most suitable for them. By downplaying the therapeutic benefits of alternative treatments or treatments found on the Internet, they were likely motivated by a logic of care; they wanted to reassure patients that their disease was not within their control. In other words, that it did not matter if they followed every new health care fad (e.g., drinking green tea, juicing, taking supplements) because it would likely have no effect on their cancer. But this was not often the way that patients interpreted this message. Rather than see this dissuasion as one of the means by which their oncologists ‘took care’ of them, they often felt that their doctors were not acknowledging how hard it was for them not to do anything. They found it hard to hold onto the ‘hopeful’ plot when there was nothing that they themselves could do to ensure its continuation.

I show that within the space of advanced cancer, it is possible, and even happens sometimes, that a “healing drama” ensues, but that it struggles to emerge from the tension between the oncologists’ and the patients’ primary plot preferences. Living in the ‘subjunctive mode’ for patients incorporates these various complexities – being unable to participate fully in their recovery, and being unable to ‘do’ anything to provide an optimistic turn to their story. Yet despite these difficulties, I show that patients still manage to live in the “the mood of maybe, might be, as if, hypothesis, fantasy, conjecture” (Turner 1986:42). In terms of the kinds of narratives or plots that are sustainable, the doctors have a clear sense of death as the end result, whereas patients do not. Thus, hope for each group creates different horizons of possibility and with it different ideas about the results or possibilities of treatment. Uncertainty for the patients creates hopeful futures, whereas the finality or certainty of death for doctors results in a different set of actions and interpretive frames.

The Limits of Language

Despite many articles and books devoted to the subject, communicating about negative diagnoses, poor prognosis, and approaching death remains a problem. Rodin et al. recently concluded that “the literature examining the patient-provider communication interface is large,
challenging to integrate, and of varying quality” (2009:642). Much in the medical literature on communication focuses on a very narrow and literal reading of communication, i.e., how do we tell patients? The common tropes in communication research frequently use terms like the “bad news delivery” (Barclay et al. 2007; Goncalves et al. 2005) and provide step-by-step instructions on how to set the stage for good clinical interactions. Often, this translates to what words should be used, in addition to directives to sit down, be calm, and look people in the eye. A great amount of effort is put into training doctors how to speak more empathically to their patients and to respond to their feelings (Buckman 1992). And these efforts are all important, because what oncologists say in the consultation room and how they say it matters. But communicating a diagnosis or relaying bad news in a follow-up appointment is not a uni-directional transmission of substance from one person to another. A person does not receive news in the same way she might receive objects, like packages or flowers, yet the word is often used in the same way. In this way, news “delivery” is a kind of container metaphor, such as “I couldn’t get my ideas across,” which makes explicit how language and meaning is seen as a substance of transaction (Lakoff and Johnson 1980). The understanding or the ‘emplotment’ of that information may come much later through dialogic interactions with family and friends, and with subsequent conversations with the oncologist.

Additionally, the content and quality of any possible communication is always constrained by what is happening outside the consultation room – how many more patients doctors and nurses need to see, how much time they have to spend with each patient, how many difficult cases they are dealing with on any given day. For oncologists, the challenging task of being the person responsible for disclosing bad news is not just something that happens once in a while: it is their daily experience of being at work. In my research, I observed that doctors often walked from one bad news conversation to the next, with little time in between to gather their thoughts or feelings. The impact of such a responsibility has not been adequately addressed in the literature, and should be considered in collaboration with patients’ experiences of care in oncology, as well as institutional factors such as the time allotted per appointment, and the number of patients seen in the clinic each day.

Practices of disclosure about incurability in cancer have changed dramatically in the past 50 years. Two large review studies published in JAMA demonstrate this sea change: whereas in 1961, 90% of 291 doctors surveyed did not tell patients their cancer diagnosis, by 1979, 97% of 264 doctors surveyed indicated a preference for telling patients (Oken 1961; Novack et al. 1979).
In the late 70s and early 80s, sociologist Kathryn Taylor (1988) examined 118 communication ‘events’ where a breast cancer diagnosis was disclosed, and found that in 45% of the cases, doctors used a technique she called “evasion,” which meant that they did not give a prognosis that was individualized to the patient and tended to respond indirectly to patient questions. Thus, although more physicians were disclosing the cancer diagnosis, patients were not necessarily always being informed of their individual prognosis. More recent studies of prognosis confirm that this is still the case, several decades later (Christakis 1999), and that doctors may only offer information about prognosis if they are explicitly asked (The et al. 2000).

Hope is a central feature of clinical interactions. Good and colleagues (1990, 1993) found that doctors often feel pressured to speak in a language of hope that encourages patient optimism and provides continued options for care. Oncologists initiate a discourse of hope in order to rouse patients into fighting the disease; the alternative of letting go or ceasing treatment is a more difficult admission on their part and more challenging to follow through on (Good et al. 1990). But research has also revealed that patients want their doctors to be realistic in discussing prognosis; Hagerty et al. (2005) surveyed patients and over 82% said that using euphemisms in disclosing prognosis would not facilitate hope. As Simpson (2004) has demonstrated, hope is an emotional attitude that is not generally well understood. She points out that patients cannot maintain hope alone, since they need health care providers to support their hope(s); however, supporting patients should not take the form of protecting patients through incomplete disclosure or evading the truth (Simpson 2004). Her ideas concerning the “dynamic and sometimes fluctuating nature of hope” (Simpson 2004:433) are useful for understanding how patients can maintain a ‘double awareness’ (Rodin and Zimmermann 2008), which encapsulates hope for the future within a process of dying.

Much of the research on communication takes up either the patient’s or the physician’s perspective, but my research attempts to bridge these perspectives. I follow Mol (2002), who argues that it is less useful to speak of perspectives, than it is to speak of what is being enacted in practice. Mol’s (2002) work examined how atherosclerosis as both a biological and social phenomenon is made in the hospital setting through the instruments, people, and practices that are involved in the diagnostic event. She argues that a patient may have symptoms before he enters the room, but he does not have the disease, because the diagnosis comes out of the interaction. Similarly, the doctor cannot diagnose without a patient present in the room, since he needs answers to his questions, a physical examination and a clinical history to make a diagnosis.
Thus a diagnosis is practiced, or enacted, to use Mol’s term – not given. Mol’s ideas provide agency to both partners in the consultation room. Where it is common to see the consultation as an event where the doctor actively diagnoses the patient and the patient passively receives the diagnosis, Mol’s analysis recognizes the dynamic nature of the interaction and the diversity of possible scenarios that may emerge: “when doctor and patient act together in the consulting room, they jointly give shape to the reality of the patients’ hurting legs” (2002:27). Mol’s work serves as an important reminder that the diagnosis of incurability is never a ‘given,’ even when “cultural scripts” (Mattingly 1998:156) may be familiar. Mol’s approach gives primacy to how an incurable cancer diagnosis is ‘brought into reality’ and socially constructed through the words, texts, communications, gestures, and practices that I observed and recorded.

**Plots in Oncology**

**I. The ‘realist plot’**

In this section, I demonstrate how the ‘realist plot’ materializes, most often by oncologists during first consultations. Recall in Mary’s first consultation described above, Dr. Lawson allowed her to speak about her hopes for her future for the first few minutes (“I plan on putting cancer behind me,” “Aside from this cancer I am healthy”), before firmly setting her down in the world she lived in – in other words, setting her path along a ‘realist’ plotline (“I think we are here to be realistic that we are not going to make it go away forever,” “Survival is not going to be in decades”). Sitting in on oncology consultations, I heard what I call ‘realist plot’ being invoked over and over again. The ‘realist plot’ seemed to be defined by the scientific literature that describes the nature of the disease, disease progression, and the chances of survival. As in Mary’s case, it was often brought into the consultation by the oncologist as a method of redirecting the conversation into the realm of the ‘possible’ or the ‘probable’, and often in response to a patient expressing too much hope in the progress of treatment.

In lung cancer, in the conversations that I witnessed, the diagnosis was always made clear as “incurable.” There were some variations, but the script was almost always the same: the oncologist explained that they did not have a “cure” for this disease and that the best they could hope for in this case was to keep the cancer “under control,” to “put it into remission,” or to “shrink it down, and to improve your symptoms.” Whether or not patients retained or heard
that information is a different story. For instance, when I asked Paul, a 62 year-old man with lung cancer, what his diagnosis was in my pre-interview demographic questionnaire, he replied,

I have (using scare quotes) inoperable cancer. Dr. Lawson never once said clearly what it was, but also did not say cure either.

I realized that I seemed to know more about his disease than he did, since I had read his chart, and had seen that he had stage IV lung cancer – the most advanced form. Thus, initiation into this new world of advanced cancer begins with a harsh diagnosis. Dario, a 57 year-old man with stage IV lung cancer, recalled that during his diagnostic appointment, they told him his diagnosis and then they left the room. He said that from the description, and the way in which they spoke about it, having stage IV disease seemed “very commonplace.” He described their approach in sharing this news very directly and unemotionally as if there was “no realization of what they are telling people.” This comment serves as a good reminder that while inside the world of cancer at Lady Ann’s, it is generally understood that stage IV disease means a certain, and potentially swift death, outside the world of cancer, ‘stage IV’ is somewhat meaningless. This point is well-demonstrated in the endearing indie film Beginners (2010), in a scene between father and son, where the son asks his father, “Dad, don’t you know what comes after stage four?” when he notices his father is still smiling after he finds out his cancer staging. The father ventures a hopeful guess, “Stage five?” The son must then tell his father that he is dying.

In ovarian cancer, where I was not present in first appointments, but in treatment-planning appointments following surgery, the metastatic nature of the cancer was never hidden, but the same focus on treatment persisted. The ‘realist plot’ was invoked when too much hope seemed to be invested in those treatments, as in the following example, based on a one-time observation with a middle-aged woman with metastatic ovarian cancer, Jane. Her daughter was also present at this visit. The consultation began with Jane saying something about how she felt “as good as before the diagnosis.” Dr. Girard contended that Jane was doing well, but that based on her recent scan, liver lesions [i.e., liver metastases] were definitely present:

Dr. Girard: ‘They are definitely there – liver lesions. Compared to previous scan which was June 13, they are smaller.’ ‘There has been some improvement but still there’. ‘You are doing well. The disease is still – there’s still disease’… ‘With liver disease – this is not something that we are going to cure’ (think she says more than this – something about how we can give her chemo – 6 cycles is normal). ‘But we have to be realistic about the goal here’

Jane: ‘This is making me so anxious’
(I have had my head down writing and look up and notice Jane is staring at the floor. Her
daughter has her arm around her.)

Dr. Girard: ‘Things are going in the right direction’

Jane: ‘What about radiation?’

Dr. Girard: ‘Radiation only treats cancer that is focused.’ (She gives her an example – such as
aiming at a particular lump in breast cancer.) ‘In your case, your cancer goes from
your breast bone to your public bone’ (implying lots of space), so lots of side effects.
‘So this is something we need to tackle with chemo.’ (She says something about not
excluding that radiation at some time may be beneficial, but not now.) ‘It’s not
realistic. I need to be honest when I’m counselling you.’

After the consultation, Dr. Girard and I are in in the hallway, and she is using her back to hold
open the door of another consult room, where a different patient waits with a medical student.
Dr. Girard says to me, “I’ve told her this many times before we are not going to cure this but it
doesn’t sink in.” She is pointing to her head and making a motion with her hand – not a ‘crazy’
motion, just indicating that it is not being accepted I think.

This dialogue between Jane and Dr. Girard exemplifies that “patients, therapists, and other
key actors routinely designate the ‘same’ behavior differently, each seeing what is going on as
part of a different unfolding narrative” (Mattingly’s 1998:110). You can see with this example
that Dr. Girard twice interjects with the ‘realistic’ take on the situation – once about the need to
be “realistic about the goal here,” and once about how it is “not realistic” to think that radiation
will be beneficial in Jane’s case. Jane has metastatic ovarian cancer. Dr. Girard sees hundreds of
patients like Jane every year. The ‘realist plot’ that she advances has much to do with the fact
that in her line of work, she knows that once ovarian cancer has metastasized to the liver, it is not
curable. She works here to provide this perspective to Jane. In fact, she seems to feel somewhat
obligated to ‘emplot’ the reality of the situation into the consultation. Dr. Girard clearly feels a
sense of responsibility to make sure that Jane understands the seriousness of her cancer, referring
to her “need to be honest” when she is counselling Jane. She was visibly frustrated with Jane
when she spoke to me in the hallway. In particular, she was bothered by the fact that she had
“told her this many times before” but it was not “sink[ing] in.”

But, from Jane’s point of view, it is possible to see how this conversation can be perceived
in several ways. If things are in fact, “going in the right direction,” then why is it so far-fetched
to believe that she is on the mend? Jane interprets Dr. Girard’s words as contributing to her
‘hopeful’ plot, and the life that will be lived. This plot is supported by her assertion that she is
feeling as good as before her diagnosis. Conversely, Dr. Girard sees the evidence in light of a
different story – one where regardless of what she does for Jane, ovarian cancer will still claim her life. What is implied, but missing from the text of this consultation, is that Jane’s treatment was always limited in scope. In Jane’s story, a ‘realistic plot’ relates to what Dr. Girard believes is likely or expected to happen, juxtaposed against a more ‘hopeful’ plot that Jane is trying to hold onto. The dialogue between them points towards “different perceptions of what kind of life story [Jane] is living out” (Mattingly 1998:110).

The features or qualities of the ‘realist plot’ were sometimes adjusted, depending on the patient. Recall Mary’s story outlined above. Now, here is an excerpt from a different first consultation I observed in the lung clinic, where a 69 year-old woman, Sheila, was diagnosed with stage IV lung cancer:

Dr. Lawson: We don’t consider you palliative right now – we do and we don’t. You are not to go home and dig a hole and die. We have treatment options to offer you. But when we no longer have lots of options we will be honest with all of you

Sheila: What is the prognosis?

Dr. Lawson: Hard to say – average if I took every patient – 1 year or so

Sheila: Only that

Dr. Lawson: But I think you are on good side of average – hope for something in years (emphasizes the ‘s’). Will it be 10 or 15 years? Not likely

Sheila: So maximum 2 years?

Dr. Lawson: I didn’t say that. More than 1, less than 10.

In Mary’s consultation, Dr. Lawson had joked that she would not live until she was 95. But at 54, that was 40+ years away for Mary. Here, Sheila has asked for specifics and she has been given a much shorter timeline – less than 10 years – and told the average would be much closer to one year. Even accounting for age differences – a gap of 15 years between Sheila and Mary – their realities are differently cast, even though they face a similar diagnosis. Sheila also asked a lot of questions, including, “What is palliative care?” introducing that topic into her consultation. In doing so, she indicates to Dr. Lawson that she wants to know the ‘realist plot.’ This does not mean Sheila is not hopeful or does not desire to live longer (her response “only that?” indicates her disappointment), but rather her willingness to engage with the predicted survival of her disease, even while she hopes to outlive it. Mary, on the other hand, took the first few minutes of her consultation to emphasize how she was prepared to fight and “be aggressive” with
treatments, and to convince Dr. Lawson that she intended to live past her disease. The difference in patient presentations may account for the slightly different narratives that Dr. Lawson emplots. In other words, it is more challenging for Dr. Lawson to bring the ‘realist plot’ into Mary’s consultation than it is in Sheila’s, because Mary seems convinced she will live, while Sheila’s direct line of questioning about palliative care indicates that at some level she has accepted her terminal diagnosis. So while Dr. Lawson does situate Mary in a ‘realist plot,’ she quickly shifts away into what she will be able to do to ‘treat’ the disease (an example of what I will describe as the ‘treatment sub-plot’).

Sheila’s consultation also demonstrates how messages can be perceived to be somewhat contradictory, as she is told that her situation is considered at the same time “palliative” and “not palliative.” This message was likely intended to be aimed at instilling a ‘hopeful plot’ – to balance the new reality of a serious diagnosis with the promise of treatment. But when Sheila pressed about whether treatment could prolong life, she was told, “there is palliative therapy – chemo, radiation – it can be very active treatment in the middle with the goal of prolonging life, with the goal of keeping you well as long as possible.” So treatment that can prolong life is offered under the umbrella of “palliative care” with the doctor’s understanding that its ability to do so is short-lived. But to Sheila this may seem like a conflicted sentence. How can her treatment prolong her life if its goal is not to cure? Oncologists measure survival in added weeks or months of life. Although patients may be grateful for any added time, when they hear things are “going in the right direction” or treatments can “prolong life,” they do not imagine that the treatment’s benefits will be so short-lived. Based on my conversations with patients, they always hope that treatments will be able to cure the disease, even when their hopes have been tempered at their first visit to Lady Ann’s.

Ovarian cancer has a less brutal prognosis than lung cancer, but its ambiguous rate of recurrence makes the ‘realist plot’ particularly difficult to withstand. Ovarian cancer is a disease that has a “history of recurrence” but doctors do not know and therefore cannot tell patients when or if recurrence will actually occur – only that it is very likely. This ambiguity proved very frustrating for patients. For example, when Elizabeth, a 37-year old woman who was undergoing treatment for metastatic ovarian cancer, pressed the oncologist for details about her prognosis, she got the following response from the doctor:

Is it going to be 20 years? Maybe not. I can only tell you what we see. 3-5 years is what we tend to see here. But then again, you could be cured.
This is a kind of statement that is capable of forwarding “multiple possible plots, multiple possible selves” (Mattingly 2009:250). On one hand the oncologist is asking Elizabeth to contain her hopes for a long-term future (‘realist plot’); on the other hand she also offers the very rare possibility of being cured (‘hopeful plot’). Elizabeth is one patient who wanted to know what her real chances were. A few months later, in an interview, this topic came up again, as she was discussing her friend’s reaction to her diagnosis.

Alyson: Did he want numbers? [i.e., survival statistics]

Elizabeth: I wanted numbers.

Alyson: Did you get numbers?

Elizabeth: I didn’t get numbers. I’ve not gotten numbers. I know that doctors tend not to like to give numbers because if they don’t come true they can be held accountable for those numbers. But I personally would prefer for you to tell me numbers and if it’s less or if it’s more…I’m not going to blame the doctor for that. It’s my own body.

So Elizabeth wanted the ‘realist plot’ mapped out for her and made clear. But not everyone is the same. In fact, what makes oncologists’ work very difficult is that no two patients are the same and likely interested in the same amount of information. Research has demonstrated that since patient preferences vary, communication style must be individualized (Rodin et al. 2009).

Contrary to Elizabeth, Deo was very disturbed when the seriousness of his prognosis was reaffirmed with him, right at the moment when he was starting to feel better.

*Today Deo was discussing the medical student who said ‘It’s stable for now, but it will come back’. He likened it to winning a sporting event in the Olympics and then being told that ‘we have to check what you had for breakfast’. ‘You know? Keep your medal, but hold on now...we have to look into this’. He said he wasn’t sure why they had to do this. He knew what he was dealing with. He didn’t need to be constantly reminded.*

Manuals for breaking bad news often emphasize this: as the physician, you need to find out what kind of patient you are dealing with, how much or how little information they want to know, and how much of a leadership role they would like you to take on (Buckman 1992). However, in practice, this is more challenging than it seems. A doctor may dutifully ask these questions in a first consultation and find out that the patient wants to be very involved in treatment decisions. But that may change, depending on how well or poorly things are going. People who said they wanted all the information up front, may want less and less information if it is going to be bad news. Many of the follow-up patients I worked with talked about how hard it was to keep getting
bad news. For example, I spoke with Mary close to two months after that first consultation in mid-March. She told me, “Every appointment has been bad news – every time.” She complained that she had received “not one piece of good news” and that she wished for “just one thing to go right.” She was still very convinced that she was going to get better: “I’m still as determined as I was before that I am going to put this behind me. It’s just that the mountain keeps getting steeper.” At this meeting, Mary acknowledges that it is much harder now for her to maintain her ‘hopeful plot.’ But despite its increasing difficulty, she is determined not to give it up and allow all the “bad news” to determine her own narratives.

In describing a consultation between a man who has diabetes and his physician, Mol (2008) notes the need to acknowledge that having diabetes is not a good thing.

At the same time, however, patients should not get overwhelmed by misery. Thus, the doctor will stress that, fortunately, there are good treatments for diabetes these days. The balance is precarious. There should be space for sadness, but not too much. A doctor should offer consolation, but also encouragement. And while suffering must be recognized as bad, the disease must simultaneously be accepted as something that needs to be dealt with in one way or another as life goes on (Mol 2008:50).

Contrary to diabetes, a chronic illness that can be controlled through careful medical attention and support, oncology offers little in the way of “consolation.” Despite this, oncologists work just like Mol’s doctor to maintain the balance between the ‘realist’ and ‘hopeful’ plots that patients find themselves in. This is because, just like Mol’s diabetic patient, patients with advanced disease must “learn to live with it” (Mol 2008:49) because their lives do go on, sometimes for a very long time. Learning how to live with and support multiple plots becomes necessary to patients’ survival.

So the ‘realist plot’ has several features. Patients are introduced to this plot through a memorable conversation with their oncologists. They hear what the oncologist says at the same time as they ‘emplot’ or hope for a different future than what has been forecasted. The ‘realist plot’ speaks primarily in the indicative mode, which involves statements of fact, often based in the language of ‘science’ (e.g., survival statistics). Oncologists are rooted in this world of realism and feel a responsibility ‘be realistic,’ not only because of their medical training and its high valorization of the scientific literature, but also because their daily work brings them into contact with many patients who do not survive their disease.

II. The ‘hopeful plot’
In May of 2011, I sat in the waiting room of the thoracic clinic with Paul, who had completed treatment (a combination of radiation and chemotherapy) for his lung cancer several months earlier. For all accounts and purposes, he looked pretty good – a bit on the thin side – but with few other tell-tale signs of cancer. He was in the clinic that day for his regularly scheduled two month follow up appointment with his oncologist. As we were waiting to be called in, he told me that as he saw it, there were three possible outcomes for today’s appointment: a) that he would be cured and the cancer would be gone; b) that the cancer was keeping at bay and not growing; or c) that there would be progression of the disease. He was hoping for a) or b), and in fact emerged with what is regularly interpreted as ‘good news’ in this context. The cancer was not growing. In the words of the oncologist, “The chest x-ray looks stable.”

I was struck by the presence of option a) in Paul’s mind. I remember being a bit confused as I sat next to him in the waiting room, wondering how he could see 3 possible outcomes for today’s appointment, when in my mind (and I assumed the oncologist’s mind as well), there had only been two options available since diagnosis: option b) stability (which means the cancer is still there, but is not growing at this moment in time); and c) progression of disease (signs that the tumour is actively growing). How was it that he managed to hold onto option a) – hope for a cure – in the space of advanced cancer? Paul’s story illustrates how patients can “cultivate multiple storylines at the same time” (Mattingly 2009:260). Paul’s ‘hopeful plot’ is that he will ultimately be cured. But he also makes room for lesser hopes within his emplotting – that his cancer will be stable. He looks to the consultation to provide him with the information he needs to keep both of these plots going. What he learns at each consultation is crucial to the kinds of narratives he can imagine for himself.

From my observations, it is easier for patients to narrate a ‘hopeful plot’, than it is for doctors. After all, for patients, it is their own mortality that is at stake, and it is very difficult to see that objectively. But oncologists have seen hundreds of patients before them and watched as they were captured by the ‘realist plot.’ Eve’s ‘cemetery’ filing system, described in Chapter 1, is a constant reminder on her desk just how many patients have been lost to the disease. Observing in the Gyne clinic one day, Dr. Girard suggested a patient from her clinical list that would be appropriate for my study, saying, “She could be good for you, she will die within a year for sure.” I noted at the time that she expressed this with no callousness – it was more a statement of fact. In her job, patients regularly died.
While oncologists want patients to have hope and to approach their treatments with a positive outlook, there is a fine balance between having not enough hope and too much hope. They want patients to muster enough hope to be able to endure the emotionally and physically demanding treatments, but not so much hope that they believe that the treatments will actually cure them of their disease. So patients struggle on their own to make plotlines that lead towards optimism. An interview with Dario in September of 2011, exhibits this struggle well:

Dario: Without that ray of hope, you really don’t want to be around. You always have to have that hope. That’s what I feel these guys take away from you.

Alyson: The ability to hope or just to have some?

Dario: Yeah, to have any kind of hope. Uh…they seem too regimented, you know…closed-doored on their mannerisms and their treatments. They don’t really give you that ray of hope at the end. You know, ‘Listen, yeah, you’re serious, you’re a bad case…but you know maybe …you know – there’s that hope – you know maybe we can help you’

Alyson: So as a patient you find you are kind of struggling to hold onto that

Dario: Yeah, yeah

Alyson: But you’re not really getting any help

Dario: Yeah, for me as a patient, without hope – you’re doomed. If you know you’re toast, well what’s there to live for? Right? So you always want that ray of hope you know maybe… is it 5%, is it 10%, is it 2%? Well, you never know, maybe you can be that lucky one

(Later on in the interview)

Alyson: So you’re saying even if it was small, you’re just – you need a little space for that or you need to have ---

Dario: Yeah, yeah

Alyson: To be allowed to sort of have a ---

Dario: Yeah, you realize that – you know, hey, the odds aren’t good.

Alyson: Right

Dario: But I mean, you know…some kind of hope. I think everybody holds onto that

Alyson: I think it’s human right, yeah
Dario: It’s what I feel anyways

Alyson: But you feel like you’re not getting a lot of help in sort of holding onto it here

Dario: Yeah, yeah, I really think that here is an awkward place, you know kind of thing. They don’t give you that…ray too much

When I asked him if hope ever came up in his conversations, he replied:

No, it’s never come up with them because since they told me, I don’t really pursue it anymore, right? I just try and take it…I’ve always been told your mental train of thought I guess is a big thing towards…carrying on…with this disease, supposedly. So I try to stay as positive as you can

Dario struggles to “stay positive,” along with his wife, who he confides to me is “incredibly anxious” every time she sets foot in Lady Ann’s. Trying to hold onto his ‘hopeful plot’ is an act of recovery – of what has been “take[n] away” from him by his medical care providers.

Frustration with not being ‘allowed’ to hope or to imagine a positive future was also reported by Deo. In a fieldnote above, I documented how Deo was resentful one day that a medical student took pains to remind him that his disease, though temporarily controlled, would “come back.” He found that whole incident highly offensive. A few weeks later, I asked him about it in an interview:

Let’s come to the point. When the fellow is going to come to the waiting room and he’s also impressed with my results and he’s nodding his approval. Scans are showing decrease in tumours and so far and almost at the end of that nice conversation, that little ray of hope that little ray of sunshine, that is coming through the ceiling, because your life is somewhat dark and dismal – not many people know that, you don’t show it – so that little ray of encouragement and light comes and then this fellow is going to stare at you in the eye and say that ‘Mr. [Deo] - let’s not get too – whatever word he’s going to say – ‘let’s not get too carried away. This disease is going to come back.’ And he stated it very matter of factly, like he knows this. Like this was embellished in steel or gold or whatever – however the saying going. He even raises his body off of the chair and comes a little bit closer (he is miming out, his voice gets closer to the microphone) and he says, ‘Did you hear me? This disease that you have is going to come back.’ And then he tries to qualify that by saying ‘when it does, not if it does, when it does, we must be prepared – physically. We must be ready to start fighting again.’

Now, that may be so. And perhaps that is so. But to the patient, it is from a high to a down. It is almost to your mind and the power of positive thought has been destroyed, damaged. That to my mind is unnecessary. Totally unnecessary. Because if he’s telling you that, what hope? He has no confidence in himself, he has no confidence in the system? Whatever chemotherapy can do, whatever therapy can do for this disease must be lauded and applauded, to the utmost degree. It is all there is.
That’s all they’ve got. And if it works, even slightly, there must be kudos and hats off to that. But you cannot tell the patient, ‘Don’t rest on your laurels. This is going to come back.’ It makes absolutely no sense. You’re putting – it’s like you’re breaking the ladder and allowing the patient to fall flat on the ground. And that has happened to me twice. And in both occasions, I resented it.

Here, Deo also refers to a ‘ray of hope’ as a potentially powerful tool in helping him to cope with his disease. Both Deo and Dario’s narratives demonstrate that the ‘hopeful plot’ is so powerful, that it requires very little to maintain it; according to Dario, even a 2% chance is a potential ray of hope for him. Deo also describes a “little ray of encouragement” and how hearing that he was doing well on his treatment helped to alleviate the “dark and dismal” state of his everyday life. Both men speak to the real challenge they have in accepting the certainty that the disease will come back, a message that, in Deo’s words, seems “embellished in steel or gold.” They reject the kind of emplotting that their oncologists are providing, and they try to reintroduce uncertainty into the equation. Because in the world of incurable cancer, uncertainty or ambiguity allows them to forward their ‘hopeful plots.’

In both narratives, the men’s sense of frustration and disappointment are evident. Simpson (2004) writes that in order to have hope, a person needs to be able to see an outcome as a “realizable possibility,” even though it is uncertain whether or not that outcome will occur. Simpson draws on the work of psychiatrist William Lynch, and describes how important it is to be able to imagine “different possibilities for the future in order to be able to hope” (2004:434). In both Dario and Deo’s comments, we hear them struggling to imagine a different future than has been predicted for them. In order for them to maintain their ‘hopeful plots,’ they need to be able to see living through their disease as a “realizable possibility.” In their earnest yearning for a “ray of hope,” we see how impossible it is for them to live only in the ‘realist plot’ – in a truly ‘hopeless’ condition.

Moreover, the men’s sense of isolation in their plotting is palpable. Simpson (2004) argues that patients cannot maintain hope alone, and that they need their health care providers to support their hopes. Both Dario and Deo want their physicians to support the stories they emplot, which “requires developing a shared, and subjunctive, narrative of hope” (Mattingly 2009:260). Contrary to feeling like this aim has been fulfilled, they provide powerful images that suggest they feel that their doctors have confined them to a single storyline: the one that leads to death. Dario describes what he sees as an intentional ‘witholding’ of hope on the part of his oncologists. Deo provides the metaphor of the “ladder” being kicked out from under him, allowing him to
“fall flat on the ground.” Rather than feel supported by their physicians in their ‘hopeful plots,’ they feel that they must do all the work themselves to keep that narrative alive.

As renowned scientist Stephen Jay Gould famously wrote in his often-cited essay, *The Median Isn’t the Message* (1980), patients naturally look for the hopeful forecast in their futures. After being diagnosed with peritoneal mesothelioma, which had a median mortality of 8 months, Gould examined its survival graph. He knew it would be skewed to the right, because the right side of the median would account for all the people who lived longer than 8 months (i.e., from 9 months to several years), where to the left of the median would only account for those who lived from 0-8 months. Gould chose to situate himself in that long tail on the right side of the median, which extended several years longer than the 8-month median. Paul, Dario and Deo all plot towards that possibility as well. They see that plot because they must, in order to go on living each day with some sort of hope. Thus, it is possible to see in Paul’s three plotlines, and Deo and Dario’s “rays” of hope, the fodder for their ‘healing dramas’ (Mattingly 2009:260). As Deo said to me in the same interview, “There is no false hope. There is only hope.”

But oncologists too must sometimes engage in sustaining the ‘hopeful plot.’ Whereas, sometimes I observed doctors responding to a lot of optimism with a dose of realism, at other times, I observed oncologists responding very well to patients’ optimism. I remember watching Dr. Girard interact with Laura, a patient she knew well, who always said positive things. She said to her, “You are my optimistic patient.” As Laura spoke about her hopes for the future, Dr. Girard smiled, looked at me and Laura’s social worker, and joked, “The eternal optimist, eh?” She seemed to be energized from Laura’s positive plotting for her future. In a later consultation, when it came time to talk to her about the end-of-life, Dr. Girard struggled to break down her wall of optimism as sensitively as she could. Similarly, when Dr. Girard jokes with Melody, “You’re not dying!” she seems to be saying it just as much for herself as for Melody.

Also, recall Mary’s story where we started. Dr. Lawson’s words to Mary were: “We have to have realistic goals – for you and your family and for the team here.” Although she refers directly to the ‘realist plot,’ a more ‘hopeful’ plot is indirectly referenced, in addressing that her staff need to be able to keep coming to work everyday. In a lung clinic focusing on stage IV disease, her team members could quickly become despondent if they saw every lung cancer death as a failure. Thus, although oncology staff live in the ‘realist plot,’ they too hope for the best for their patients, and for the unrealistic plot twist that will lead them back to life.
III. Intersections of the ‘hopeful’ and ‘realist’ plots

Plots do not always develop the way they seem like they will. Sometimes there is a sudden change in the narrative as new information or new situations must be dealt with. In this section, I use fieldnotes from one day in the Gyne clinic where I sat in on a ‘bad news’ conversation with Isabelle, one of patients I was following longitudinally, who was coming that day for the results of a recent CT scan. I use this example to demonstrate how easily doctors and patients shift between the ‘hopeful’ and ‘realist’ plots – even within the same consultation. The shifting discourses occurred in this interaction because the information that Isabelle was not doing as well as they expected came as a surprise to both Isabelle and Dr. Girard. This observation also reveals that bad news conversations do not emerge out of ‘ideal’ clinic conditions, but rather unfold in the everyday life of a busy oncology clinic, and that both doctors and patients must work to hold onto their driving narratives in dealing with surprise plot twists and turns.

On that day, the doctors and nurses in Gyne had many patients to see in addition to Isabelle – 21 on the morning clinic list. There was also a lot of other non-medical business happening. The clinic had been painted over the weekend and each new staff member who came down the hallway had something to say about the choice of colour (often not positive, like the doctor who said that the chosen colour of green reminded her of the TB hospitals from the 1930s and 1940s). Dr. Girard, who had helped to choose the colour, quickly grew tired of this negative feedback, saying, “I don’t want to hear it.” Dr. Girard had a medical student, an associate doctor, two staff nurses, as well as the visiting anthropologist, who all required her supervision. She still took time to go through her list and talk to me about potential recruitment of 3 patients.

I had met Isabelle, a 64-year old woman with metastatic ovarian cancer, about 3 weeks earlier and had sat in on an appointment with her then. Since that date, we had met up once for an interview. In the course of the interview, when I asked her if the doctor had explained to her the diagnosis, Isabelle replied, “Yeah. She explained. I didn’t ask details. I didn’t want to know details,” and also, “She [Dr. Girard] seemed to be very positive about what was happening.”

And um…that um usually 65% of the women react very well to the chemo, and then the surgery and the chemo again. And so many you know more or less, and then only a small amount not. And um…so that was nice (voice starts to waver)...and uh, to hear...that uh, that the odds are kind of high (voice wavering).

I remember that upon hearing this, I thought that perhaps the odds for ovarian cancer were much better than I thought they were, and that maybe Isabelle was not as sick as I thought she was.
By the time Isabelle arrived for her appointment that day, it was past 11 am, and the clinic was in full steam. I had already observed one session in which Dr. Girard spoke with a woman whose first language was not English, accompanied by her daughter. She had to counsel the daughter about the appropriate age to get a preventative hysterectomy and mastectomy, since she had tested positive for one of the genes linked to ovarian cancer. The mother was upset, was crying a lot at home, and agreed to have a referral to the psychosocial oncology team. I had only sat in on this one session, but by the time Dr. Girard got to Isabelle, there had likely been other challenging conversations. I went out to greet Isabelle, that day accompanied by her husband Derek and her son, and brought them into a consult room.

Once in the room, I ask her how scan was. I joke that it must have been quick, because she was gone by the time I came back with the photocopy of her consent. She is very pleasant. She looks good and I tell her so. She says thank you. I remember that she didn’t have a contact form for the clinic and ask the nurses for one on the way in, and then take it in the room. I also get her a glass of water – room is hot, which I point out. I leave the door slightly open after returning with the water, but then pull it shut because I fear they will overhear something – about scan or about someone else, before doctor goes in.

It’s 11:30 now, and in the clinic fairly quiet, about 1 hour behind. I note that Annie [one of the Gyne nurses] has just brought a patient who is by herself into room 9 (the room next to Isabelle’s) who seems kind of stressed and unhappy.

As Dr. Girard is getting ready to go in to Isabelle’s room, she is flipping through the chart (standing mid hallway, in front of the door to the supply room), saying something about how she has not consented yet to surgery and that we should do that today. I say I have already said hi, and that Isabelle is here for CT results. Dr. Girard starts looking at the sheet with the CT report and stops and goes and puts the chart on Annie’s station and reads more carefully. She says something like “Progression? Oh no – it’s not looking good,” and reads through the note more carefully, picking out details from the report. It does not seem very positive. She asks Jo [Gyne nurse] for a CA125 reading from last time – wants to see the trends. It seems to be going up – from 300 something in December to 425 today. Also says the stent is not doing well and will have to talk to [stent Dr.] about that. She says to me, “This isn’t going to be a happy conversation” and takes a deep breath as we go near the door. I ask, “Do you want me to stay out?” She says, “No, come in,” and we go in together with Jo.

When we enter the room, I take my seat in corner. Dr. Girard asks, ‘How are you doing’? There seems to be some water on the floor and she starts wiping it up with a paper towel underneath her foot. She seems kind of distracted, or like looking for a temporary distraction.

Isabelle: ‘I’m feeling anxious, very nervous’

Dr. Girard stops wiping up floor and goes to sit at the desk, starts looking at the report. She starts with her CA125 marker.
Dr. Girard: ‘We’ve seen little change in your CA tumour marker – but it is not great, but not too bad either.’ In lungs, nothing specific. What is a little concerning is the CT of your abdomen. We are going to need to talk to [stent Dr.] about your stent – wanted to see the scan first and decide what to do, but we will get a hold of him (she seems to be stalling, not getting to the point). (Now looking down): ‘Compared to Dec 14th CT scan, the overall picture is not better (looking up at her now).

Isabelle looks shocked.

Dr. Girard: ‘From water collection point of view’ seems to be better, eating better, etc. ‘But when look at deposits of tumour, they are bigger than they were before’

I notice that Isabelle’s husband is holding her hand.

Dr. Girard: ‘Looking at surface of bowel, near the liver, eroding into the bowel 4.3 in diameter, used to be 3.7. We would expect the opposite. The bowel has deposits on the surface that have grown. Cancer near the liver doesn’t seem to have changed. But the Radiologist is calling this progression. ‘When I look at you, I’m quite surprised’

Isabelle: ‘Me too’

Dr. Girard: ‘How we go forward – I think we should operate and see what we can do. May require bowel resection, will have a general surgeon available in case that happens on the day of surgery. I think this is the ‘safest way of going’ not focusing on the pelvis, but not looking optimistic.

Isabelle: ‘I’m so surprised’ because I feel good

Dr. Girard: I’m surprised too. Usually I can tell patients are not doing well. These scans are ‘hot off the press’ – we don’t have time to review ahead of time, I just looked at these scans before coming in the room. Unless you say you are not well enough? (for surgery I think, implied). Maybe these deposits of tumour on the bowel, maybe we can shave them off. Want a general surgeon involved, because if I need to do a bowel resection they are the best to do it.

Isabelle asks what he would do and Dr. Girard explains, using her hands, passing them over her stomach area.

Dr. Girard: ‘This is not quite what I was expecting’ (she also seems a bit shocked)

Now there is a long exchange between Isabelle’s son and Dr. Girard. The son asks questions about whether the cancer is actually stomach, like they first suspected. Then there are other questions from the three of them about whether the chemo was the right chemo, and why she would be feeling better if things are worse, including statements from Dr. Girard like, ‘Physically you are much better than you were when first met you.’ Dr. Girard advises that they should go ahead with chemo this week, since ‘for some patients, there is a delay in chemo, it kicks in around cycle 4 or 5. So should plan to have chemo this week – 4th one.’ As the discussion about
the upcoming surgery, now more complicated than they had predicted, comes to a close, Isabelle asks:

Isabelle: Is there any hope?

Dr. Girard: ‘We need to see what happens at time of surgery. If we can resect, then it comes back to chemo.’ ‘Think it’s a bit premature to say that’

Isabelle: ‘I feel as good as I did before’

Dr. Girard: ‘I am surprised. I have to be realistic, let’s pursue with chemo this week’

They talk a bit more about the upcoming surgery, with Dr. Girard going into ‘standard’ type of speech re: surgery description.

Dr. Girard: ‘Let’s keep our fingers crossed. Don’t want to be pessimistic, want to be realistic.

(Looking at Derek and son and Isabelle): Do you have questions before I get her to change (for her exam)? Derek and son say no, so Dr. Girard and I go out of the room.

She gives me a slow wink on the way out – not a ‘happy’ wink, more like a recognition of what just happened in there.

I notice I am visibly shaking as I am standing in the hallway. I go over with her for a second to Annie’s station, and then to Jo’s, where I am writing, but my hands are shaking.

Derek and his son come out of the room. I ask Derek if he wants to wait and he kind of turns and shows me the money in his hand (parking). Son smiles and says, ‘Bye’ to me and walks his dad down the hall. As they go through the big door, I can see him rubbing the back of his dad’s neck.

I notice that Dr. Girard has gone immediately into the room beside us, and can hear her saying her greeting, just has to jump from one to the next patient. When she comes out of room 9, she has to deal with questions from the associate doctor about another patient. Then the patient coming out of room 9 (the one I noticed before looking annoyed) asks her a question in the hallway. Dr. Girard seems distracted, is trying to go back into Isabelle’s room, to do her physical exam. She says aloud, ‘There are too many things are going on at once.’ The patient from room 9 is asking her about a polyp that was removed, and she advises her to call the doctor who took it out, saying it could be in scanned documents so doesn’t come with the physical chart. She still takes time to answer her even though she is being bombarded with questions.

Derek comes back down the hallway looking completely lost. He tries to go into 2 different consult rooms before he gets to us – these rooms have doors open too. I grab him and say his name and put him in front of the right door, thinking it is like he is blind, can’t see.

Jo is getting ready to go in and describe the surgery. When Dr. Girard walks by she says ‘You should go in and sit with them Alyson.’ So I go back in with Jo. Now very ‘standard’ teaching re: surgery. Can see it in her presentation. I don’t take too many notes. Nurse is going over forms and where she needs signatures. When she is done, she says, ‘We are waiting for the chemo appointment from the front’ and leaves the room.
I am sitting awkwardly on the corner stool. Once she leaves, I say, ‘I can go now if you two would like some time alone, I don’t need to be here.’ Derek says yes, okay.

I feel like I can’t leave without saying anything. I go over and grab Isabelle’s hand and she clutches mine tightly and I say, ‘I’m so sorry,’ and am holding back tears. She breaks slightly and almost starts to cry – this is the first time that happened in the appointment. I can’t remember what she said afterwards. I say, ‘I think everyone is surprised, Dr. Girard seemed very surprised.’ ‘I know I just talked to you last week. I know this was not the news you were hoping for today.’

Isabelle: ‘I was so sure I was going to be cancer free’

I hold her hand for a bit longer and she says ‘Well, it’s not over yet’ and I say, ‘Yes, you have some things to focus on’ (not sure if I say ‘for now’ – really hope that I did not). And Isabelle says ‘Yes, surgery and chemo.’

I awkwardly put my hand on Derek’s knee as I leave as I feel the need to acknowledge him as well and then go stand in the hallway, where everything is proceeding as normal. I find it hard to believe that the world hasn’t stopped moving, as it certainly felt like time had stopped. So strange that everything is going on as ‘normal.’ Still no chemo appointment. Dr. Girard’s secretary shows up and goes in the room to sign the forms for surgery and then comes out. I go to the front, no chemo yet, but I think it has been scheduled when I come back. Jo checks again and it is in the system this time. The door opens and Isabelle and Derek come out. I tell her ‘They have your chemo and they got it for Friday am.’ She is pleased about this (was concerned earlier when they said there was no booking. She said it should be this Friday because that would be 3 weeks). I say, ‘I will see you soon’ as they leave the unit.

Later on, I overhear Dr. Girard say, ‘I’m just getting killed today with a busy clinic’ and something else. She pokes her head out of a room at one point and calls for a nurse to come and assist her – needs supplies. Jo says, ‘She’s just in a grumpy mood.’ I leave shortly after this.

Isabelle’s story illustrates how a ‘bad news’ conversation can come as a surprise to both patient and doctor. Rather than something that is carefully planned or deliberately staged, bad news turns up all the time in an oncology clinic and it is the doctor’s job to convey that news. This causes a shift to the plot. You see from Isabelle’s comments to me afterwards – “I was so sure I was going to be cancer-free” – that this was not the outcome she was hoping for or the next element in the plot she was building for herself. Dr. Girard’s comments throughout the session reveal that she knew she was dealing with an advanced cancer, and yet she was also surprised by the CT results. She was also convinced by the patient’s physical presentation that things were going better than what the scans reveal. So this new plotline must now be dealt with: now she must explain a more complicated surgery than the one she had been planning for, and she must be honest about the possibility that the treatment may not be working. For Dr. Girard, there was no time to plan for the kind of conversation she wanted to have; she saw the results and
had to go into the room because she had more patients waiting to see her. For Isabelle and her family, there was no time to plan the kinds of questions they wanted to ask, since they had come to that appointment hoping for a much different outcome. Both parties then are responding to this sudden plot twist on their feet, and struggling to accept this new information and to figure out how they can move forward from this point.

The story shows that in spite of this news, Isabelle struggles to maintain her ‘hopeful plot’ (“I feel as good as I did before”; “I was so sure I was going to be cancer free”). In reaction to these comments, Dr. Girard tries to reinforce the ‘realist plot’ as gently as she can – by showing her genuine surprise at the news as well, by focusing on small details that are descriptive of “progression” (the changes in centimeters in the radiology report). Mattingly (1998) describes one encounter between Lin (a therapist) and John (a patient with a spinal cord injury). She says that John and Lin “tell different kinds of stories. Lin is more often the voice of hope and John the voice of despair. Yet it is not that simple” (Mattingly 1998:126). Here, Isabelle is more often the voice of hope, and Dr. Girard is more often the voice of despair. But as in Mattingly’s case, it is never that simple. When Isabelle falters in trying to hold onto her ‘hopeful plot,’ (“Is there any hope?”) Dr. Girard picks up the cue and takes the torch (“I think it’s too early to say that”). She refocuses Isabelle’s attention on the things she can do – the upcoming surgery, her chemo on Friday that is going ahead as planned. Doctors sometimes manage to emplot for hope by asking patients not to look too far into the future, as Dr. Girard does here. As I show in Chapter 5, this is well-intended advice, and works in the moment for the consultation, but it has longer term consequences on patients’ time horizons.

IV. Sub-plots: the ‘treatment plot’

Sometimes certain ‘sub-plots’ – plots which develop in relation to the primary ‘realist’ and ‘hopeful’ plots – contribute to how well those two primary plots can be sustained. In this section, I argue that the overarching focus on treatment in oncology serves to muddy what was a clear message of incurability. The patient thinks: there are treatment options; I am not yet dying. The oncologist thinks: there are treatment options; they may help to delay death or improve her quality of life. The oncologist wants to hope that the treatments could have a more enduring effect and improve the patient’s survival, but this is not the outcome she has been taught, through her studies and her clinical experience, to expect.
Each time patients and their families come to the hospital it is with intention: whether it is for a consultation, a treatment or a test, each has the potential for something to go wrong (Mattingly 2009). This means that each trip to the hospital holds significance. Consultations are especially nerve-wracking: if patients are on treatment, they wait with trepidation to hear whether their bloods will be “good enough” (i.e., platelets and white blood cells are at sufficient levels) to receive chemo that week; if patients are on follow-up they wait to hear whether their recent scan or other diagnostic test is showing that they are still clear and the cancer is stable.

Sitting with Paul outside the lung clinic one afternoon, chatting as he waited to be called in, I asked, “You are on 2 month follow-up, right?” He replied yes, and “it was a treat.” He said that it was “great” to be able to walk out of the clinic with “2 months” ahead of him. But his anxiety went up as his “2 months” started to run out, and it got closer and closer to his appointment time.

This means that each consultation provides a key point in the story, and the story that is being told is often about treatment: if you are not on treatment yet, then it is about the possibility of treatment; if you are on treatment already, then it is about whether you can get your next cycle; and if you are off treatment, it is about when you can start again. Even when there is no treatment to offer, the ‘treatment plot’ may still constitute the focus of the conversation, as in the following example. Olivia, diagnosed with a low grade ovarian cancer in her early 20s, had recurrence at close to 30 with a much more aggressive disease, and recalled this conversation with her oncologist:

He basically said to me, ‘There’s nothing to treat you with. We’ll just follow you….um, yeah, this will eventually kill you. I have some patients who’ – cause one of my friends, I had two people with me, and one of them said, ‘Is she going to die?’ ‘Um,’ he said, ‘Yeah, this will kill you eventually. Um, can’t say when. I’ve had some patients who’ve been living with low-grade cancer for 10 years. I mean the problem is that at 30, 10 years doesn’t really seem like much.’

So having “nothing to treat you with” here constituted the focus of the conversation, obscuring other topics that could have been covered in more depth. Notice that it is her friend that introduces the question of death into the conversation. The doctor does address it when it comes up, but through the lens of realism. He states the problem with this kind of cancer and its history of ambiguity. But he does not relate to her in way that shows he is thinking about how this message might be perceived by her. Where is the space for hope in such a declaration? In focusing on the ‘treatment plot,’ he references the ‘realist plot,’ but makes no rooms for Olivia’s ‘hopeful plot.’
So much in the hospital is focused on what can be done, and oncology is a prime example of this general tendency in medicine. At a research talk at Lady Ann’s, the speaker shared this joke, “Why do they put nails in coffins? To keep the oncologists out!” and the room full of clinicians and researchers erupted in laughter. One of my field notes, 3 weeks into fieldwork, captures my amazement at seeing so much focus on treatment, as well as my questioning of whether or not I was getting people with metastatic disease, since very few of the patients seemed to be acknowledging that they had an incurable diagnosis:

Feb. 22/11. One thing I am thinking about is how strange and almost unbelievable it is that all these people I have recruited have advanced disease according to their primary physician and yet none of them are focusing on that. Except Melody maybe – but this is her 3rd time having cancer. All are focusing on treatment. Even I can’t focus too long on the fact that these people are all not well – hard to believe they could have short prognoses. Have I recruited the right people?

I sat in on Elizabeth’s first meeting with Dr. Girard in July 2011 after surgery to remove her ovaries, and noted throughout the conversation that the push towards treatment was very strong. Dr. Girard told Elizabeth that her ovarian cancer was of “serous” cell type, which could be high grade or low grade, which had to do with the microscopic look of cells – “how aggressive cancer cells look.” She told her that her case had been brought up already at the tumour board:

Dr. Girard: High grade – cells are bizarre looking. Low grade ---

Elizabeth: (interrupting) That’s better, yes? (smiles)

Dr. Girard: Better? Yes and no. I will tell you. When we have serous cancer we almost always think about chemo. With low grade we know they respond not as well. In our experience, low grades are sometimes harder to treat. Having said that – you now have disease not isolated to 1 ovary. There are 20 people in a room – we had a discussion – should we treat with chemo as would standard serous high grade? Group is divided.

Elizabeth: (jokingly) Sounds like a special ed team. (to me) I’m a teacher.

Dr. Girard: The bias is – treat you. Some people worried about putting you through chemo if we are not sure it will do it [i.e., take away disease]. When I have a patient who is not that aggressive, I say, ‘we have to be aggressive’ – that’s my professional role. The flip side is now we have microscopic disease. But the majority are saying – I think we should try. You may say ‘let’s try.’ We asked our fellows to review the literature. I will give you the benefit of that discussion. But my feeling is we are heading to chemo.
Elizabeth asks a question about the chemo that I miss. Dr. Girard replies and says they know the chemo will circulate and get cells that float around.

Dr. Girard: If you want my bias, we would treat you.

Then they have a long discussion where Dr. Girard explains the kind of chemo she would be getting and its standard symptoms and side effects, and about getting tested for genetic predisposition for ovarian and breast cancers. As part of that conversation regarding genetic testing, Elizabeth says, ‘My attitude is I’ll do what I need to do.’ As the conversation wraps up, Dr. Girard comes back around to the question of the plan for Elizabeth:

Dr. Girard: I’d like to do the booking today [for chemo], but you can have a change of heart. You can contact Annie [Gyne nurse] for information. After the group discussion on Monday, I will call you.

Elizabeth: At this point, I’m all for doing whatever it takes.

Dr. Girard: If I were in your shoes – you didn’t ask me that but I counsel my friends – ‘If you were my sister, I would say, ‘You’ve got to do it.’’

This encounter exemplifies that at this moment the patient and the oncologist are a perfect coupling: oncologists are very good at giving treatment and finding something that ‘can be done’ even in very bad cases of disease, and patients very much want to receive treatment. As Mattingly (1998:107-108) cogently argues, therapists are driven to create compelling plots because of “a need to locate desire.” They must offer a new life direction to patients, because “old directions are no longer intelligible” (Mattingly 1998:108). In this story, the new “direction” is treatment. Dr. Girard takes the lead on emplotting the “desire” or push for treatment, but Elizabeth is very willing to follow that lead. She was glad to be offered something ‘to do’ in the face of this (albeit slow) growing cancer. You can see from Olivia’s comments above that having “no treatment options” is devastating for patients. Dr. Girard does not avoid the realism of the disease; she confronts very readily that other oncologists at the tumour board were not in agreement that treatment was the best option. But it might be easier in the abstract, when confronted with the ‘science’ of the disease, to suggest no treatment. It is a different matter for the oncologist who has the patient in front of her, and knows that the story of cancer is not just limited to its science. She must try, as Mol argues (2008:49), to be honest with the information and yet to allow some room for hope. She does this by leaning heavily towards treatment and finding that the patient easily follows her down that route. So she has provided a narrative with two possible plots: one where the treatment will work and one where it will not.
The challenge then becomes if conversations in oncology are always about treatment, when is it okay to shift the focus? Both patients and doctors want to concentrate on the action and the ‘fight’ against the disease. Although two sub-plots about treatment are being advanced here, I think that patients believe that the treatment plot points toward recovery (The et al. 2000). If they do not believe it rationally, then they very much hope that this will be the case. But oncologists might be thinking differently. After that appointment, I stood with Dr. Girard in the hallway and she noted to me that Elizabeth had a “good attitude.” I said yes, and asked if it were likely she would not do well. I asked the question finding it hard to believe that that could be true, given how healthy she looked. Dr. Girard replied simply, “That’s the way the disease usually goes.” So the focus on treatment may preclude or eclipse a lot of other conversations from happening.

IV. Sub-plots: the ‘care plot’

The ‘care’ sub-plot concerns whether or not patients feel that they are being ‘cared for’ and how the presence or absence of care relates to sustaining ‘hopeful’ or ‘realist’ narratives. Mattingly refers to the doctor’s role as the “messenger” position, due to doctors’ specialized training and ability to translate medical tests and other information about the sick body for the patient. She says, “how important it is to trust a messenger who journeys to such hidden places and who has the power to decode the mysterious texts he returns with” (Mattingly 2009:266). I asked most patients that I interviewed if they felt that someone was in charge of their care. Initially, I thought this was a pointless question, since it seemed very obvious to me that the oncologists were ‘running the ship,’ so to speak. To my surprise, although a few people did identify the oncologist as that person, just as many others said ‘no one’ or identified themselves or someone else (a G.P. in one instance, a spouse in another) as the person in charge. My conversations with patients suggested that when they felt the presence of a ‘care plot’ – meaning they felt ‘taken care of’ by their medical team – it had the ability to buffer any negative experiences they endured at Lady Ann’s. Conversely, if the ‘care plot’ did not materialize in their daily interactions at Lady Ann’s, they were left feeling as if no one actually cared about what would happen to them.

When I interviewed Norma in the summer of 2011, the ‘care plot’ was a central theme in our discussion. I had not even gotten to my question of whether someone was ‘in charge’ of her, when I felt I already knew the answer, because everything she had said so far about Dr. Girard,
her nurses, the Gyne staff, and Lady Ann’s in general, was qualified as “so great.” She recounted her first day at Lady Ann’s, and how a volunteer had escorted her to the Gyne clinic site, quickly alleviating her initial sense of being lost. From the moment she met Dr. Girard, she had liked her and found her to be both professional and caring. On that first day, Dr. Girard had “tapped her” – using a technique called paracentesis, Dr. Girard had removed 5 litres of fluid that had accumulated in her abdomen due to ascites caused by the ovarian cancer. This procedure provided Norma with much needed relief from pain and discomfort. She said she remembered thinking, “Oh my God, that doctor is so great.” A second event that impressed Norma was that Dr. Girard had been able to confirm the presence of cancer cells by giving special instructions to the laboratory, which had produced an inconclusive result when they first tested the fluid.

She said she told them to do every bottle and to shake the bottles. Shake the bottles all up. So she really had to – she was really the authority. That was really so good.

Another time, Norma had to visit the ER in a different hospital in Lady Ann’s network, and Dr. Girard had called over and insisted that they not do the CT scan they were planning to do. Norma recalled, “Cause I was telling them, ‘No I don’t want to do it, because I just did one’ but they didn’t listen to me. Luckily I have my boss – the oncologist – and then they listen to her and they never let me do a CT scan.” The last experience that cemented her feelings about Dr. Girard was her surgical experience. After her surgery, she had to stay in hospital for 5 days, “And every single day that lady came. Oh my goodness. She covered 5 days. Every day she came. Just to check up, see what’s happening – see if I pass feces, if I pass gas, and then she told them to give me a suppository or and whatever. But she came every single day.” Norma repeated this sentence 6 more times, clarifying that Dr. Girard came at different times of day, but still came every day that she was in hospital. It was obvious that these daily visits made a lasting impression on her.

Alyson: So that was important for you. Just to help you feel like…?

Norma: Yeah (smiling). Yes. It was good. Every day she was there. And ah… You know what I like about the clinic, too? Like sometimes it’s the physical – you know you have to take care of the physical. Because just like – they just make you feel so happy. And tell you look nice, “Oh my goodness, you look so good today!” I think that emotional – building up you emotionally – ‘cause like when I came and I was really pretty – I wasn’t physically like that sick because the cancer had just started. It wasn’t like stage 3 or 4 – it had just started. Because she had said to me, “[Norma],” Ovarian cancer is in the making.” Like, in the making?
And but like, it’s just – you know they are so encouraging! You know, they are always so cheerful, always smiling. “Oh, you look so good today!” And these little things really help you – I think it really helps in the healing process.

Alyson: Yeah?

Norma: Build you up emotionally. Yes, I think when you have cancer you really feel down. You can really feel down and out, and depressed, and you know what I mean? You can’t heal that way. So just little things can really I think encourage you, and help with the healing process, emotions.

(I mention that she always does look nice when she comes. In fact, I had just said to same thing to her last week.)

Almost every time you come, she’s [Dr. Girard] always that little compliment. That little (snapping her fingers) You know like, some doctors, they are just like doctors – and they just do the physical. But you know, just those little comments, I think they are really so amazing. I think everybody down there is really so great. I remember the first or second time, this nurse, she told me she had cancer. She said “[Norma,] if you are sick, if you have cancer, this is really the place to come for treatment.” And I’ve really found that out. From when you step in, and just like everywhere from the volunteers, when you go to do your bloodwork, when you go to do pharmacy, and when you go up to chemo, it’s just the teamwork, it’s everything. I think it’s just a great place to be, as the nurse said. If ever you have cancer (laughing) – you don’t want – this is really the place to be. I think they are really super at just taking care of you really so well, physical, emotional, just being so helpful.

The presence of a ‘care plot’ shines through in Norma’s story. Notice that these long sections of positive comments are offered up, without provocation by me, and directly follow her story of Dr. Girard coming “every single day” post-surgery. She clearly feels cared for not only in “the physical” sense, but also in the “emotional” sense as well. Her feeling of trust in and respect for Dr. Girard, her primary caregiver, permeates everything else that happens to her at Lady Ann’s, and these are exactly the things that help Norma “to heal.” Of the patients I interviewed, hers was the most positive one I recorded. She simply could not say enough about how much she appreciated the care she had received. This overall feeling was reflected in her answer to my question at the end of the interview about whether she could describe for me the ‘culture’ or ‘atmosphere’ she felt at Lady Ann’s.

To me there is a culture of care. You know a culture of just wanting to help you get well. I think it just gives – to me, all the doctors, all the nurses, they are not just here for money. I get the feeling that everybody love what they are doing. Honestly, that is just how I feel. Sometimes my friend and I, we are just at awe at this place. We just talk about it, and we are always saying, ‘Man, really, if you don’t like people, don’t get into like nursing.’ Like here, every single one of them you can see –
honestly, I can definitely see, in 98% or more, it’s not about the money, it’s really just about caring for people.

Cause sometimes I’m here for chemo, after they take one hour to poke this thing, 5 hours is gone, it’ll be like 6 and so, and that poor little nurse is there with me, not really fussing, yes, still there with me until everything is finished, 5:30 or whatever. So you can really see that culture of care and concern, and you know it’s not about money, it’s about taking care of my patient. You know what I mean? You get the feeling that it’s not just a patient, it’s like ‘my patient’ – you know?

Contrary to Norma’s story, the absence of a ‘culture of care’ or a ‘care plot’ was a central theme of my interview with Paul in May of 2011.

Paul: So, I meet with her but the very first thing she says is “I’ve reviewed your file and you’ve got – the reason – the first thing they discovered was your rectal cancer, but that’s not what’s killing you. What’ll kill you is your lung cancer. So that’s what we’re going to treat (makes a wiping out sound) – forget that. Don’t even think about it. Don’t want you to think about that – we’ll deal with that one day. First we’re going to deal with your lung cancer and your potential bone cancer.’ My reaction was, ‘ok’. She says, “From now on, I’m the quarterback.”

Ok and now here’s Paul’s editorial comment about that. Yes, she said ‘I’m the quarterback’ but you know what? Now that I think about this, in preparation to talk to you, I never had a coach. And if you know anything about football at all, the quarterback runs the offence and has very specific things to do about one part of the game. Just like she had something to do about thorax. But, she – the quarterback doesn’t worry about the overall health of the player or the overall game. The quarterback only tries to drive down the field. They’re not an expert in defense at all.

Alyson: (interrupting) Nothing with defense?

Paul: Nothing to do with defense. So what I go was when she said ‘I’m the quarterback’ I immediately went, ‘Ok, this person is completely in charge of everything, of me.’

Alyson: Like a coach?

Paul: Like a coach. And I superimposed coach on that myself. And now that I think back on it, I’ve never had a coach. Closest I’ve had to a coach is my G.P. and he’s…not enough of a specialist in anything, to really be a great coach. He’s a better listener and he’s more of a wall to bounce things off of rather than – nobody’s really given me any advice, really.

So anyway. So I wish I would have had a good coach. I mean Sue [his wife] has been my best coach throughout all of this and it’s only because she’s been through it. Had she not been I’d be in more of a mess…I’d be in a mess, mentally. Like I really rely on her. ‘Cause if she doesn’t know, she’ll find out. And she’ll inform herself and then she tells me what I need to know or pushes me in certain directions. So she’s been my coach in all of this.
As Paul reflects on his first meeting with his oncologist Dr. Lawson, he articulates well the sense of not feeling like someone was in charge of his care, which he refers to here as a “coach” position. Mattingly writes of the therapist as helping to shape the session; she says there is a sense “of teamwork, of patient and therapist being part of the ‘same story’ which is still unfolding, one neither have tremendous control over” (1994:257). Paul’s account reveals a lack of teamwork. When patients like Paul do not perceive a ‘care plot,’ it gives them an added responsibility to make sure they are keeping on top of what is going on.

‘Patient-centred care’ is one of the current buzzwords in hospitals, and Lady Ann’s is no exception. We want the system to be organized in such a way that it best serves the patient; however, I have heard both staff and patients express frustration with this concept. This idea seems tied to ideas about ‘patient empowerment’ and notions that patients should be ‘responsible’ for aspects of their care, i.e., getting answers to their questions, asking for second opinions, keeping track of their drug regimens, writing notes during consultations so that they have a record of what happened. But in practice, ‘taking responsibility’ is often very difficult for patients. It’s hard to write when you are listening; it’s very difficult to ask your oncologist, whom you want to continue treating you, for a second opinion; it’s challenging to interrupt the doctor and ask questions, or to hold onto your questions for the end of the consult when they might be rushing out. The reality is that patients are not often in control of the consultation. Rather, the doctors or nurses are, and so the patients often follow along with what is happening and try to get at least their main concerns addressed.

Similar to Paul’s experience, a few other patients told me about the lack of a sense of ‘teamwork’ in their experience at Lady Ann’s. For example, when I spoke with Mary and her son, 6 weeks after her first initial visit, she said that she felt like she was “external to the process.” She said that information had not been passed along well; things had not been presented to her as “choices” – e.g., ‘Here’s our recommendations…’ but still allowing her to make a choice. She said, “People need to know: I’m a patient and I’m new to this. I don’t know what I don’t know what I don’t know.” Mary said that she had “expected more in terms of doctor-patient contact,” and was disappointed in her relationship with her team (which now comprised a medical oncologist, a radiation oncologist and an orthopaedic surgeon). One example she gave was her upper left arm. Since late February, she had known there was cancer there and wanted them to do radiation. However, they told her it would be a good ‘marker’ for
the chemo, “to see if the chemo is working.” Since they had not irradiated there, the tumour on her arm had continued to grow, and she had lost feeling and use of three fingers in her left hand. She seemed saddened and frustrated by this exclusion from her own care plan. Dario had a different experience; he felt he was not being provided enough guidance to know what was the right decision. He spoke to me about how they often explained things in terms he was not familiar with. He said, “They are asking me, ‘Do you want radiation?’ How am I supposed to know?” He said he had no idea whether or not radiation would be a good idea, until a nurse explained to him that he would only be able to get it once, so he should wait until his symptoms got worse first. He reminded me, “I’m a contractor,” suggesting that they needed to use layman’s terms so he could understand. So while Mary wants to be part of decisions and feels excluded, Dario is being asked to make choices he feels he is not equipped to make.

In clinical appointments, I regularly saw doctors ask patients to confirm medical records; they do not have time, as they move swiftly from one consult to the next, to do a close reading of the medical record before entering the room. So they ask the patient: ‘What cycle is this? How many of these have you had? When did you have that? What trial are you on?’ These questions seems to serve as prompts for the doctors; a kind of shorthand to help them skim through the file without really reading it. But patients take note of this and it makes them a bit worried. They think: ‘Why don’t they know what drugs I am on? Why are they asking me when my test is? It’s in the file, isn’t it?’ Moreover, it puts onus on the patient to really know their stuff – to be a ‘responsible’ patient and to keep track of their own medical history and appointments. A contradiction is that patients who take on too much responsibility are not seen in a positive light; they may, for example, be considered too demanding. So, for example, patients can request copies of their CT or MRI scans or bloodwork to take home. However, radiologists write CT and MRI reports for a medical audience; it is up to physicians to read, distil the overall changes, and communicate those to the patient. Nurses and physicians become sometimes frustrated when patients receive copies of their results because they may read something into the report that was insignificant or not worthy of comment. This happened once with Melody, who read something about the ‘pancreatic tail’ in her most recent CT scan and then sat at home for 3 weeks prior to her appointment, worrying that she now had pancreatic cancer. General knowledge is that pancreatic cancer is very fatal, so this caused her a huge amount of needless fear and anxiety, since as soon as she saw a doctor, he was able to clarify that she had nothing to worry about. The radiologist had to report on everything they saw, even if it was not significant. So the health care
system allowed for patients to take home copies of their scans, but there was no one to translate them to patients. The system allowed for it to happen, but both patients and medical staff were not satisfied with the outcome. In this case, ‘being responsible’ did not seem to help patients or staff, but rather produced a new consequence (misinformation) that had to be addressed.

Mol’s recent articulation of the ‘problem of patient choice’ (2008) seems useful here. She demonstrates that while the language of choice is suggestive of agency, what it really does is turn very difficult decisions over to patients and families, who have no medical knowledge or basis from which to understand the given options. We want patients to be ‘responsible’ for their care, but we do not often note the challenges they might have in attempting to do so. The logic of choice ideology suggests we choose for ourselves what we desire, but as Paul, Mary and Dario’s stories show, there are many obstacles that might prevent them from ‘choosing.’ And Mol (2008) would argue that giving a patient choices without appropriate guidance or care is disrespectful of the very real differences that exist between patients and doctors – that patients’ sick bodies will always preclude them from being full agents like doctors.

Conversely, a logic of care (Mol 2008), as evidenced in Norma’s story, has a protective ability to shroud patients from some of these difficulties in their care. Norma’s over-riding sense she was being “taken care of” helped her to trust in her team and to emplot her own “healing process.” Other patients shared stories of when they had experienced caring practices. Pam recounted how a nurse had held her hand and asked if she was ok the first time she had a physical exam, and that caring practice had helped her to get through an uncomfortable internal exam. Isabelle recounted that when she was delayed 3 weeks in starting chemo because of scheduling, it made a difference to her to know that Dr. Girard was also “upset” about the delay and had done everything she could to move up the start date. It exhibited that Dr. Girard cared about her and wanted the same things she did. Mattingly argues, “having multiple selves, is not simply an individual experience, but one that is interpersonal, and in complicated ways, socially negotiated” (2009:259). Thus, when patients see evidence of a ‘care plot’ in their interactions with their health care team, it makes a huge difference to their cancer experience. When it is absent, they feel as though, in Dario’s words, “nobody gives a damn about [them] here.” Feeling ‘cared for,’ and ‘cared about’ helped patients to sustain their ‘hopeful plots.’

Conclusion
In this chapter, I have argued that patients want to live in the ‘subjunctive mode’ and want support crafting a ‘hopeful plot’ that envisions them getting better and walking away from the cancer. This “subjunctive world” is one in which “healing is an open possibility, even if miracles are necessary” (Good and Good 1994). Oncologists, conversely, mostly live in the “indicative mode” and feel responsible to keep patient narratives tied to a ‘realist plot’ – one that is based in science and their clinical observations. But in clinical practice, patients and staff switch back and forth in driving forward these primary plots, and other sub-plots (‘treatment plot,’ ‘care plot’) also run in tandem.

In encountering the patient in the space of the consultation room, the oncologist must continually ask herself, “What story am I in?” (Mattingly 1998:160). At Lady Ann’s, the responsibility to ensure that patients understand the ‘realist plot’ sometimes seems to impinge on patients’ abilities to emplot a more positive view of their future. Ideas about which stories hold more weight are not created in the abstract; oncologists “inherit narrative anticipations, and narrative proscriptions, from colleagues and the ethos of the institutional milieu” (Mattingly 1998:151). Thus, patients’ various forms of emplotting need not only to be recognized by their treating physicians, but also by the institution of Lady Ann’s. The recognition of patients’ struggles would help Lady Ann’s to project the “culture of care” that Norma experienced, but was absent for some other patients.

Within the profession of oncology, perhaps there is need for further recognition and support for those who are able to craft therapeutic plots in a way that engages the patient as actor. The occupational therapists that Mattingly interviewed saw a distinction between their “work” – the objective, measurable outcomes that they would report in medical charts and the “talk” that inevitably took place within the work – the subjective experience where the therapist must consider “the meaning of a disabled body for the life of the patient” (1998:144-145). Similarly, in oncology, the various forms of “talk” that physicians regularly engage in may not be recognized as holding the same value. For example, it is likely that Dr. Girard was unaware that the regular compliments she gave Norma on her hair or her outfit played such a large role in forwarding Norma’s ‘care plot.’

With the increasing specialization of medicine, it is becoming easier for oncologists in specialized centres like Lady Ann’s to refer their patients elsewhere if they feel uncomfortable discussing the meaning of the illness in the patient’s life or her fears of approaching death. But that essentially reduces them to a technician’s role – a kind of doctoring that is only concerned
with the biomedical body, and not with how there remains a person within that body (Livingston 2012:91) – a person that needs their help learning how to live with their illness (Mol 2002).

Some patients I spoke with did benefit from these various sub-specialties, such as psychosocial oncology and palliative care. But regardless of their significant contributions, patients always looked to their oncologists as their primary care providers – they were the ones that seemed to control their fate – and thus, they are the ones who must become more actively engaged in emplotting outside the confines of the ‘realist’ plot. Mol notes, “even if good care strives after good results, the quality of care cannot be deduced from its results. Instead, what characterizes good care is a calm, persistent but forgiving effort to improve the situation of a patient, or to keep this from deteriorating” (2008:23). In the case of advanced disease then, being motivated by a logic of care and supporting patients’ multiple plots might be enough, regardless of how they end.

Notes

120 I use scare quotes in data drawn from consultations to indicate text that was written into my fieldnotes in quotation marks, noting to myself that I had captured the exact wording. The dialogue is very quick during consultations, and it was not often possible to capture every word that was spoken.

121 For example, when anthropologist Robert Murphy was diagnosed with a tumour in his spinal column and referred to neurology, he noted that as a medical specialty it “occupied the same position in [his] mind as oncology, the science of malignancy: It was bad news” (1990:16).

122 The et al.’s (2000) study is particularly renowned because it was published in the British Medical Journal (BMJ), which rarely publishes qualitative papers. The BMJ has very high impact factor, and thus the study results reached a large audience.

123 Their idea of a “recovery plot” is based on Arthur Frank’s “restitution narrative,” which is captured in the following synopsis: “Yesterday I was healthy, today I am sick, tomorrow I’ll be healthy again” (1995:75).

124 Although The et al. (2000) collected data from outside the consultation room (e.g., the main researcher interviewed some patients and family members at home), they still treat what happens in the consultation room as the ‘main event’ – the prime determinant of what patients know or do not know about their illness and prognosis. Thus, they still characterize the problem as one about “communication,” whereas I frame it in terms of therapeutic emplotment.

125 As an African American single mother, Aliyah is particularly concerned that her daughter receives the best care possible and not experience racial prejudice. Mattingly indicates that her long-term research with African American families found that these parents were highly concerned that their children might not be receiving the best care, because they were black and poor. Therefore, for Aliyah, living as long as possible means that Keisha is getting access to the newest and best drugs, and not being treated poorly or experimented upon (Mattingly 2009).

126 Similarly, in her research on cancer disclosure, Taylor (1988) found that doctors tended to use the same “technique” – “a predictable, rigid approach” – in telling women they had breast cancer. She said that they “routinized” the task, which allowed them to regain a sense of control over the event, and reduced its ability to impact them (Taylor 1988).
Chapter 4
Treatment as a Way of Life:
The Liminal Space of Advanced Cancer

Olivia, a 32-year old woman with metastatic ovarian cancer, is describing her reaction to a Facebook posting by another woman she knows, who is also in her thirties and living with recurrent ovarian cancer. The posting was about how the woman was on a break from chemo, which she shared by writing, “I have another year of treatment left.”

And I was like, ‘No, you don’t have a year of treatment left, because if you have a year of treatment left it means either you’re going to die in a year or you think you’re going to be done treatment at some point and you’re not. You’ve been a recurrent ovarian cancer [patient] for 5 or 6 years. You don’t have a year of treatment left – you have a lifetime of treatment left.

This chapter is about how a “lifetime” of treatment for patients with advanced disease creates a unique kind of liminal space of existence. Following a diagnosis of advanced cancer, patients regularly became fixated on treatment, and shared stories that demonstrated their desire to get past treatment, which greatly signifies their desire to get past cancer. For example, Pam shared with me a dream she’d had where she had gone into the basement of a house and had experienced “ghosts with no faces whoosh past [her] right shoulder.” In reflecting on her dream, she interpreted these ghosts rushing by as her way of telling herself, “Let’s get rid of this cancer and move on with my life.” But, Pam had her dream several months after completing her first round of chemotherapy for ovarian cancer. Her dream and interpretation illustrate that although she is not currently on treatment, cancer is still very much part of her everyday life. The reality is that Pam’s two goals – getting rid of the cancer, and moving on with her life – are not sequential. She must learn to move on with her life with cancer very much in it. Although for most patients, being ‘done treatment’ signals an important step away from the hospital and towards ‘normal life,’ for the patient with advanced disease, treatment is never over.

The chapter is broadly concerned with the transitions that make up everyday life and what happens when a person is in a transitional state that is not recognized by society. Specifically, I focus on the transitions that patients with advanced cancer go through as they move forward from diagnosis, from a life ‘pre-cancer’ to a life ‘with cancer.’ Although a life ‘post-cancer’ is what they most desire, for patients with metastatic illness there is “little hope of a disease-free
future” (Bell and Ristovski-Slijepcevic 2011:629). Like other cancer patients, they receive one or a combination of the standard treatments of surgery, radiation, and chemotherapy, but those treatments are often labelled as “palliative” rather than as “curative” in intent. Palliative treatments are intended to slow down the disease and improve symptom control and management (e.g., pain), but they are not expected to make the disease go away forever. Patients may get breaks from treatment for a certain period, but they are always called back to the hospital for more. Within this context, treatment becomes not the means to an end – something to be tolerated for the time being in the hopes that it will bring about cure – but rather a means to the end – a way of life that must be endured for the time that remains.

I argue that it is this specific context of a “lifetime” of treatment – the availability of modern cancer treatment in terms of what can be done and for how long – that has produced the liminal space of advanced disease. In doing so, I draw on the classical literature examining liminality in anthropology (Van Gennep 1960; Turner 1967, 1969; Douglas 1966), but also work to demonstrate how incurable cancer presents a unique kind of liminality. My approach in applying this concept to advanced cancer came about in the three years I spent volunteering at Lady Ann’s while I prepared for fieldwork. In conversations with patients facing serious cancers, it seemed to me that they inhabited a kind of ‘middle ground’ between, on the one hand, the world of oncology and its culture of cure and survivorship, and, on other hand, the world of palliative care and its culture of death and dying. I draw primarily on Turner’s elaboration of the liminal stage of rituals or rites of passage, where he argued, “liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by custom, convention and ceremonial” (1969:98). In the context of advanced cancer, diagnosis serves as the point of separation, treatment as the marginal or liminal stage, and survivorship or death as aggregation (Turner 1967; Van Gennep 1960). In particular, here I am concerned with what happens in this “anti-structural” state, when liminality is prolonged and reincorporation or aggregation into the social body is not possible. As Olivia’s quote demonstrates, patients with advanced cancer become permanently liminal, in that they are unable to leave behind the life of treatment. Several scholars have argued that liminality has this potential for persistence (e.g., Murphy et al.’s “permanent liminality” of physical disability (1988:240); Kaufman’s “prolonged and chronic” liminality of patients in persistent coma (2000:76); Little et al.’s “sustained liminality” of cancer survivors (1998:1492)), but each of these applications does not quite account for the distinct
social structural positioning of the patient with advanced cancer. Thus, I work to revamp this classical anthropological concept and to expand how we think about liminality.

In doing so, I build on the work of several scholars who have previously introduced the concept of liminality to the field of cancer (most notably Stoller 2008, 2009; Frank 1995; Little et al. 1998; see also Blows et al. 2012). Frank’s “remission society” (1995:9), Stoller’s “continuous liminality” (2009:148), and Little and colleagues’ “sustained liminality” (1998:1492) are all variations on Turner’s concept of liminality, designed to accommodate the patient with cancer. Each author uses his variant of liminality to demonstrate how hard it is for cancer patients to adjust and get back to “normal” life after they have completed treatment. For example, Frank argues that people who have suffered serious illness never fully reintegrate into the land of the healthy, taking up residence in a kind of “remission society,” where recurrence may call them back to the land of the sick at any time (1995:9). However, crucially, patients with advanced disease never fully leave the land of the sick. They are always considered to have active disease in their bodies, which is only controlled through ongoing cycles of treatment. Similar to Frank, Little et al. argue that sustained liminality begins when patients “reach the convalescent phase” (1998:1492). But patients with advanced disease often never reach this stage; they remain tied closely to the hospital precisely because they are undergoing, or waiting to undergo, more treatment. Therefore, these concepts cannot speak to the reality of treatment for patients with advanced disease, for which there can never be a normal life that does not include cancer, and thus treatment for cancer. I demonstrate that although all cancer patients live with the threat of recurrence, for patients with advanced disease this threat is made much more acute because they have been told from the outset that their cancers are “incurable.” This means that recurrence is not a question of if, it is a question of when. Thus, the liminal space of advanced disease does not separate the lands of the “sick” and the “healthy” as Stoller (2009) has suggested, but rather the worlds of the living and the dying.

By directly relating the liminality that patients experience with the phenomenon of treatment that is “never over,” my research makes a unique contribution to the literature examining the transition between life and death (Rodin and Zimmermann 2008; Ho et al. 2013; Nissim et al. 2012; Anderson 2007; Kelly 2008; Bruce et al. 2014). Although several of these authors have argued that cancer and other life-threatening illnesses result in people being in a “liminal” space that is somewhere between life and death, they often take at face value that it is the inherent difficulty of moving towards dying that accounts for their liminal status. For
example, Ho and colleagues (2013:964) argue that in Chinese society “customary rituals for recognizing the distinction from living to dying are nonexistent.” Their research advocates for the use of clinical tools such as the ‘advance care plan’ and the ‘life review’ to stand in for the ritual actions that might better help to recognize that a terminal cancer patient has made the transition from “living” to “dying” (Ho et al. 2013:965). In my research, I found that there is no one moment of transition that moves patients from living towards dying: they have one foot in each world at all times.

Thus, my research makes a substantive contribution to this literature, by proposing that it is not only that patients are moving towards dying that makes them unrecognizable in society, but also that their treatments are cyclical, rather than terminal. While society does recognize people who are dying imminently, there are fewer roles available for people who are living with a life-threatening illness but not currently dying from it. My findings indicate that the patient living with advanced disease does not see herself as ‘dying’ and her oncologist does not speak to her as though she is most of the time. Conversely, the majority of actions and conversations that take place in consultations are about treatment. Thus, I argue that it is the wide range of what can now be done in terms of treatment possibilities (standard treatments, 2\textsuperscript{nd} and 3\textsuperscript{rd} line, clinical trials) that hides patients’ liminality. Treatment hides their liminality precisely because they enter into treatment (e.g., separation) very much like other patients with more curable cancers. Once in treatment (e.g., the margin or \textit{limen}), they can also be confused with patients with curable cancers, because it is assumed that at some point treatment will be over. It is what happens post-treatment (e.g., aggregation) that reveals patients’ liminality, for patients can never move beyond the life of treatment.

For example, when we sat down for her interview on the day she spoke about the Facebook posting that opens the chapter, Olivia told me that when she was waiting for me in the lobby of Lady Ann’s, she had been looking at a poster advertising a session with a radiation oncologist about “getting back to life after treatment.” She said,

I thought, how hard would it be or how unusual it would be if they were offering sessions on how to live with cancer through treatment...through treatment – there is no end to it.

As Olivia’s words indicate, this poster may have appeal for some patients, but it excludes the experience of the patient with advanced disease, such as herself, for whom there is “no end” to treatment. For Olivia, the marginal phase of treatment extends indefinitely towards her end-of-
life. Turner argued that liminal beings are often only tolerated in structured activities like rituals, where the duration of the liminal stage can be controlled (1974:48). For patients with advanced disease, the liminal stage’s lack of clear boundaries and time delimitation make it even more challenging to endure. Furthermore, the kind of never-ending treatment they must submit to is not well recognized in our culture, where people associate ‘treatment’ with cure potential and with a time-limited experience. For Olivia and others like her, there is no potential reintegration into society, because the category of the person living with cancer, but not currently dying from it, is not recognized. Nor can they identify as survivors, because they cannot walk away from treatments and still live.

Using Douglas’ terms (1966), patients with advanced cancer are thus ambiguous, capable of being perceived as actively living or actively dying – epitomized in the advice that they “hope for the best, and prepare for the worst” (Teno 2001) – as well as anomalous, in the sense they are in a specially marked time between life and death, where they are living with their disease, but not yet dying from it. As the previous chapter demonstrated, living in the “subjunctive mood of culture” (Turner 1986:41) is hard work for patients, and the permanence of patients’ liminality makes it even more challenging. Although the liminal space of advanced cancer shares certain features with classical ethnographic examples of initiation rites, I demonstrate that it does not conform to all the tenets of classical anthropology. For example, as a marginal state, it is not a pure form of socially sequestered “anti-structure” (Turner 1967). Because the transitional state takes over lived time, patients cannot be excused from all social responsibilities forever, and some elements of “structure” (e.g., family roles, jobs) permeate into the transitional state. Turner also demonstrated that the homogeneous composition of initiates broke down the normal hierarchies that separated people, allowing for the feeling of group camaraderie or what Turner called *communitas* to develop (1969:102-103). Communitas has been observed for cancer patients in a rehabilitation program (Tjørnhøj-Thomson and Hansen 2013), but not in the context of ambulatory care, where patients come in and leave the hospital regularly. This constant turnover of outpatients makes it more challenging for group camaraderie to develop between strangers. Lastly, Turner (1967) emphasizes the role of the community in aiding the liminal subject. However, unlike an initiation ritual where initiates are guided carefully by ‘experts’ (Turner 1967) or ‘ritual officers’ (Rappaport and Overing 2000:230), patients with advanced cancer lack such designated figures to ensure their protection and guidance while they are in the anti-structural, ‘dangerous’ (Douglas 1966) state.
My contribution to liminality scholarship is thus twofold: 1) to demonstrate a contemporary context in which Turner’s ideas can be applied in an in-depth way, and to expand on his ideas by showing how the prolonged liminality of advanced cancer has some important differences from the ‘anti-structural’ temporary state that he developed; and 2) to examine the modern availability of cancer treatment as a means of making patients liminal. In the process, I demonstrate the utility of a liminality framework for connecting several areas of scholarship, including the anthropology of classification (Turner 1967, 1969; Douglas 1966), the anthropology of ritual in hospitals (Tjornhoj-Thomson and Hansen 2013; Lewin and Green 2009) and studies of aggressiveness of care at the end-of-life (Baszanger 2012; Earle et al. 2004, 2003; Matsuyama et al. 2006). Ultimately, I aim to demonstrate that in order for us to see the experiences of patients with advanced disease, we must be able to recognize that they are at once sick and not sick – getting better at the same time as they are getting worse. This is a difficult challenge for society, and one that has not yet been taken up with respect to cancer, since it is much easier to rely on stereotypes of the Fighter, the Survivor, or the Dying Person.

I begin by providing a brief review of how liminality has been used by anthropologists and researchers in the health services field to examine people who cannot fit themselves into the categories offered by their culture. Often in the health services publications, the concept of liminality is extracted from rituals and rites of passage, and its use is intended primarily for pointing out an inability to be classified. These authors do not often parse out what it is that makes people so invisible. Conversely, the work of several anthropologists demonstrates how liminality can be used in a richer, and more in-depth manner. In applying the term here, I aim to return liminality to its roots in social anthropology, and to bridge its theoretical offerings with its applied aspects found in the health services literature.

I then turn to my ethnographic examples, beginning with the detailed analysis of one particular hospital ritual: the ringing of the chemotherapy bell. Patients ring this bell after they complete the last cycle of a round of chemotherapy. Taking as my starting point that chemotherapy is, in itself, a kind of ritualistic activity, I use the ringing of the bell as “a communicative element within a surrounding culture” (Clifford 1983), which demonstrates how patients with advanced disease are left out of available cultural categories. I show the event of ringing the chemo bell as exemplary of the challenges patients face in trying to leave cancer behind and transition back into their pre-cancer lives. Ringing the bell normally signals a patient’s departure from the world of cancer treatment and his or her hopeful step towards the
world of cancer recovery. All patients, including patients with advanced cancer, want to believe that they can beat cancer and survive, and the bell serves as a symbol of a small victory in this larger fight. Yet patients with advanced disease come to an end of their treatments with cancer’s continued presence in their bodies and in their lives. Rather than ring the bell and be initiated into the survivorship phase of care, finishing treatment and being told that the cancer is “still there” takes the small victory of the bell away.

After examining the ritual of ringing the bell, I analyze two additional examples that help to showcase how liminality in advanced cancer is tied to further cycles of treatment. The first example is the idea that tumours that may be held off or stop growing temporarily will always come back. This was often expressed by oncologists in terms of the futility of patients’ actions in preventing cancer recurrence, in the sense of “there is nothing you can do.” For example, as described in the previous chapter, just as he was finishing his first round of treatment for lung cancer, a medical student in Dr. Lawson’s clinic communicated to Deo not to “rest on [his] laurels.” This medical student sat Deo down and told him very clearly, “It will come back. And when it does we must be prepared to fight again.” Deo was highly resentful of this conversation, not only because he knew full well what he was dealing with, but also because of its timing, coming just as he was finishing up several months of difficult and taxing treatment. Deo wanted to celebrate his success of finishing treatment, even if it was to be a short-term success. But the medical student’s forceful warning hardly allowed him any time at all to revel in his accomplishment. The certainty with which this message was conveyed to patients was always unsettling and made it very difficult for them to move forward in their lives, when what they were moving towards was the likelihood of more cancer, and hence more treatment.

The last ethnographic example relates to both the ringing of the bell and the certainty that metastatic disease will come back. When the disease progresses and patients’ tumours grow (either in the primary site or its metastases), patients will commonly receive more treatment. But they will not receive a second round of chemo (also called a ‘second line’) right away. Their doctors will give them a break, and let their bodies recover from the first treatment, before they prescribe another round of chemo. This break from treatment means that patients might not receive more treatment until their symptoms have worsened and the cancer has started to grow again. This plan is sometimes called the “timed arsenal,” putting the war metaphor commonly employed in cancer discourses to full and explicit use, or sometimes the “watch and wait” approach. Although clinically it is an evidence-based approach, I observed that it was very
difficult for patients to wrap their heads around this idea, which they understand as meaning “When you are sick again, then we will give you treatment.” Patients find it unbelievable that this ‘reactive’ approach to their care (i.e., dealing with cancer after it comes back) is better than a ‘preventative’ approach. But prevention only makes sense when complete reversal of the disease is the goal. Their oncologists and nurses have long since abandoned that goal, because they know that disease reversal is impossible. But patients still hope for this outcome, so they view this piecemeal approach to treatment as nonsensical or even negligent.

In both of these latter ethnographic examples – cancer’s certain recurrence, and waiting to be sick to receive more treatment – patients were extremely frustrated by their inability to act to change the outcome. Being unable to do something is especially unpalatable in a cancer hospital that is predicated on action. The value of ‘doing something’ over ‘doing nothing’ is also reinforced in wider culture, where people assume there is always something to be done, “as though an effort of the will could indefinitely prolong life” (Little et al. 1998:1491). The focus on action presents the cancer patient with two equally unattractive alternatives. If she chooses to ‘do something’ (i.e., take treatment) she is culturally supported, but must deal individually with the treatment’s inevitable downfalls and its limited ability to make her cancer go away and not come back. She may internalize the treatment’s failures and blame herself for them. If she chooses to ‘do nothing’ (i.e., not take treatment) she is culturally abandoned, and blamed for her choice. The pervasive connection between morality and health in North American society leaves patients feeling that they should be doing something even in cases where there is nothing to be done.

Liminality in other contexts

Liminality is a core concept of anthropology used to recognize changes in identity and in one’s place or position in a social structure, which often denotes a “zone of socio-cultural non-identity, non-existence” (Rappaport and Overing 2000:230). Anthropologists have used liminality to examine the space between illness and health (Lewis 1975), physical disability (Murphy et al. 1988), chronic illness (Jackson 2005), refugees’ positionality (Malkki 1998), refugee health (Gaur and Patnaik 2011), persistent coma (Kaufman 2000), cancer rehabilitation (Tjornhoj-Thomson and Hansen 2013), and cultural hybridity (Werbner 2001). But as a theoretical construct it has gained traction outside of anthropology as well: it is perhaps one of
our most profitable exports. Due to a widely cited study by Little and colleagues published in *Social Science & Medicine* in 1998, liminality has become a kind of ‘go to’ concept in the health and social science literature to describe any group that finds itself temporarily or permanently excluded from the social order. Many authors use the concept of liminality to talk about people who are located outside of “structure” – who defy categorization in the Douglasian (1966) sense or who are betwixt and between different stages of life in the Turnerian (1967) sense (e.g., Little et al. 1998; Navon and Morag 2004; Blows et al. 2012; Ho et al. 2013; Bruce et al. 2014; Kelly 2008; Broom and Cavenaugh 2011; Frogatt 1997). For facility, I group two broad kinds of research that is produced when liminality is adopted in health services research, which will each be discussed in turn, followed by a more anthropological framing of liminality.

The first group of literature uses the concept of liminality like a theoretical rack to hang its coat on – they address that a group is “not classifiable,” argue that this is evidence of liminality, and provide scant elaboration of the concept (e.g., Bruce et al. 2014; Kelly 2008; Broom and Cavenaugh 2011). There is sometimes acknowledgement that the concept stems from Van Gennep and Turner’s writings of the late 1960s on Central African rites of puberty and initiation, but in applying the concept to examine hospice as a liminal space (Broom and Cavenaugh 2011), several different kinds of chronic illness, including cancer (Bruce et al. 2014) and the support networks of people with AIDS dementia (Kelly 2008), the authors argue simply that their participants are between identities and thus liminal. Their usage of the concept is thus fairly shallow.

In the second group of literature, the authors often attribute liminality’s origins correctly, provide some in-depth examination of its meaning and substance, but do so concentrating solely on the experience of the people who cannot be classified. For example, Little and colleagues’ (1998) study was based on interviews with 10 colon cancer patients in Australia, who were at various stages of survivorship, ranging from 3 months to 12 years post colectomy surgery. The authors found the concept highly appropriate for describing the “subjective experience of illness” for these cancer patients. Their work makes little mention of the role of doctors or family and friends who are present around the liminal subject, and thus are involved by nature of their being witness to the patient’s transition from healthy person to cancer patient. Perhaps this is because they explicitly remove liminality from the ritual or rite of passage context, arguing, “unlike Van Gennep, we do not conceptualize the liminal as a demarcated tripartite process” (Little et al. 1998:1490). They are interested in using liminality only to examine the experience of the
“liminal subject” and not “to categorise the changes in social relationships inherent in being ill” (Little et al. 1998:1490). By so narrowly defining their interests, they deprive liminality of its inherent social implications, in essence stripping it of its anthropological inferences, in order to pursue their own argument based in existentialism and philosophy.

A similar use of liminality is found in Morag and Navon (2009), who argue that after treatment for prostate cancer in Israel, men reported changes in their bodily related masculinity, and thus could not “classify themselves into culturally available categories,” which stress male potency and able-bodiedness (2009:2337). The male participants in their study were prevented from re-establishing closeness with intimate partners, due to treatment side effects (Morag and Navon 2009:2341). Thus, prostate cancer treatment caused the “liminal state’s persistence,” and a feeling of being “permanently unclassifiable” (Morag and Navon 2009:2343-44). While their study offers an important example of another context of permanent liminality, they draw only on interviews with men post-treatment in order to make their arguments. Thus, their study presents a flattened out version of liminality, elucidating that patients feel unable to attach themselves to the male roles they are offered, but failing to show how they came to be in that position. In other words, they extract the theoretical concept from the ritual setting; by only interviewing the men themselves, they do not include how the social body fails to incorporate these men or present an understanding of liminality as a process that implicates more than the liminal subject.

A flimsy or shallow use of the concept misses several key points: 1) that liminality takes place within a ritual, which is by nature social, and thus cannot just involve the individual “novice” or liminal subject; 2) rituals and rites of passage have a social function, allowing groups to “become adjusted to internal changes and adapted to their external environment” (Turner 1967:20). In much of the health services research, rites of transition and of reincorporation are not even mentioned, resulting in a decontextualized version of liminality. Most likely this is because researchers often rely on qualitative interviews as the primary means of data collection, precluding any observation of symbolic actions or ceremonies.129

One study from the health services literature that does well to acknowledge the social and ritualistic aspects of liminality is Ho and colleagues’ recent work examining the experiences of terminal cancer patients in China (2013). They demonstrate that although Chinese society has formal rituals to transition the body into a corpse (through funeral rites), and to transition the spirit into an ancestor (through mourning rites), there are no similar rites to help the person transition from living to dying. This is an important and useful observation. However, the goal of
their research differs slightly from my purposes here. They are explicitly concerned with showcasing how liminality relates to the preservation of dignity at the end-of-life, based on the assumption that people can “achieve healing despite suffering” (Ho et al. 2013:964). As part of that goal, they advocate the use of two clinical tools – the advanced care plan and the life review – that they argue will help to stand in for the ‘missing’ rites transitioning the living to the dying (Ho et al. 2013). It is difficult to imagine how the use of these individually-based clinical tools can stand in for ritual actions, as they seem to detract from the sociality of the process itself.

In contrast to the health services research, anthropologists who use the liminality concept tend to provide a deeper level of analysis. Each of Malkki’s (1995), Murphy and colleagues’ (1988), and Jackson’s (2005) treatments of liminality have inspired aspects of my theoretical framing. Malkki (1995) shows how Burundian refugees living in Tanzania experience a sense of liminal existence – both for those who are living “in camp”, and therefore only among other refugees and not trying to acculturate to Tanzanian life, and those living “in town” and working to downplay national differences between themselves and Tanzanians. Liminality is shown to be internalized by each group in discrete ways; in the camp, the transitional state represents one that must be accepted in order to return to the “homeland,” but in town, it is accepted as a lifelong state, where identities shift in relation to security and adaptability to Tanzanian life (Malkki 1995). Where Malkki argued that Burundian refugees threaten the categorical order of the nation (1995:5), here I examine how not-surviving-not-dying cancer patients threaten the categorical order of sickness and wellness.

Murphy and colleagues’ (1988) important study examined how physical disability creates a kind of permanent liminality. Using participant-observation and interviews, their thorough paper accounts for how people with physical disabilities are made liminal and how communitas can be formed with other people undergoing physical rehabilitation therapy. They describe the rehab therapy that must be endured in order to get better as akin to the “bush schools” that Turner outlined for his male novices (Murphy et al. 1988). I am inspired by their work not only in this detailed application of Turner’s concept, but also in their ability to describe the severe levels of stigmatization and invisibility that disabled people experience. One difference is notable: whereas Murphy et al. (1988:237) argue that their subjects live a “cloistered existence” because they cannot go out independently, and are treated as invisible when they actually do, I argue that the liminality experienced by patients with advanced cancer is profoundly problematic because
they are ‘out in the world,’ unprotected by the normal social conventions that guard and guide the ritual subject.

Lastly, I draw inspiration from Jackson’s (2005) research on liminality, stigma, and moral hierarchies of care in chronic illness. Patients with chronic illness are assumed to have illness ‘all in their heads,’ and therefore lack the physical, bodily manifestation of the problem that biomedicine so prioritizes. Where Jackson describes a clinical tool – diagnosis – as the mode that renders patients with chronic illness liminal, here I posit that it is another clinical tool – treatment – that is the primary mode through which patients with advanced disease become liminal. Similar to Jackson (2005), I aim to demonstrate how the cultural responses to patients both inside the hospital and in wider society contribute to their experience of liminality. I begin by revealing how socially symbolic and meaningful events such as rituals are relevant even in the contemporary, highly technical world of a cancer hospital.

The Ritual of Chemotherapy and the Transformative Power of Treatment

We are increasingly the generals who march the soldiers onward, saying all the while, “You let me know when you want to stop.” All-out treatment, we tell the terminally ill, is a train you can get off at any time – just say when. But for most patients and their families, this is asking too much. They remain riven by doubt and fear and desperation; some are deluded by a fantasy of what medical science can achieve (Gawande 2010:49).

A person diagnosed with an advanced cancer at Lady Ann’s is still likely to receive treatment. All of the patients I met took at least one round of chemo, and some took multiple rounds on several different drugs (both standard and clinical trial medications), or had radiation in addition to chemo. The possibility of being enrolled in a clinical trial, for a drug that is still in the testing phase, opened up even more treatment possibilities for patients with advanced disease. Whereas in the relatively recent past, patients might have exhausted surgical and radiation treatment options rather quickly, the advent of chemotherapy in the 1950s, means that treatments can now continue almost indefinitely (Baszanger 2009). This has created a problem in that, as Gawande points out, once a patient has boarded the “treatment train,” it becomes very difficult to know when it is time to get off of it. A secondary problem created by the advent of treatment is its still limited ability to cure. Being offered treatment does not mean it will have the effect patients desire it to have; despite doctors’ knowledge that treatments are not aimed at cure,
research has shown that this information is not well understood by patients and their families (Weeks et al. 2012; Chow et al. 2001). Matsuyama et al. (2006) found that many patients with metastatic disease are willing to undergo very toxic treatments that offer only limited benefits, but there are few decision aids available to help them to think realistically about prognosis, choices and typical treatment outcomes. This leaves oncologists in a difficult position because they are very good at giving treatments and patients often want whatever treatments are on offer (The et al. 2000). As one oncologist in the documentary The Truth about Cancer (2008) astutely summarizes, “People want to live and some people will do almost anything to live and sometimes that’s your job: to hold people back and say, ‘You can’t do that – that’s going to hurt you.’”

For the patients I followed, chemotherapy was the primary means of transforming them from a patient with cancer to a cancer survivor (Feuerstein 2007:7). Chemotherapy is at once both routine and ritual. Here, I am using Buchbinder et al.’s terms, where they describe routines as “habitual series of patterned behaviors or interactions” and rituals as acts that have more “symbolic meaning” (2009:214). As Douglas elaborates, “it is not too much to say that ritual is more to society than words are to thought. For it is very possible to know something and then find words for it. But it is impossible to have social relations without symbolic acts” (1966:62). I will discuss the routine and ritualistic aspects of chemotherapy in turn.

For patients prescribed one or multiple chemotherapy regimens, chemo soon becomes a routine activity and one aspect of their care where they know what to expect. Chemo is something that patients prepare for: patients reported stocking their freezers, dressing comfortably for a long day of sitting; packing their “chemo bags” with reading material, laptops, snacks and drinks. I sat in on numerous chemotherapy infusions over the period of fieldwork, and noted that the patients found the routines comforting (as did I). Regardless of patient or chemo nurse, the actions almost always follow a similar pattern:

- The patients is called into her chemo chair
- The nurse arrives, introduces herself, and wraps the arm to be infused in a warm blanket
- The nurse asks standard questions: about bloodwork, about any fevers/chills, about any new symptoms or side effects since last chemo
- The nurse takes the patient’s vitals: blood pressure, temperature, and oxygen saturation
- The nurse sets up the IV ‘kit’ (sterile container of supplies). She sticks several pieces of white medical tape to the table in preparation
- She lays down the disposable blue/white paper cloth, palpates the arm in search of a ‘good’ vein. When one is found she swabs the area with alcohol, inserts the needle, and then retracts the ‘sharp’ leaving the plastic catheter in to hold open the vein for infusion. She tapes the
infusion line onto the patient’s arm, then leads the IV line up towards the patient’s shoulder and tapes it there as well. She starts the infusion.

• When the infusions are complete, this process is reversed. The tape is removed, the plastic catheter is removed, the area is cleaned, and a Band-Aid is applied to the puncture area.

Sudden changes to the routine, such as an extra saline flush, or an extra drug or vitamin to be infused, at times threatened the stability and comfort of that routine, as it caught patients off guard. For example, at Pam’s last cycle for her first round of chemo, she was told she needed to stay an “extra 30 minutes” after her infusion in order to ensure she had no reaction to the Carboplatin. Pam was not impressed with this change in plan: she just wanted to ring the bell and get out of the hospital as soon as she could.

Chemo also takes a routine toll on the body. Treatment may introduce new symptoms that are difficult to tolerate, and patients come to expect how they will feel after chemo. One patient had to put up with diarrhoea for months on end, a side effect of one of her drugs, which meant she never left the house without first planning access to a washroom. Another patient had to give herself needles every day, to counter the effects of one drug with another drug, which made her stomach look like a bruised pincushion. Chemo was often given once every 3 weeks. Day 1 is the day they receive chemo, and Days 5–7 were always reported to be the hardest, corresponding with the days when their platelets and white blood cell counts were at their lowest. After they made it through the first week, they spent the second week feeling very tired and wiped out. By the third week, they often started to feel pretty good again, but then they had to prepare to begin the whole 3-week process all over again. This schedule is difficult to tolerate for the 4–6 months that it requires for most people to get through 6 rounds of chemotherapy. For patients with advanced disease, this schedule (or some variation of it) will be repeated over and over again, so it is not a temporary purgatory, but a permanent one.

Chemotherapy is also ritualistic, because it is the means of transitioning patients out of the life of a cancer patient. Here, I am guided by the work of Tjornhoj-Thomson and Hansen (2013) and Lewin and Green (2009), who have examined the ritual of cancer rehabilitation in Denmark, and the ritual of TB treatment in South Africa, respectively. The actions of chemo become routine, but its symbolism as that which is “fighting” their cancer never escapes patients. For example, when Pam tells me she hopes the chemo will “zap [her] even more,” she is expressing her wish that it will clear out the cancer in her body. In this sense, chemo is a “symbolic action” that “carr[ies] bundles of meanings” (Robbins 2006:124). People invest a lot in ‘getting chemo’ because it means there are still treatment options left for them, which they equate with meaning
that they are not dying. Chemotherapy is comparable to the symbol of the milk tree that Turner (1967:25) describes for Ndembu culture; not only does the tree exude a kind of ‘milk’ when scratched, comparable to human breast milk, but it is also danced around during girls’ puberty rituals. When girls sit around the tree during the puberty ritual, they are seen to “swallow instruction” akin to swallowing mother’s breast milk, but what they are swallowing is “instruction on tribal matters, values, and images” which are the intended moral values to be transmitted through the ritual (Bell 1997:41). Analogously, as chemotherapy is ‘swallowed’ or infused into patients’ bodies, it is transferring North American values of treating cancer with the strongest medicine on offer for as long as it is offered. Thus, the ritual of chemo constitutes a kind of “strategic socialization” process (Bell in Tjornhoj-Thomson and Hansen’s 2013:269).

Within the ritual of chemotherapy, the bell ringing ceremony serves as a sacra (Turner 1967) or the primary symbol. The bell symbolizes patients’ hope to move from the world of cancer treatment out into the world of cancer survivorship. As an audible symbol, it is not unlike other bells that we are familiar with, such as bells that call children to school or signal a town meeting. In their work on ritual in the care of TB patients in South Africa, Lewin and Green argue, “rituals provide boundaries to categories in the context of transition, for example, between being ‘well’ and being diagnosed with TB, thus allowing social actors, such as health care providers, family and friends, to respond appropriately” (2009:1465). Similarly, the act of ringing the bell serves as a public announcement at Lady Ann’s that a patient is finishing up treatment, and walking tentatively forward towards survivorship. As such it constitutes the ritual that signals the transition (for some cancer patients) from being in treatment (thus, dying) to not being in treatment (thus, living). The end of chemotherapy makes it an appropriate time to ring the bell, because it signals this transition between their lives as sick persons and (they hope) their lives as non-sick persons. Although the ritual is meant to signal transition to re-incorporation, it inspires ambivalence on the part of advanced cancer patients precisely because, for them, the end of chemotherapy treatment does not translate as aggregation into the cancer-free world.

“I’ve Rung That Bell Three Times Already”: Ringing the Bell and Failing to Transition out of Treatment

I am sitting in the chemotherapy waiting area talking with Melody, a patient waiting to be called in for treatment in mid-February 2011, during the first month of my fieldwork, the first
time I hear the chemotherapy “bravery bell” (Figure 4.0) go off. It sounds like an old schoolhouse bell, calling children back from recess, or perhaps a ship’s bell, calling the masses to dinner. The ringing is followed immediately by much clapping and exclamation. The entry to the chemotherapy unit has no door, and I look up to see three women taking pictures, smiling and laughing. Melody offers as explanation, “It means someone has finished their chemo.” Followed by the quick statement, “I got to ring that.” I note that the women seem so positive and happy, that momentarily the waiting room seems to ‘perk up’ thinking about someone finishing and how happy she must be at that moment. Or maybe it is just our little group – Melody, her friend and myself – as we sit and wait for her to be called in. At the time, I did not think about the implications of Melody’s statement – she had ‘rung’ the bell and yet here we were, waiting for her to be called in for chemotherapy that day. I knew then that she was a Canadian woman in her 70s, who had survived breast cancer 20 years earlier, and was currently receiving treatments for advanced ovarian cancer. I know now that since 2008 she has completed more than six rounds of chemotherapy for this disease.

The significance of ringing the chemotherapy “bravery bell” (as its inscription reads) very quickly became a familiar refrain in my research. In August of 2011, I witnessed the experience of Deo, a 62-year old man originally from Guyana, ringing the bell at the completion of 6 cycles of chemotherapy for stage IV non-small cell lung cancer. I had been following Deo since his first day at Lady Ann’s in March, where it was very clearly explained that there was no cure for his disease. Throughout his treatment, which was very hard on both body and mind, and required him, in his words, to “fight back against the cancer bully,” he had been looking forward to ringing that bell. We had talked about it several times.

**Figure 4.1. The chemotherapy bell**
On the day it happened, we positioned ourselves in the main hallway through which patients enter and leave the chemotherapy unit. The bell hangs on the wall in this hallway, just beside the glassed in nurses’ station. The site is ideal, as nurses are in close proximity when someone prepares to ring it. It is also ideal because family and friends coming to witness a loved one ringing the bell do not have to go further into the chemotherapy unit. The bell’s location not only maintains privacy for the numerous patients receiving treatment, but also prevents people who may be unfamiliar with the hospital from the daunting sight of a full room of people hooked up to IV poles. Smiling, Deo grasped the small piece of rope dangling from the bell and pulled on it vigorously, and it rang out loud and clear. His wife and daughter stood with him and several pictures were snapped. The nurses hugged him and wished him well, and he handed over the specialty cupcakes he had brought for them – a sign of appreciation for all the support and care they had provided him through the past five months. Seconds later, the event was over and we moved downstairs to the wide-open space of the hospital’s atrium. Sitting on a chair in this main entrance, he told me that he was “very emotional” and had “no idea what to say, which for me is very uncommon.” Where minutes before he had appeared so triumphant, he now appeared somewhat stunned and a bit numb.

The chemotherapy bell figures prominently in the everyday life of a cancer hospital. Learning what the bell signifies becomes one of the pieces of knowledge patients gain through their experience of the hospital. As Jennifer, a 41-year old woman with metastatic endometrial cancer told me, “Being around the hospital a lot going to appointments, I’d hear the bell occasionally, and I was like ‘what’s that?’” Patients hear the bell ring out almost every day they are in chemo and quickly pick up its significance from watching other patients or from staff. As a researcher studying the culture of the hospital, it was something that I came to know as well. I came to recognize Deo’s experience as somewhat typical of this kind of celebratory moment that normally signals a patient’s departure from the world of cancer treatment and his or her hopeful step towards the world of cancer recovery. Because of its public nature – the noise which draws attention to the patient and supporters, the photo opportunity, the shared smiles from other patients and families close by – aspects of the bell-ringing event are reminiscent of having ‘happy birthday’ sung to you in a restaurant by staff, with other patrons joining in. Yet, the latter celebrates a rather banal, annual activity, while the former is a highly symbolic activity, heavy with emotion.
While this activity was generally greatly anticipated by patients, my observations of the actual event itself were that people’s reactions to ringing the bell or choosing not to ring it were much more complex. On the surface, it seems very celebratory. But Deo’s reaction was similar to what I observed for Pam on the day she rang the bell — in the moment, she had a big smile on her face and kept her eyes closed, and when it was over it seemed like she could not get out of the hospital fast enough. So although it is seen as a kind of ‘celebration’ — and, in fact, feels like this when you are witnessing the instant of the ringing — patients’ feelings that precede and follow the act are indicative of a much more ambiguous experience. I was able to capture these experiences because I followed patients longitudinally, and more importantly for this circumstance, I followed them out of the chemotherapy unit and downstairs to the main doors. This means that I witnessed not only the moment of triumph, but also the moment of doubt and worry that seemed to set in as soon as they had left the chemotherapy area.

**Not being “done treatment”: Choosing to forgo ringing the bell**

Some patients chose not to ring the bell. When I asked patients about this, casually sitting in chemotherapy or in semi-structured interviews, their reasons for electing not to ring the bell were very similar: they all had something to do with the feeling of it not being “over yet.” Whether to them ‘it’ represented the small-scale activity of treatment or the larger scale experience of cancer was less clear. But what I heard several times was that people found it hard to believe that the experience that had dominated their lives since their diagnosis was coming to an end.

For example, Norma, a 57-year old woman with ovarian cancer, tells me,

I didn’t ring the bell. ‘Cause after surgery she [Dr. Girard] said I’d do 2 [cycles of chemotherapy], and good thing I didn’t ring the bell cause I ended up doing 4. At 8, I didn’t ring the bell either because I wasn’t sure if there would be need for another one, so I’m pretty cautious.

Norma chose not to ring the bell, because she was not sure she was done chemotherapy. Her “cautious” approach to celebrating the end of treatment was in line with her chemo experience: from being promised “2” cycles of chemo, she had actually gone on to complete “8” cycles. In other words, Norma recognizes her state as liminal, and does not see herself as having crossed the threshold into land of the “not sick” — the land of survivorship — yet. We had this conversation during an interview that took place a few weeks after her last chemo. I pointed out
that I supposed she could go back and ring it now. She joked, “Probably I need to go ring it, right.” I said, “Only if it’s important to you” to which she replied, “I’m fine.”

The reality of having to continue other kinds of treatments even after chemotherapy finishes also disrupts the normal symbolism of the bell. Elizabeth, a 37-year old woman with metastatic ovarian cancer, tells me, “I don’t want to ring the bloody bell ‘cause I don’t really need people staring at me, so I’m not going to ring the bell.” As she completed her first round of chemotherapy in November of 2011 she elected not to ring the bell partly because she did not want to draw attention to herself, but also because she had been taking a clinical trial drug concurrently with chemotherapy, which continued even after chemotherapy stopped. This required her to continue to come to the hospital every 3 weeks to receive the drug, which is given to her through an IV in the chemotherapy unit (although it is not a chemotherapeutic agent). The irony of having to continue to come to chemo to get a non-chemo drug is not lost on her, and contributes to her decision to not ring the bell, as she says to me, “I’m coming back anyway, right? …So I’m not done.” To her, ringing the bell would be false because she knows she has to come back for the clinical trial drug.

It was only after she had completed the standard treatment for ovarian cancer, that Elizabeth found out that she was to be given the clinical trial drug “indefinitely.” This information was revealed to her during a very awkward conversation in which the oncologist asked the trial nurse when the trial drug would stop. The nurse’s response, “Indefinitely,” came as new knowledge to Elizabeth, who was sure her consent form for the trial had outlined a timeline of 2 years. I was able to interview Elizabeth again in June of 2012, seven months after she had finished her chemotherapy. Now that it had been several months since she had been coming to the hospital regularly for the trial drug, I asked her how that was going. She replied that she was “frustrated” about not knowing whether or not taking the drug was even necessary.

Elizabeth: Especially when I have everybody asking, “Oh, how are you doing now? You look great. You must be so happy you’re done dadada.” “Sure yes, I’m done, thank you.” Like I’ve gotten to the point --

Alyson: You don’t tell the rest of the story --

Elizabeth: I just tell people I’m feeling great, thank you. Unless it’s someone I’m close with but then they already knew that I was on the clinical trial. But any parents at school that ask, that kind of thing, I’ll just say “No, I’m feeling great, got my energy back, thank you very much”
Alyson: So the clinical trial in a way has kind of extended… ‘Cause it’s like yeah, like you finished treatment, but you didn’t really

Elizabeth: Exactly, I’m still going

For Elizabeth ringing the bell would have been futile; her life post-chemo is almost identical to her life on chemo. As of December 2015, Elizabeth remains on this clinical trial drug. Going to Lady Ann’s every three weeks to be infused with this drug has become her way of life.

As a teacher who continued working even as she went through chemo, Elizabeth now must manage two personas: 1) the public individual who has completed treatment for cancer and is thus expected to have moved beyond the threat of cancer, as her colleagues and the parents of her pupils wish to see her; and 2) the private individual who is still very much going through treatment and knows too well that the threat of cancer has not been abated. Rather than try to clarify that her situation is perhaps more challenging than they imagine, she finds it easier to just agree with them that she is happy that she is done. In other words, some patients choose to act as if they are through the liminal period and are aggregating into the cancer-free world. Thus, Elizabeth chooses to respond to her interlocutors that she is “feeling great” and has “got her energy back.” This choice indicates that trying to explain one’s liminality to others – that is, trying to make oneself legible and recognizable to one’s community in the absence of cultural categories that would make this easier - is a burden, one that many advanced cancer patients, like Elizabeth, choose not to take up.

Both Norma and Elizabeth’s stories showcase that they take the bell as a symbol of being “done treatment” very seriously. The bell as a symbol of transition is reified through their stories, even as the ritual itself excludes their own experiences. In wider culture, the binary categories of being “on treatment” or “off treatment” are regularly recognized, and caught up in those binaries is the idea that treatment for cancer is a time-limited activity, which, at some point, will be over. But the case of advanced disease proves to be an exception to this widely held notion. Both women exhibit a liminal status that is not easily communicated to others.

“It just didn’t feel over”: Ringing the bell, but doubting its meaning

Even patients who did ring the bell found it hard to believe that the treatment phase of their experience was over. For example, Jennifer chose to ring the bell but seemed to have mixed
feelings about it. When I asked her how her experience of ringing the bell was, she replied, “It was weird that day, it didn’t feel real.”

Alyson: No?

Jennifer: No. When you’re finished chemo, you ring the bell, and every time you hear the bell ring in the hospital it means someone has finished their chemo [...] So when I was actually ringing it, it didn’t feel real, it didn’t feel like there was...it just didn’t feel over, it didn’t feel done.

Alyson: Do you think it’s because it’s so close, because literally you are just getting up [i.e., out of her chemo chair]? Or do you think it’s because you knew you had more treatment?

Jennifer: I don’t...I just didn’t feel like – I still had that feeling that it wasn’t – that things aren’t done yet. I still kind of have that feeling.

In Jennifer’s case, her oncologist was sending her for radiation, following the completion of her chemo. This is the “more treatment” that I bring up, as I was also aware she was not finished in terms of her current plan for treatment. This interview actually took place after she had finished both her chemo and her radiation. I asked her if there was a bell or any kind of symbolism at the end of radiation.131

Jennifer: No, they don’t have anything. I wandered out of the hospital and sort of just walked around the streets.

Alyson: Do you remember how you felt?

Jennifer: Yeah, I walked to the [large mall in the area]. I wanted to buy something when I finished chemo that I’d remember. I remember I bought earrings. When I finished radiation, I wanted to do something and I ended up just wandering around – like walking down [street name] to get to [street name] to get to [friend’s house] and just go to sleep. It just didn’t feel...just didn’t feel...There was no real end. The bell’s an end I guess. But it’s still... (pause). Radiation there’s nothing. It’s just like you’re going to see them the next day anyways.

Alyson: Do they still congratulate you like chemo?

Jennifer: No, it’s more kind of – they – I’m not sure they know. Chemo, you’re with a nurse all day but with radiation, you’re in 5 minutes and out so you don’t get the same connection with the nurses. Not everyone knows it’s your last appointment, they just know what appointment that day. Each week your times change, you come wherever you fit.

Alyson: So either time when you finished it didn’t feel like a celebration?
Jennifer: No. Yeah and I hope that doesn’t mean….I hope that doesn’t mean that I think... I have the feeling that chemo’s not done. I kind of wonder if that’s because I think that I’m likely to have a recurrence and I don’t want to get too excited.

Alyson: That’s a hard place to be, though, right? That’s a really hard place to be I can imagine.

Jennifer demonstrates that even though she did not feel that ringing the chemotherapy bell made the end of her treatment “real,” the symbolism that this hospital routine offered was still important to her. Having participated in the bell ringing in chemotherapy, she found the lack of an endpoint in radiation difficult; her comments in the interview, weeks later, suggest that it bothered her to get up from treatment and go out in the world and try to create her own symbol. Ethnographic research conducted in South Africa on patients coming to the end of 6 months of direct-observed therapy (DOT) TB treatment similarly revealed that patients were interested in a symbolic endpoint to mark the end of their treatment. Lewin and Green (2009) found that patients would complete the 6-month DOT treatment, and would sometimes request that they continue coming to the clinic until the week ended.

That patients would want to prolong what, for many, was a burdensome daily clinic visit to receive treatment suggested that DOT had become an integral part of their routine. Yet its completion – a significant event – went apparently unmarked. Staff would record the patient’s completion of treatment into the TB registrar but, for the patient, there was no ritual marker of their reintegration into the social body. … At a point when some ritual might be expected, these patients were left seeking a natural end point, the weekend, to mark their new status as ‘healthy’ (Lewin and Green 2009:1465).

These researchers demonstrate that although there is lots of ritual behaviour in hospitals, in this case, there was nothing planned to help patients make the transition from ‘active TB patient on DOT’ to ‘person who has completed DOT.’ Similar to these TB patients who used “the weekend” as a symbolic endpoint to mark the end of their treatments (Lewin and Green 2009:1465), Jennifer went out shopping after radiation to try to mark her transition from ‘active cancer patient on treatment’ to ‘person who has completed cancer treatment.’ Jennifer reveals that she does not want to get “too excited,” because, just like Elizabeth and Norma’s stories revealed, she is not ready to believe she is done treatment yet. She disclosed her realization of her liminal status to me one day as she was nearing the end of chemotherapy, when she said to me, “I am not sure whether I am surviving or dying.” These words demonstrate that she is caught between the worlds of the living and the dying, and as a patient with advanced disease, it is
difficult for her to tell which side of that divide she inhabits. Being liminal makes it hard for her to move forward in her life, and to trust that she is getting better because she knows that the reality of advanced disease means that a recurrence is likely in her future.

“But I already rang the bravery bell”: Ringing the bell a second time

In December of 2011, four months after Deo finished chemotherapy, I accompany him and his family through the hospital on a routine visit. Along the way, I point out the newly renovated chemotherapy unit. Deo and his wife Prisha hardly take a moment to glance in that direction, saying quickly, “We won’t be going back.” But in early March 2012 when I see them again, Deo has a different story. He tells me that in January, his doctor had sent him for radiation, and then when she saw him in February, she had suggested further chemo. He recounted what he said to her at the time: “How are you going to send me for chemo again? I’ve already rung the bravery bell and all of that.” He said she replied, “Well, you can ring it twice.”

By the time I see him, he has had some time to digest this news. Deo says that when he was still in chemo, he had overheard a young man call out to the nurses that he would “See them after radiation.” So he has been thinking about that young man and has realized that lots of people go from chemotherapy to radiation. He tells me that he did not realize you could ring the bell and still have treatment to do; he seemed surprised by this and actually kind of comforted by this news. Overhearing the young man’s experience helped to normalize it for him. He says to me, “I will do my 6 cycles and if I need to do it, I will do more, and I will ring the bell again.” So he has adjusted his perspective, but he has had to do that on his own. He has realized that he will go back to the world of treatment and that it is okay to go back and ring the bell a second time.

Deo’s story demonstrates a ritual process in which liminality seems to proceed towards aggregation, but then reverses back to liminality. Each time Deo begins a new round of treatment, he believes he is moving towards aggregation and leaving the uncertainty of the liminal stage behind. Yet, over and over again, he is brought back into the liminal stage. Each new chemotherapy regimen holds yet another opportunity to ring the bell, even if its symbolism fails to translate into a cancer-free outcome for patients like Deo. The doctor’s simple reply about being able to ring the bell “twice” discounts the very powerful symbolism of the bell that Deo uses to gauge his own future. While her comment brought him comfort, it reveals that she
may not have understood just how important the symbol is for patients going through treatment. Thus, advanced cancer patients only ever appear to leave the liminal stage, because they return again and again to treatment, creating a kind of liminality that is in essence ‘permanent.’

“I will never ring it again, and here I go again”: Ringing the bell – the series

March 30/12. Writing this on Monday and have been avoiding it for 3 days now. Friday was not an easy day. I got up to chemo around 2 pm on Friday and couldn’t find Melody at first. Went to the reception desk and one woman there overheard me asking and said, “Transfusion? She’s long gone,” but I clarified that she was to have transfusion and then chemotherapy, so thought she was still there. They told me she was in “Orange, chair #30.” I walked into the Orange section and walked right by them. I walked the full circle, following the numbers up to the high 20s in Orange, and into Yellow, which started in the low 30s. So walked back through Orange and asked a chemo nurse if he could help me. He made fun of me in a playful way – said I couldn’t count –and then he walked me back towards the door.

I had forgotten. Orange #30 is the room just across from the bathroom, just to the right of the ‘bravery bell’.

I go in and find Melody, hooked up to an IV with a blood bag, and her friend Victoria sitting beside her. When Melody sees me, she says, “I’m getting the vampire blood” and shudders a bit.

She tells me that earlier in the day, when Victoria was also out of the room, she had a bad reaction to the chemo and the nurses had to rush in and stop the chemo because she was in heart failure. She makes it clear to me just how much she fought with them to stay on it. She was hardly breathing, and was choking for breath – she imitates this for me, by lowering her voice and hardly getting any air in. She said she could feel her heart racing. The nurses told her they were going to have to “cut the line” and she tried to argue with them. “How much do I have left? No, I need to stay on it.” She says she had about two-thirds in and wanted to know, “Does this cancel the rest of it?” (Meaning, I think, was it worth it to get any at all?) She said she went back and forth with them – they said that after she settles, they would see about chemo, which made her relax a bit. Then they told her they would get in contact with Dr. Girard (which is probably why Fiona [nurse from the Gyne site] comes up).

Melody tells me, “I felt relieved – the cat was out of the bag.” I ask, “What do you mean? Relieved in what way?” She kind of avoids the question at first but she repeats the word “relieved” several times that day – she comes back to it and says the cat expression again.

She said when Fiona came up to chemo, she sat on the bed and said, “No more chemo.” Later, (in response to one of her comments about how she knew something was wrong), I say “Your body is trying to tell you something” and she nods and says that is exactly what Fiona said – that sometimes chemo can do a lot of good and sometimes it does harm, and this is a time when it is
only doing harm. That her body ‘knows’ that it can’t take this treatment anymore – she has pushed it to the limit with this chemo and so she can’t have any more of it.

For the 4 hours I am there, I can see Melody grappling with this information. She says a few times, “I’m not sure what will happen with me,” wondering aloud what they will do with her.

She says to Victoria, “Remember how I was saying that this chemo was not like the others? Ever since the beginning – I just don’t seem to bounce back.” She had just said this to me over the phone the day before.

Today she says that she could tell that something was different, but she didn’t want to tell Dr. Girard because she knew they would stop the chemo right away. So she felt a little relieved I think to have the truth come out – what I interpret to be relief in not having to hide how she is actually feeling. I ask her this, “Did you tell her that you weren’t feeling well?” She said yes, she told her a few things. But she thinks that Dr. Girard could tell right away from her blood work – very low Haemoglobin, which would explain her low energy.

She tells me, “I don’t think I will ring the bell this time. Maybe it will bring me good luck.” The irony is that the bell is right outside her room and it is ringing the whole afternoon we are in there, going off several times with different patients. And she is having the worst day – so long and depressing. I worry that she is getting sicker, and notice she is wearing black wide-leg, loose pants and a billowy black top, but can see that she is bloated all over.

On that day in March, Melody was in a life or death situation brought on by her chemo, and was saved by the quick attention of the nursing and medical staff. In essence, she had received so much of this chemo drug in her lifetime as a patient that it had reached toxic levels in her bloodstream. This means she could never receive this same drug again. But despite almost dying on this chemo, Melody tried as she might to get them to hold off on cutting the line, so scared was she that it might signal the permanent end of treatment for her.

But this was not the end of her treatment story by any means. When I met Melody in February of 2011, she was in the middle of her second round of chemotherapy for ovarian cancer. This instance occurred towards the end of her third round, cutting it short. But she began chemo again the following winter, on one round from Jan 2013 until June 2013, and then on a new round in December of 2013. She remained on treatment until March of 2015, making it over the threshold of one year – 16 months – of continuous treatment, which was a milestone even for a long-time patient such as herself. In March of 2015, she decided to go off treatment and take a trip to the U.S. to visit her son. But she started up chemo once again upon her return.

This is the life of treatment – the life of multiple bell ringings. In preparing to ring the bell at the end of her second round of chemo, she said to me, “I rang that bell last time and said to myself I will never ring it again, and here I go again.” Melody had in fact “rung that bell three
times already,” as she informed me on another day – once for breast cancer, 20 years ago, and twice since 2008 for ovarian cancer. In preparing to “not ring the bell this time” to mark the end of her third round of chemo for ovarian cancer, which she revealed at this encounter in March of 2012, she was hoping that a change in her routine might bring her some sort of luck. Melody, more than anyone, knows that the outcome she is hoping for is very unlikely. On more than one occasion, I overheard Dr. Girard tell her, “There’s always chemo…we can always start again,” when she was temporarily off treatment and feeling particularly badly. But that reality does not prevent her from hoping in this moment, that some small change in her behaviour might tip the scales in her favour.

Ringing the bell brings into relief the liminality of patients facing advanced disease, for whom life may be lived as a cycle of ringing bells. For patients like Deo, who celebrated the moment and believed in its transformative power, the bell comes to assume a different meaning for him once he finds out he might ring it again. For someone like Jennifer, the bell’s symbolic power is important, but she can hardly believe it to be true. For others like Elizabeth and Norma, the bell’s link to reality is too sharp: it cannot be rung until treatment is really “done” and since they are both unsure of when that will be for them, they are not interested in ringing it. Melody, someone who looks forward to ringing it and to the end of treatment, is already well-versed in its symbolic potential and limitations; she knows too well that ringing the bell is a transition that will fail to take her back to the life she was hoping for. Rather than something that must be endured and then moved beyond, Melody says, “I will live my life like this. I will be on chemo for the rest of my life.”

**The chemotherapy bell as a multivocal symbol**

I came to see performances of ritual as distinct phases in the social processes whereby groups became adjusted to internal changes and adapted to their external environment. From this standpoint the ritual symbol becomes a factor in social action, a positive force in the activity field. The symbol becomes associated with human interests, purposes, ends, and means, whether these are explicitly formulated or have to be inferred from the observed behavior (Turner 1967:20).

The symbolism of the bell and all it represents becomes imbued with myriad conflicting feelings – hope, fear, disbelief, confusion, mistrust – as patients come to realize that further treatments might be in their future. I focus on the bell ringing because it is foremost a symbolic
activity and a performance. According to ritual scholar Catherine Bell, Turner’s contribution to the literature on symbols was to argue against Levi-Strauss, who saw them as timeless entities, and to show that they do not have fixed meaning but “can condense many meanings together” (1997:41). This means that symbols are “inherently multivocal” (Bell 1997:41). The meanings associated with chemotherapy are indeed multivocal. As one of my participants described to me, it is highly ironic that what all cancer patients are ‘hoping’ and even ‘begging’ for is chemotherapy – when they know that getting the drugs will actually make them feel sick and depleted. Even the name of the “bravery bell” has a conflicted meaning. Patients do not ring the bell when they are feeling particularly brave, but when they have attained the goal of finishing treatment. Its name recognizes that chemo itself is scary business, and takes the form of an assault on the body. Thus, getting to the end of chemo does signal a kind of victory that should be recognized.

Turner also argued that ritual symbols must be analyzed within the context of action in which they unfolded “for symbols are essentially involved in social process” (Turner 1967:20). Along the same vein, Van Gennep (1960) argued that the meaning of a ritual could not be deduced from looking at one aspect of the ritual; rather, the whole sequence of events and what came before and after it needed to be analyzed (Bell 1997). The bell ringing provides a prime example of one hospital ritual that can be examined as it unfolds in action. None of the nurses in chemo, in asking patients if they are going to ring the bell and gently encouraging the practice, ever say “this will be the end of treatment for you.” In fact they would never say that, even if they hoped it to be true, as they do not know each patient’s case in detail. But this is what patients infer from the practice, which takes place in a very social space, with many witnesses. For example, Jennifer told me in an interview that on the day she finished chemo, her nurse had joked with her, “I’ll see you at Loblaws sometime”:

Alyson: It wasn’t because you had seen her in Loblaws?

Jennifer: No!

Alyson: Oh, that’s so interesting. I would have interpreted that that you must have run into her there before

Jennifer: No! That was her way of just kind of saying, ‘I don’t want to see you back’ but you know, ‘I’ll see you, I hope that I’ll see you’
Jennifer brought up this nurse’s comment, saying, “It was just the perfect thing for her to say, because you know, you say to somebody, ‘See you again!’ You don’t want to say that when you’re leaving chemo.” So although the nurse did not say to Jennifer, “You are done treatment,” she conveyed that this was her wish for Jennifer.

Turner (1967) also took pains to highlight the performative role of rituals in helping groups to adapt to internal changes and to the external environment, and the bell ringing is no exception. The purpose of the bell ringing performance, like other rituals, is to “enact and institutionalize culturally constructed categories” (Lewin and Green 2009:1465) such as those that delimit who is sick and who is well. The event serves as a kind of “drama” that works to reinforce the importance of the transition that it symbolizes (Turner 1969:59). The bell ringing is a very public activity: patients stand near the doorway opening into the chemotherapy unit and are flocked by family members and friends, along with nursing staff. The liminality framework helps to recognize these witnesses and participants in the bell ringing ritual, and the importance of their role in recognizing the status change in the patient that is symbolized through the ritual.

Thus, the bell ringing ritual attempts to reintegrate “the ‘sick’ person into the ‘healthy’ social body” (Lewin and Green 2009:1465). Chemotherapy removes patients from the normal social order and submits them to a period of time where their actions and behaviours must be strictly monitored. For example, they must remain vigilant about sickness and any risk of infection from family or friends or from members of the public. I can remember talking to Paul one day in the lung clinic and we were celebrating a recent appointment in which he had been given good news, and rather than hug he suggested we “touch elbows.” This was the modified behaviour he had come up with in order to still have physical contact with family and friends and keep himself free from potential germs. Many chemotherapeutic agents still cause hair loss, and this was experienced by all of the Gyne patients I followed. Hair loss is the most visible and recognized bodily manifestation of cancer in contemporary culture; completing a round of chemotherapy gives hair a chance to grow back, allowing a person to once again fit into society without being marked as a ‘cancer patient.’ Lastly, although patients today coming to chemo are treated in their regular clothes, Melody and her friend Victoria had both been treated for breast cancer at Lady Ann’s predecessor 20 years prior. They recalled for me with vivid clarity that in those days they were required to put on striped hospital gowns, which they described as “prison outfits.” Their outfits, in addition to their being made to wait all day in order to receive
treatment, certainly heightened their experience of being made to feel ‘other’ and separate from the normal social body.

One important difference from Turner’s (1967) original formulation of liminality is that the bell ringing performance does not actually help patients adapt to a new identity, because there is no new identity on offer. Unlike most liminal subjects, living with advanced cancer requires that they manage multiple identities – with some aspects of their identities foregrounding their liminality, and others hiding it, so they are not always part of the socially sequestered anti-structure (Turner 1967). Elizabeth’s story reveals that she is participating in the social structure and returning to her work responsibilities; however, she is also part of the anti-structure, because she conceals the reality that her clinical trial treatment continues. In this sense, Elizabeth confirms the experience of a participant living with life-threatening illness interviewed by Bruce et al. (2014:40), who recounted that “different kinds of stories needed to be told to make his diagnosis either visible or invisible.” Rather than see herself as ‘sick’ or ‘not sick,’ a firm resident in the “village of the sick” or “the village of the healthy” (Stoller 2009), Elizabeth’s health status seems more fluid, as she moves between these two polarities and varies her response to the question of ‘treatment being over’ depending on her audience.

In this section, I have shown how a rather banal object – a bell – comes to take on a highly symbolic meaning when it is placed in the context of everyday life of a patient with advanced cancer. The bell ringing serves as a cancer “milestone” – a symbolic action that marks a particular part of the cancer patient’s journey. Buchbinder et al. (2009) found that parents with cancer used similar symbolic means of conveying their progress through treatment to young children. For example, in one household, a family member got to eat off a special plate if something special happened to them that day; a mother reported eating off this plate on the day that she finished chemo, because she wanted to translate the symbolism of the day for her children and she wanted them to “understand her health as moving in a positive direction” (Buchbinder et al. 2009:224). In this sense, both ‘special plate’ and the ‘chemo bell’ carry the same symbolism.

Despite the very positive, celebratory nature of the ringing the bell, it may serve as yet one more reminder to patients with advanced disease that they should not get, in Jennifer’s words, “too excited” since their situations are not the like others. For patients with advanced disease, the ringing of the chemo bell is a somewhat “flawed ritual” (Lewin and Green 2009:1467) – there is no aggregation or re-incorporation to a cancer-free life, there is only more liminality. While no
cancer patient ringing the bell can know whether his cancer is really ‘gone,’ patients with advanced disease have not begun treatment with any assurance from the oncologist that it would be curative in intent. In choosing to ring or not ring the bell, patients make a statement about their liminal structural position. Patients’ variable perceptions and experiences demonstrate how ongoing cycles of treatment place patients in the liminal space of advanced disease, and that it is a space not easily left behind. Patients participate in the ritual of ringing the bell, but the ritual itself serves to hide their liminality. The internal struggles that patients endure are made invisible through symbols like the chemotherapy bell.

“There’s Nothing You Can Do, But It Will Come Back”: Living with the Assurance of Recurrence

Once patients complete the first line of treatment (chemotherapy or radiation or surgery or often, some combination), marked by ringing the bell or not, they try to move forward with their lives. They are often given a reprieve from treatment. This allows the body to recover from an aggressive therapeutic regimen and to see what will happen to what was a growing tumour. If the tumour remains stable or reduced, or there is no longer visible sign of it, there might be a long period between this first round of treatment and subsequent rounds. This time between the first treatment and what will be future treatments varies for each patient, as each person’s cancer is unique to his body. This waiting time is very difficult to withstand for patients, because the message they receive from their oncologists is that there is very little they can do to fight the cancer in the present or prevent it from coming back in the future.

For example, I spoke with Julia, a woman who had been treated for ovarian cancer in her native country of Peru, where she was first diagnosed in 2003, as well as receiving treatment in the U.S. before moving to Canada. She said in the U.S. she was being followed regularly “every 3 months” with a “blood test and CT scan once a year.” When she moved to Canada, she was referred to a doctor at Lady Ann’s. She reflected on her first conversation with this physician:

Julia: He was a senior person, so he was already tried in all kinds of battles. So the one thing I asked him is, “Is there anything we can try to prevent this from coming back?” ‘Cause that was like my main concern throughout those years – is this going to come back? And he said, “There’s nothing you can do.”

So this is when we discuss how often should I see him – whether it should be a year or 6 months or what.
And he said, “Well, there’s really not much point in seeing you very often, ‘cause there’s nothing we can do to prevent this from happening. As soon as it – if it comes back, as soon as it comes back, then we can do something, but in the meantime there is really nothing we can do.”

Alyson: That must have been hard to hear

Julia: “There’s no preventive treatment, there’s no nothing.” So we agreed that I would come every 6 months. And that was good enough – I was happy at least with…the fact that we had that discussion.

Um, so I think that was a good experience with him. But he was blunt about it. He said…he also said things like “It may” – I was already 5 years after, so many people with other types of cancer think – or they used to say, I’m not sure if they are still saying it – after 5 years you are kind of --

Alyson: Home-free

Julia: You can consider yourself cured. He said to me, “Not with the kind of cancer that you have. It may come back every 2 years after, 5 years after, 10 years after, 15 years after. It may not come back – we don’t know. But this is a cancer that has a history of recurrence. And it’s a good thing that it hasn’t recurred so far, but that is no guarantee that it won’t.”

So he was very clear about that. And he also said, “There’s nothing we can do.” So, you know… (laughs uncomfortably)

Alyson: That’s pretty hard to hear

Julia: So yeah…so at the time I guess, I take this information with my rational mind I suppose. And like…when I’m feeling okay – when you are feeling fine physically, you can take a lot more of this because it’s just a mental kind of exercise. It’s when you’re sick that any of this becomes really…overwhelming and difficult to take in.

As this interview reveals, Julia is caught somewhere between trying to move on with her life and the reality that it is likely that the ovarian cancer will recur. And in fact in her case it did – the reason I had met her was because she had come to have treatment again for a first recurrence. She is reflecting on that time in her life when she felt that perhaps she had moved beyond the cancer and was hoping that in this first meeting with her oncologist at Lady Ann’s, she was going to gain some support for that position. But the doctor cannot say that it will not come back; all he can say is that with a “history of recurrence” it tends to come back.
Elizabeth expressed similar frustration with not being able to know for sure whether there was still disease in her body at the completion of her first treatment. In her case, she went through a first round of chemotherapy to treat a slow-growing ovarian cancer that had been detected when she was preparing to undergo IVF. They had found her tumour by accident, and submitting herself to 10 months of treatment was a very different plan for the year ahead than she had been hoping for. She got through treatment and then waited with trepidation to hear the outcome of that treatment, which she assumed would be obvious from the CT scan ordered post-treatment. In general, the first appointment following the completion of chemotherapy was a highly anticipated appointment, as patients hoped that they would be told that the chemo had reduced the cancer in size or made it disappear completely. In actuality, when Elizabeth went to that first follow-up appointment post-treatment the doctor told her that since her disease had been microscopic, the scans did not reveal whether or not the chemo had worked and they would have to wait for the tumours to grow larger again before they could be detected.

When I interviewed her shortly after this conversation, she admitted that she had been expecting that they would be able to see cancer in the CT scan, “I had it in my head that CT scan showed everything.” She said, “Finding out that it didn’t show, wouldn’t show…” and her voice trailed off, showcasing how difficult it was for her to accept this news. This was not only because it was not a positive result (being cancer-free), but also because it was a non-result (no definitive answer). During the interview, when I asked her about what she would hope for in terms of communication with her oncology team, she replied, “Ask me next week when mom and I try to insist there’s got to be a surgery of some sort to tell whether there is – to find out definitely if it’s gone or not.” So in that moment, she seemed to be rejecting the medical uncertainty she had been offered and had devised a plan to try to push for more information. However, she did recognize that it was likely the “nature of cancer” that accounted for the lack of a “definitive answer,” saying to me, “They can’t give me one because they don’t know.” While Elizabeth hoped for further clarification about her specific case, her comments indicate a general acquiescence to the limits to her doctors’ knowledge and ability to predict her future.

When we sat down for a second formal interview in June 2012, the lack of a “definitive answer” still bothered her:

I also still don’t know whether I still even have cancer. Which is my most frustrating thing. I don’t know whether I still have the cancer. So am I really needing to put these toxins in my body? ‘Cause maybe they are doing something – maybe they are
keeping the cancer at bay – maybe they’re completely unnecessary. Who knows? We don’t know until it grows back.

Where she was frustrated in November, her comments in June suggest her perspective about her situation had changed slightly, as there was no more talk of “pushing for a test.” During those 7 months, she continued to come to the hospital every 3 weeks to receive the clinical trial drug. Although she continued to be disturbed by “not knowing,” she had in some way accepted her predicament and had learned to live her life with that uncertainty. And, in fact, as of December 2015, Elizabeth continues to take the clinical trial drug, going to Lady Ann’s every 3 weeks to receive treatment, almost five years from when she began. A routine she started in July of 2011 and which continues indefinitely.

What both Julia and Elizabeth’s stories illustrate is that they are a little bit stuck in the liminal phase – both wishing they could move on from cancer and leave it behind, but both being unable to do so. Despite what we see in the movies and hear about in the press, there is nothing that they can do which will change that situation. The challenge of advanced disease in contemporary times is astutely summarized in a quote from an oncologist in a recent PBS documentary entitled *The Truth about Cancer* (2008): “Cancer doesn’t fight fair. It doesn’t matter or care how strong you are, what you look like, or how much money you throw at it, or how dedicated you are…If you have an aggressive cancer there is nothing you can do.” Both women can only wait to see what happens. But of course waiting produces consequences on both their lives. In other words, the liminal stage of advanced cancer is not pure, socially sequestered “anti-structure”; patients continue to work, care for families, and so on. In Elizabeth’s case, she was hoping that after chemotherapy, she would be able to re-consider IVF treatment.

I sat through the conversation with the oncologist where she raised this topic – something she admits was much harder to talk about than her cancer experience. After her appointment in November, she recalled, “Some friends are like, ok, what’s the next step, what about fertility?” I had to say, ‘No, it’s probably off the table.’” So she can move forward with her life, but not with the things she had planned for herself. Although cancer has no definite return date in her life, it has definite consequences on her life. For Elizabeth, it is the “not knowing” that she finds extremely frustrating. She uses her hands to indicate two clear scenarios, and how she likes things to be “black and white.” With her gesture, she physically demonstrates how she is caught in the ‘middle ground’ grey area of liminality. This is not an acceptable position for her, because
it seriously curtails any plans for her future. Living with the certainty of recurrence with no certain timeframe keeps patients stuck in transition.

“If You’re on Your Last Legs, Maybe We’ll Treat You”: Waiting to Get Sick Again to Get Access to More Treatment

March 23/11. I’m observing in the lung clinic today and have opportunity to meet and recruit Dario into the longitudinal study. I sit in on his consultation with one of the lung cancer fellows (Dr. Lisette). The doctor enters the room and goes through some standard introductions, telling him, “I’m just one of the cronies working with Dr. Lawson. I’ve never seen you before.” She asks if he is having any typical symptoms, such as nausea or vomiting, cough, appetite, chest, diarrhea, constipation. He says yes to the nausea or vomiting, but then says, “To tell you the truth I feel fine’. Dr. Lisette replies, “Yeah, you’re like an asymptomatic.” Then she gets into the nitty gritty of his current treatment plan:

Dr. Lisette: With respects to the plan, last time you had radiation, then chemo. That ended in December. We’re following you up on regular basis? You haven’t heard of anything else? [my fieldnotes include question marks, indicating that these were asked as questions, rather than statements of fact]

Dario: Hadn’t heard

Dr. Lisette: This is how it usually goes. You get the full treatment. We need something to treat (emphasizing) – if something growing somewhere, then we can go back & treat

Dario: (bringing up something that happened before) Downstairs…it surprised me and my wife – are we doing any follow up MRIs?

Dr. Lisette: No

Dario: If we are waiting for symptoms, wouldn't I be worse?

Dr. Lisette: A lot of cancer goes like that, but that’s maybe not comforting to hear. They’ve done studies to see that seeing people intermittently does not change reaction. How we follow lung cancer here is x-rays and bloodwork

Dario: I thought x-rays don’t show much

Dr. Lisette: Sometimes CT as well but not as often as x-ray

(Shi is explaining, seeing his perspective. They move onto the physical exam and then as they are wrapping that up, Dario asks her whether stem cells would work for his “condition,” and then he shows her something on a piece of paper that I can not see. It seems to be about some kind of drug treatment, as she comes back around to talking about treatment cycles.)
Dr. Lisette: Wait for progression. It’s like ‘line-ups of chemo.’ Do 1st, then wait. If progress, go to 2nd. ‘Sort of like a timed arsenal’

Dario: If this is worth trying...

Dr. Lisette: (says the name of the drug on the paper) I’ll bring it out

Dario: Suppose it did help to extend life. I’m not at that point yet, but...(trails off). I’m looking for something to do rather than sit here and wait. Better that we try

Dr. Lisette: You do have to be careful that you don’t get everything too quickly at the start. We’ve found that what prolongs survival is to give one at a time. Sometimes people will go through everything too fast

This short interaction between Dario, a patient who was at the time on 2-month follow-up, and the representative of his oncology team (that day Dr. Lisette) demonstrates the kind of resistance that patients run into when they try to move forward in their treatment plan. I remember this interaction very clearly, because I recall how patiently Dr. Lisette explained why going forward with treatment was not the best approach right now. In late March I was just short of two months into fieldwork and so this came as news to me as well. Yet, sitting in the room with Dario and Dr. Lisette, I thought what she said seemed to make sense, especially because it was being framed within the language of “studies” (i.e., ‘science’). But of course it was not me who was sick or me who was being put off from pursuing a potential treatment option that perhaps had brought some comfort; this was Dario’s life we were talking about – not some abstract amount of “prolonged survival”, but his survival.

When I spoke with Dario about this interaction, several months later informally in a chemo visit one day and subsequently in a more formal interview, he held onto the disbelief that this was the right approach to take. As he said on that day in March, “If we are waiting for symptoms, wouldn't I be worse?” cutting to the real substance of the issue, i.e., if symptoms mean the return of the disease, then why are we waiting for that to happen? Dr. Lisette is ready for the question and took the time that day to really try to explain it to him in a way that made sense rationally. But it is not an abstract thing Dario is talking about: it is his life. He wants to know why they are not throwing every treatment at it and trying to do their best to prevent it from coming back. In our interview, he brought up the issue of not getting any follow-up care after the radiation to his brain, which he touched on in the March appointment:

I had the radiation and I think I asked the question “when are you going to…how are we going to follow up on the brain?” And basically I got told ‘we’re not’ -- unless
you have symptoms. So until I start experiencing headaches, nausea, falling down where they know there could be a problem, that cancer’s recurring in the head, or has recurred, they are not going to scan or put an MRI on my head. (pause)

I think I asked the question “I thought we’d be proactive, rather than reactive?” “No, no it wouldn’t affect the treatment we’re going to offer you”. And this is where it kind of flabbergasts you, right, and you go ‘why?’

Dario recalls being “flabbergasted” with the idea that they were not going to be proactive with his care. Talking to Dr. Lisette that day, he said, “I’m looking for something to do rather than sit here and wait. Better that we try.” Here, he is referring to both the treatment for his brain metastases and for his primary lung cancer. In his mind, it would be better for his oncology to give him any medication at all, rather than waiting for him to be “worse.” He finds it very difficult to accept that the best strategy moving forward is to wait until he is sick again before initiating more treatment. Later on in the interview, when I tell him that I recalled that conversation because it was the first time I had heard it explained that way, he replied, “Yeah, like you know, you sit there, ‘Okay, if you’re on your last legs maybe we’ll treat you.’ That’s kind of the interpretation you get from it.” Although he conceded that perhaps there were some variables affecting the limits on treatments (e.g., you can only get whole brain radiation so many times), he insisted that knowing you had treatment options and they could be pursued “definitely is piece of mind from the patient’s perspective.”

The idea that some treatments may be held onto ‘for later’ brings to the surface that he and his team have different treatment goals in mind. From the oncologists’ perspective, they know they are dealing with a cancer they cannot cure. Thus, their goal is palliation, to improve his symptoms and give him a better quality of life as he approaches the end of life. According to Dr. Lisette, the best way to do that is to have a “timed arsenal” approach: to hit Dario with one treatment, and let him recover, before he gets hit with another one. Otherwise, his quality of life would be very poor. And since they know they cannot ultimately cure patients from their lung cancer, poor quality of life is not seen as a sacrifice worth making because the reward that patients hope for (i.e., cure) is not coming. From the patients’ perspective, the goal is complete reversal of disease. This is why Dario wants to be monitored regularly and have his brain metastases followed up on, since he knows they will cause him considerable cognitive problems. What he hears from Dr. Lisette does not make sense to him; he does not understand why his health care team is waiting for him to become sick again, rather than be preventative and take out the cancer before it comes back. But prevention is not a goal that his oncology team can work
towards, because they know that incurable cancer is just that: incurable. Thus, the “watch and wait” approach contains within it an important implicit message. What Dario’s team is not saying, but which is hidden in their decision not to follow him up after radiation treatment for brain metastases, is that they do not expect him to live long enough for the side-effects of radiation to matter.

The ‘watch and wait’ approach illustrates the limitations of oncology, and highlights patients’ liminality. Dario’s team recognizes that he is in the liminal space of advanced disease, and the only possible reintegration awaiting him is death; therefore, their treatment plans focus on making him feel as well as possible for as long as possible. Dario resists this approach, and wants his team to behave as though reaggregation as a ‘survivor’ or a ‘not sick’ person might still be in his future. Thus, from one perspective, he seems not to have come to terms with his liminal status and the trajectories that remain for him: 1) more cancer, or 2) death. But from an alternate perspective, his hopes for himself are precisely in line with his liminal status. Dario speaks in the subjunctive mood – “the mood of maybe, might be, as if, hypothesis, fantasy, conjecture” (Turner 1986:42) – and it is this mood that characterizes liminality. His story showcases that there can be resistance in liminality because in this case, the ‘ritual experts’ are guiding him in a direction he does not want to go. Dario’s story exemplifies that patients try as they might to change the direction of their care and to get support for their dreams of a cancer-free future. Unable to change his liminal status, Dario rejects the pathway towards death that he has been offered, and prefers to imagine that his illness still holds a “storehouse of possibilities” (Turner 1986:42), including the possibility that he might live.

**Liminality Revisited: The Consequences of Being Structurally Invisible**

The subject of passage ritual is, in the liminal period, structurally, if not physically, ‘invisible.’ As members of society, most of us see only what we expect to see, and what we expect to see is what we are conditioned to see when we have learned the definitions and classifications of our culture (Turner 1967:95).

What does it mean to say that someone is physically present, but structurally absent? It means that we cannot recognize them, and, in turn, they may not be able to recognize themselves. They fail to chart their own course because what is offered up to them does not match up with their experience. Olivia, who survived ovarian cancer in her early 20s only to
have it recur 7 years later in a much more aggressive form, told me everything about her cancer was “unusual”; “It’s very difficult for me to find a path that looks like mine.” These socially sanctioned ‘paths’ are how we make sense of our own experiences, and how we come to accept them. Victor Turner demonstrated that the liminal being is “at once no longer classified and not yet classified” (1967:96). He argued that liminal beings – having physical presence but structural invisibility – were dangerous and in need of hiding because “it is a paradox, a scandal, to see what ought not to be there!” (1967:97). In Ndembu society, he said they would not tolerate the existence of a “not-boy-not-man,” which is exactly what a neophyte going through a circumcision ritual is (Turner 1967). Applying these ideas to contemporary discourses on cancer, it seems worth asking then, can we allow for the existence of a “not-dying-not-surviving” person with cancer – a person who is not yet dying but at the same time not getting better?

In the contemporary discourses of cancer, there seems to be three potential sources of re-aggregation for patients: cancer survivorship, chronic illness or death. Patients with advanced cancer trouble these categories because although they would like very much to move into a survivorship phase their disease often does not give them enough reprieve to allow that to happen. The second option – chronic illness – is also often foreclosed because it is suggestive of something that can be controlled through pharmaceutical and lifestyle modifications. Although some patients live with advanced cancer for some time, it is anything but controllable, and always threatens to encroach on their lives, without warning. The last option – death – is their only option for reincorporation, but it is not imminent. Thus, no framework adequately makes room for their experiences. As such, I believe that patients living with advanced cancer are somewhat invisible in cancer discourses. They are physically present in society, and yet somehow structurally absent, because we fail to perceive their experiences for what they are.

Here I am using Douglas’s (1966) sense of perception, where she discusses how we come to recognize particular things in our culture, not because of a memorized list of what exists, but through the act of perceiving, and we slot things into categories in our minds that do not challenge what is already there. When we encounter people or things that are ambiguous or anomalous we can choose to adjust our categories, but often this is not how we behave. She outlines that we can treat anomalies in several ways: “negatively, we can ignore, just not perceive them, or perceiving we can condemn. Positively, we can deliberately confront the anomaly and try to create a new pattern of reality in which it has a place” (Douglas 1966:48). The avoidance or ignorance of people with advanced cancer is less an explicit or direct kind of
avoidance than a more implicit one. For example, when a friend asks a patient how she is doing, and if she is “done treatment?” and it becomes impossible for the patient to tell a different kind of story – one where treatment continues indefinitely in her life, as a means of staving off her disease and thus keeping her alive. It is much easier to treat patients with advanced disease as if they harmonized with the rest of the pattern (Douglas 1966); in other words, to treat them like patients with curable, less advanced cancers.  

Anthropologists have explored this feeling of structural “invisibility” for other types of persons (Murphy et al. 1988; Gaur and Patnaik 2011; Kaufman 2000). For example, Murphy et al. (1988:239) note regarding the physically disabled, “all users of wheelchairs know that when they are in public places, they are commonly noticed by everyone and acknowledged by nobody.” With respect to cancer survivors, Casper and Moore (2009:19) have shown that the hype and celebration of a figure like Lance Armstrong, who survived cancer and won the Tour de France post-illness, can potentially obscure “the mundane lives, daily struggles, and profound suffering of ordinary people with cancer.” There is a function to this kind of selective blindness. Jackson (2005) has shown that chronic pain sufferers challenge firmly-held biomedical notions about the presence of a physical or biological source of disease. In a similar way, patients with advanced disease threaten the moral order, by challenging the widely-held notion that many people diagnosed with cancer today will survive their disease. They also provide us with an uncomfortable reminder of our own mortality (Kleinman 1988). So rather than make them obvious, we must hide them or contain them. The late Canadian federal politician Jack Layton hid how sick he really was from the country, not wanting to destroy hope for other cancer patients. His mortality was never acknowledged until suddenly it was, when his death shocked the country. Being “invisible” comes at a cost to patients, and to their loved ones, because their situations are not relatable. As Gray and Sinding have eloquently argued, “people with advanced disease have to deal not only with the crushing and physical emotional demands of bodily deterioration but must also navigate a course through a societal context that makes little or no room for their circumstances” (2002:32). For the patient with advanced disease who finds that the cancer discourses that surround him have little direct bearing on his lived experiences, the disjuncture results in a feeling of isolation and social abandonment (Saillant 1990).  

Elizabeth struggled to be honest about her cancer experience with people at work and with parents of the kids she taught:  
Elizabeth: Most people assume I’m done, and unless I see them on a daily basis, I’ll say
I’m done my chemo. Obviously my kids know I go every few weeks – if parents ask I’ll tell them I’m continuing a research drug to help out, I don’t give them many details. Most people, just casual acquaintances ‘I’m doing great, I feel fine’

So yeah it does feel like it’s extending the treatments but then… it’s just what I’ve got to do, deal with, so (awkward laughing)...I don’t really have much of a choice at this point

Alyson: I was going to say, like how does it feel for you like on a daily basis to have to keep coming? You can’t, I’m guessing, feel like you’re moving beyond, right?

Elizabeth: I can’t…obviously, I’m…At work, it's like I’m totally fine. The staff every so often is, “How are you feeling?” and they will make comments about my hair growing back and that kind of stuff. But, other than that…I feel back to normal at work…

Later in the interview she comes back around to how she answers, “How are you feeling?”

I’ll answer them and tell them I’m feeling great, ‘cause that’s what they want to hear. Most of them don’t want to hear the negatives of it. They just want to hear that everything’s going to be fine. So I tell them everything’s going to be fine.

Rather than be able to be open and honest that for her treatment is not ‘over’ but continues indefinitely, she is pressured to emerge from treatment as a Survivor. To lie and say, “Everything’s going to be fine,” when she knows that not to be the case requires that she deny her daily experience and what life looks like for her. Elizabeth’s awkward laughter was echoed in a conversation I had with Pam, when she told me she had started up chemo again, and was suffering some of the same side effects that she had experienced in her first round of chemo.

Alyson: I’m so sorry you have to go through that again

Pam: (awkward laughter) It’s ok, we knew it was going to come, right?

For both Pam and Elizabeth, the awkward laughter might represent that they are unsure what is the best way to react. They know that they are not in an enviable position, and they are not happy about it, but they cannot continue to be upset about it, especially with others, so they aim for light-heartedness. But to some extent, this ‘light-heartedness’ comes at a cost to them – it requires that they deny certain aspects of their reality (that they are sick) in order to make it easier on the people around them (who would like them to be better).

In her introduction to *Improving Palliative Care for Cancer*, Kathleen Foley argues, “we have words for ‘survivors’ and those in active treatment, but even today, those with advanced
disease who are not in active treatment and who are dying are nameless and faceless without a priority” (2001:10). But what about those who are in active treatment and are at the same time moving towards dying? Where do we place people such as Melody, Elizabeth, Dario, Julia, Olivia, and Deo? We rarely think about what it’s like when people get somewhat better at the same time as they get somewhat worse. We do not acknowledge that rather than proceed from treatment towards survivorship or palliative and end-of-life care (Figure 4.1), the patient with advanced disease faces an overlap of all these three worlds (Figure 4.2), and she may continue to move between all three right up until death. This trinity has been created by the advent of modern medicine, and the availability of cancer treatments, even for the patient with advanced disease (Gawande 2010).

Thus, patients with advanced disease conform to liminality in that they move into this structural middle ground and get treated differently. They may form a sense of communitas with other cancer patients in the waiting and treatment rooms of the hospital. Turner (1967) defined this widely, suggesting that members who underwent admission to secret societies together would remember those bonds for the rest of their lives. Communitas is at times observable in the chemotherapy unit. Elizabeth noticed that she was always in the chemo waiting room with the same two patients: two older men with different types of cancer, who were always accompanied by their wives. She would watch for both these couples on her chemo days, and check in with them about how they were doing. When they did not appear on her chemo day, she would worry and wonder aloud that they were absent because they were not doing well on the treatment.

Although they conform to some aspects of the original framework, patients with advanced disease challenge other aspects. Firstly, the communitas that has been demonstrated amongst disabled persons undergoing physical rehabilitation therapy (Murphy 1988:240) or cancer patients going through an intensive weeklong rehabilitation program (Tjornhoj-Thomson and...
Hansen 2013) is not the same with cancer patients who are in ambulatory care. Ambulatory care makes it more challenging to form communitas, because patients are always entering and leaving Lady Ann’s in order to receive care, which means that are always tacking back and forth between their cancer and non-cancer lives. Although two patients may connect and have a great conversation one day as they sit side-by-side in chemo or in a waiting room, there might never see each other again. This means that patients might have to make new bonds on each visit to Lady Ann’s.

Secondly, the liminal phase normally marks a point of transition between two clearly demarcated ends. The path the initiate needs to take lies straight ahead, and he is guided or shepherded through the transition by ritual experts. Imagine, for example, a circumcision ritual, turning boys into men – transition occurs in one direction only. Doctors and nurses can be likened to the ‘instructors’ or ‘ritual experts’ that Turner (1967) refers to as guiding the neophytes through the ritual process, who bear witness to the liminal phase but do not enter it themselves. Families and friends are also present as well, and supporting the patient. However, instructors are supposed to have undergone the ritual themselves, which causes a significant challenge in the context of incurable cancer. Doctors and families may attempt to guide them on their way, but have limited knowledge about what it feels like to live in a condition of liminality if they have never faced terminal illness themselves.

Thirdly, the persistent state of liminality that patients experience means that they do not remain in the socially sequestered space of ritual. The stigma associated with cancer (and with its visible signs, such as headscarves or bald heads) means that they are actually quite visible in society. So rather than be protected and guided through their experience, they become weighed down with the expectations placed on them from cancer’s exoskeleton (Kleinman 1988) such as how to behave like a good patient, and what to do to fight back against to their illness. People want to do things in their name, like run marathons or raise money for them, and these activities often require the patients’ endorsement and some level of participation. Patients are showered with good intentions and advice about what they can do to help ‘cure’ their cancer, but these often well-intended suggestions only result in further encumbering the patient with advanced disease (Hitchens 2012). Thus, there is a certain irony in that cancer is one of the most visible illnesses in society today, due to its most frequent side effects; yet patients with advanced experiences are “invisible” or unable to be recognized. As I have tried to show, this “politics of erasure” (Casper and Moore 2009) results less from a concerted effort on the part of society to
deny their experiences, and more from an unwillingness or inability to modify our common associations between cancer treatments and cure potential. By modifying our social categories to better reflect the large range of people living with life-threatening illnesses – including patients with advanced cancer, for whom treatment continues until the end-of-life – we would allow them to live more honestly with those illnesses, rather than force them to try and package their experiences into a mould that does not fit.

**Conclusion**

In October 2014, I receive an update email from Melody:

*Unfortunately there is no chemo break for me for a while. My numbers have gone up and [the doctor] told me I’ll be on chemo until the end of the year and we’ll book another CT scan. It will be a year Dec 1st that I’ve been on chemo without a break. I’m booked for October, Nov and Dec. I’m a bit worried.*

Melody has been on treatment so long that she has to remind herself, when she is feeling lousy, “Oh right, it’s because I’m on chemo.” For her, receiving chemotherapy has become her norm; this is increasingly true as the breaks she receives from treatment become fewer and far between. For Melody and other patients in her circumstance, their permanent liminality constrains the choices they can make and narrows the possibilities for their futures. It requires that they juggle their ‘sick’ (e.g., coming to Lady Ann’s, dealing with side effects of treatments) and ‘not sick’ (e.g., work responsibilities, family expectations) lives. Melody cannot plan any long trips to visit her son because she cannot be off treatment for that long. Pam cannot plan to go back to work – something she greatly desires to do – and has been told, “not to worry about that” in the near future. Elizabeth cannot initiate in her plan to try IVF, since she has been warned that the cancer is likely to return in less than 5 years. Thus, what they are moving towards is into a new space – a life always lived with cancer – “a career of being ‘sick’” (Murphy 1990:19).\(^\text{135}\) For patients with advanced cancer, treatment is the means of keeping them alive, and thus it defines the contours of this new life. However, it is also uncomfortably related to their means of death – when it fails to shrink the tumours, when its side effects cause undue suffering or reduced life expectancy, or when treatment options run out.

By dissecting the symbolic associations with the chemo bell at Lady Ann’s, I am not trying to destroy the bell as a symbol of hope or of accomplishment or of bravery, all of which it still stands for people with advanced disease. Even Deo, who was disappointed with the bell’s
inability to move him out of the liminal phase of treatment, tells me, “I can’t wait to finish and ring that bell again.” But each time he rings the bell, he conceals his liminality, and denies the reality that the future that awaits him is not ‘normal life’ but rather more treatment, and thus further opportunities to ring the bell. Thus, I have shown how a symbol which can mean so much for some people, forces others to come to terms with their own difference within themselves when it fails to translate meaningfully in their own lives. These very real differences between patients with localized or curable cancer and patients facing advanced disease are seldom made explicit. Viewed in this way, the bell breaks the communitas of all cancer patients, and forces patients with advanced disease into their own special category: the category of the liminal space of advanced disease. This space positions them with one foot in the world of survivorship and oncology and the other foot in the world of palliative care and death and dying. Being assured that the cancer will come back and there is ‘nothing they can do,’ and being made to wait for the cancer to progress before they are offered more treatment also showcases their liminality and their positioning between worlds. One palliative care nurse I spoke with described it as a “state of non-surety” and as a “challenge that is undesirable for the human condition.”

The liminal space seems particularly difficult to withstand because it remains largely unstructured, lacking the appropriate supports in place to permit a safe and unencumbered passage towards the end-of-life. In the 1980s, a lack of structural supports for cancer patients transitioning from the world of treatment to the world of follow-up care sparked the growth of the cancer survivorship movement, a movement that has grown exponentially over the past twenty-five years (Mullan 1985; IOM and NRC 2006). Yet the success of the survivorship movement has in some ways even further eclipsed the experiences of those who will not survive their cancers. The liminal space of advanced disease exhibits patients’ challenges in residing in a largely unstructured middle ground – an essentially ambiguous state between the pathway that is hoped for (towards life) and the pathway that has been predicted (towards death).

Perhaps the rituals that take place leading up to and preceding death are even more important in contemporary North American society, where after death activities seem to be increasingly displaced to the realm of specialized health care and funeral services (Barley 1995). Rituals exist to help individuals cope with the status change within themselves, and how well they adjust to the new identity is contingent on the support they receive from society (Van Gennep in Bell 1997:38). Perhaps as a society, we ought to concentrate on liminality’s more positive attributes, such as viewing the period of anti-structure as an ideal time “to reflect
critically on the very constitution of [our] societ[y]” (Turner in Werbner 2001:139). If our social
categories have failed to account for patients facing advanced cancers, then perhaps the time has
come to revisit those discourses and to think seriously about how to have a more open discussion
about cancer, treatment, and the limits of medicine (Ho Ping Kong and Posner 2014).

Notes
127 Blows et al. (2012) provide a brief review of the literature on cancer and liminality, mostly in
the field of health services research.
128 Little and colleagues’ (1998) study revealed important understandings of how patients
experience cancer, and how their sense of being a cancer patient never goes away for them, even
though the median time since colectomy was 38 months. However, crucially, only 2 of the 10
patients are identified as going through chemotherapy, in addition to the surgical removal of their
colon. The majority of these people lived with stomas, an undoubtedly uncomfortable and
difficult way to live, but they were not facing the end-of-life; the fact that they were able to
receive colectomies for their cancers and only two of them received adjuvant chemotherapy is
strongly suggestive that they were diagnosed with early-stage, curable cancers. Thus, their
treatment trajectories cannot be compared to those examined here, where participants never
moved beyond treatment. Similarly, Blows et al. (2012) provide a decent literature review on
how liminality is a useful concept for understanding the position of cancer survivors. But, as I
have outlined in the Introduction, survivorship research does not always include the experiences
of patients with advanced cancers; thus, further research on how advanced disease presents a
unique form of liminality is warranted.
129 See Bruce et al. 2014 for an example. They include many interesting patient quotations that
exemplify “stories of liminality,” but they are all based on interviews, and the reader knows very
little about each participant. Thus, the method of design itself separates the researcher (and
subsequently, the reader) from the social context in which the patient is embedded. Bruce et al.
cannot provide an in-depth examination of liminality, because in choosing to use interviews as
their primary method of data collection, they have closed off the possibility of observing how
liminality emerges through rituals or rites of passage that are by nature social.
130 Both works take seriously the ritual aspects of treatment. Tjornhoj-Thomson and Hansen’s
(2013) work is especially instructive, as they examine in-depth how cancer rehabilitation is
‘ritualized’ by dissecting its process piece by piece – from separation (arrival at the cancer rehab
facility), to transition (downplaying relations between patients and staff, the communitas formed
between fellow patients, the use of words and symbols (sacra) to inspire patients to take
responsibility for their health through lifestyle modification), to aggregation (returning home).
131 Although I spent many, many hours in chemotherapy, sitting alongside patients as they
received their infusions, I only ever visited patients in the radiation department in the waiting
room. Unlike in chemotherapy, where visitors were allowed and even encouraged, only patients
would proceed into the radiation treatment area after their names had been called by the radiation
technologist. Radiation treatments are actually relatively short (5-10 minutes), and require that
patients lie very still under a powerful machine. For all these reasons, I did not observe or speak
with patients during radiation treatments.
132 It is worth considering whether the bell at the end of chemo in fact created the need for a
symbolic ceremony at the end of radiation (i.e., is Jennifer speaking of a true absence? Or an
absence only revealed because of the existence of the bell?). When I presented some of this data
at the 2012 AAA meetings in San Francisco, several attendees at the panel approached me afterwards and said that they had never heard of anything like the bell and to their knowledge this kind of ceremony did not exist at other cancer hospitals. Yet, a colleague of mine at another Canadian general hospital confirmed that patients ring a gong there when they complete chemo treatment. And I have seen another bell, at a very small, local hospital. So there is something about bell ringing or what it signifies at the end of chemo that results in a similar event taking place in several hospitals across Canada.

Unlike the ambulatory nurses, who work in the various clinical sites (e.g., GI, Lung, Gyne), from what I observed the nurses in chemotherapy only work in that area. They are specially trained to give chemo and as such they provide a highly technical service. Each time a patient checks into chemo, he or she is assigned a nurse based on who is on that day and who is available, which means that patients often have many different chemo nurses over the course of their treatment. (Although interestingly, a few of my patients realized that they could ‘request’ a certain nurse and if it could be accommodated (meaning the nurse was on shift and available) they could get that nurse, rather than be randomly assigned.) Chemo nurses ensure that on that given day, the patient is well and able to receive chemo safely, and they often listen patiently as patients talk to them about their overall illness experience, but it is not their place to comment on or plan their overall treatment plan, as this falls within the realm of the oncologists.

Douglas (1966) points out that individuals are free to modify their own classificatory schemes. For example, one can imagine the loved one of a cancer patient or the “ritual expert” figure of the doctor, who because of proximity and frequency of interaction with the patient with advanced disease, has learned to accept and accommodate her liminal position. But “no individual lives in isolation and his scheme will have been partly received by others” (Douglas 1966:48), making it difficult to believe in a classificatory system that few others acknowledge.

When Robert Murphy was diagnosed with a neurological disease, he knew he was entering into a time of chronic illness, which was not just “confronting an unpleasant two or three weeks in the hospital, but a new way of life, a career of being ‘sick’” (1990:19).
Chapter 5
‘Living in the Moment’ as Chronopolitics:
The Temporal Modalities of Advanced Disease

I also had flashes of insight into what it means to no longer be in time, but to live out of time (Hagestad 1996:206).

This chapter discusses the temporal nature of living with advanced disease. In focusing on time, I am concerned with the particular pasts, presents and futures of patients living with advanced cancer. These personal histories of time are often reinterpreted through the lens of cancer, allowing cancer, in essence, to ‘take over’ lived time. For example, pasts are often revised to include missed symptoms or a potential event that signalled the beginning of disease – something that perhaps should have been paid more attention (Frankenberg 1988). So even the past cannot rest, but becomes amended to include cancer. The present is the only time that can be counted on, and thus patients are encouraged to ‘live in the moment’ (Pascal et al. 2009), but this is a very challenging directive to follow as it is interlaced with the connotation that they are being entreated to do so because their futures are uncertain. In order for patients to have hope, the future itself must be wrested from survival statistics (Jain 2007) and reimagined as possible.

While these personal chronologies of time are important, this chapter also focuses on time as it is measured and dictated by clock and calendar, external to the body. Thus, I also examine the governance of time in the hospital, the times that come to dominate patients’ lives such as treatment schedules or clinical hours, and the arbitrary times that are often fabricated by patients in order to satisfy the clinical record that demands an exact date and time for each new symptom or change. There are multiple, and overlapping timeframes then, and patients with advanced disease move amongst all of them. Doctors’ and nurses’ time and time in the hospital are different in form and shape from that of patients, for whom the horizon of ‘time left’ has suddenly come into view.

The scholars who have studied time in the context of cancer argue that having cancer changes the way that people experience time. These authors suggest that once you have had cancer, you focus much less on time as it is defined by the clock or calendar, and instead think about time in terms of lifespan and making the best of the quantity and quality of time that remains. For example, using interview-based research examining the experience of cancer survivors in Denmark, Rasmussen and Elverdam argue that after a cancer diagnosis, “time takes
on another meaning for individuals who redefine clock and calendar time as temporality time” (2007:621). They draw on Barbara Adam’s (1995:510) definition of temporality as that aspect of time that is highlighted when we speak of processes, such as the lifecycle of plants or a person’s lifespan. Rasmussen and Elverdam’s (2007) patients describe “tidying up time” – i.e., being a lot more careful with how they spend their time now that they know that it might be limited.

Similarly, in what she terms a “personal ethnography” of her experience with cancer, Hagestad writes that having a serious illness “not only presents you with the issue of finitude, but more importantly, it threatens the very foundations of time structuring by removing you from life’s comforting rhythms. It becomes a struggle not to fall out of time” (italics hers, 1996:205). Stacey and Bryson (2012) take Hagestad’s idea of “falling out of time” and apply it to cancer survivorship, an experience they characterize foremost as “a temporal relation.” They argue, “Contra the conventions governing modern calendar and clock time (and the linear teleologies of normative life narratives that flow from time’s forward march) cancer introduces a more haphazard mix, deflecting us from any sense of life’s proper path” (Stacey and Bryson 2012:6). Lastly, Pascal and colleagues, examining cancer survivors in Australia, found that the experience of cancer “problematises temporality for survivors as it forces an awareness of the uncertainty of temporal existence….The question becomes not “How much time do I have?” although it may be this question initially, but rather, “What does this time mean?”” (2009:147).

In this chapter, I aim to demonstrate that while this perspective holds some truth, it reveals only a partial truth. It is true that a diagnosis of cancer forces the question of mortality into the conscious mind. People start to wonder: Is this my last Christmas? Will I see my next birthday? As we have already seen, Elizabeth is discouraged from pursuing IVF because the doctors cannot guarantee that she will not get a recurrence before too long; therefore, the future of motherhood is denied her. So lifetime questions are certainly prominent. But while the diagnosis brings with it a heightened awareness of mortality, patients with advanced disease spend a great deal of their ‘time left’ in the space of the hospital, a prime example of a place that is governed by clock and calendar time. Time in a hospital is often structured around doctors’ and nurses’ time – not patients’ (Frankenberg 1988; Murphy 1990). The scheduling and passage of time is highly controlled, in order to run an efficient bureaucracy. Thus patients cannot ‘fall out of time’ because the clinical motions of the hospital govern their lives. This is further complicated by the nature of ambulatory care; patients are regularly entering and exiting the hospital so they are
constantly changing timeframes – from spaces where they are in control of their own time, such as home, to spaces such as Lady Ann’s, where they are not.\textsuperscript{137}

Drawing on the framework of modalities, adopted from the literature on personhood in Melanesia (Strathern 1988; LiPuma 1998), I introduce the term “temporal modalities” to try to account for these various forms of time that are being elicited.\textsuperscript{138} I argue that there are many different modalities for experiencing or acting within time, and show how these time frames are often entangled. I illustrate how different circumstances and contexts allow some aspects of time to be foregrounded, while others remain obscured. To date, the cancer and temporality research has focused almost exclusively on cancer ‘survivors’ – people who have been fortunate to live past their cancers. As the previous chapter revealed, the experiences of survivors cannot be equated with those living with active disease. For the patients I spoke with, cancer is not a bad memory relegated to a past life they fear will return; rather, for patients with advanced disease, cancer colonizes past, present and future.

And yet, I believe that their experience of time is not so different that its meaning fundamentally changes, as has been suggested by the cancer and temporality literature. It is not the case that advanced cancer patients live in a different time or struggle not to ‘fall out of time’; they are in the same ‘time’ as all of us. But perhaps there are many different aspects of time they are experiencing that are not really acknowledged. I view this tendency of describing patients with advanced disease as being ‘outside of’ or in a ‘different time’ as a prime example of what Fabian (1983) called \textit{chronopolitics} – a politics that is about discursively constructing others as if they inhabited a different time, and thus creating them as essentially ‘other.’ Rather than being in an ‘other’ time, I work to demonstrate that it is the experience of advanced disease that allows for these different modalities of temporality – widely experienced, but often hidden and not well recognized – to rise to the surface and become more visible. Thus, a secondary goal of this chapter is to show how a foreshortened lifespan shines a light on people’s experiences with and through time, but that struggles with time are fundamental to the human condition.

\textbf{Studies in the anthropology of time}

In spite of its omnipresence, time is curiously invisible and constitutes one of the most taken-for-granted features of our lives (Adam 1995:503).

\textit{Classical approaches}
Anthropologists have written about time in complex ways that are beyond the limits of this chapter. However, it is worth touching briefly on the history of this literature in order to introduce some of its main offerings as they relate to the current discussion. In very general terms, two camps emerged in the scholarship on time, which was based on the comparison and contrast of monographs focusing on people’s ways of accounting for time in various cultures around the world. On one side of this debate, scholars argued that time concepts could not be equated, thus promoting a relativist notion of time (Geertz 1973; Durkheim 1915). For example, Evans-Pritchard argues with respect to the Nuer of West Africa, they “have no expression equivalent to ‘time’ in our language, and they cannot, therefore, as we can, speak of time as though it were something actual, which passes, can be wasted, can be saved, and so forth” (1969:99-103 in Munn 1992:507.) On the other side of this debate, scholars argued that although time concepts in societies could be understood using a variety of analytical frameworks, the dimension of study – time itself – remained the same, thus promoting a universalist notion of time (Gell 1992; Bloch 1977; Fabian 1983). For example, Alfred Gell argues, “there is no fairyland where people experience time in a way that is markedly unlike the way in which we do ourselves, where there is no past, present and future, where time stands still, or chases its own tail, or swings back and forth like a pendulum” (1992:315). Rather, he argues, there are just “other clocks” (Gell 1992:315) – other ways of keeping and marking time. These two anthropological positions were incommensurable in approaching the study of a society. The relativist notion of time was often critiqued as situating people in a ‘different time’ (i.e., a ‘backward time’), thus making them incapable of being understood within the timeframe of the ‘modern’ world. These debates produced dichotomies between perceptions of time in ‘modern’ (read Western) societies versus ‘traditional’ societies:

Thus it is proposed that ‘their’ time is cyclical rather than linear, qualitative rather than quantitative, reversible rather than irreversible, encapsulated in tradition rather than constituting the motor of history, organized by routine and practical tasks rather than by the clock, oriented to stability rather than change, geared to natural rather than calendrical rhythms, and reckoned ecologically rather than by an abstract scale (Adam 1995:504).

Gell’s book, The Anthropology of Time: Cultural Constructions of Temporal Maps and Images (1992), provides perhaps the ultimate summary of the history of these debates. He refers to time as a Kantian ‘category’ and includes it with other concepts such as number, space, and cause. According to him, these concepts “underlie all discursive thought” and without them “it is
impossible to think of any world whatsoever existing” (Gell 1992:5). His concluding chapter presents perhaps the most widely accepted perspective for a contemporary anthropology of time, by recognizing that all societies feature ways of keeping track of time, such as the use of clocks or schedules, and that “frustrating delays, happy anticipations, unexpected turns of events and long stretches of grinding monotony” (1992:315) are universal experiences of time.

In the West, we tend to use the clock to ‘tell’ or gauge time, and days, weeks and months to account for longer periods of time, culminating in the Gregorian calendar, representing the year, but in other places this system of accounting for time does not hold. For example, Evans-Pritchard’s (1969) descriptions of time amongst the Nuer provided one of the most renowned examples of an ‘other’ perspective on time in the early cross-cultural literature. His research revealed that the Nuer primarily used to 2 types of time: 1) oecological time, referring to people’s activities as they related to tasks that accompanied the cycles of nature, such as planting, daily cattle movement, and moving settlements; and 2) structural time, referring to genealogy and the spatial and temporal distance between relatives (Evans-Pritchard 1969; Gell 1992:15). These two kinds of time seem very different from the way we conceive of time in the Western world.140 Yet, in many societies a “multiplicity of time scales” exists (Hoskins 1993:79). Adam (1995:510) argues that even in Western society where we use the clock to tell time we can still speak of other kinds of time unrelated to the clock, such as the “right time” to ask for a raise or a “bad time” for action. The main difference between Western and non-Western perspectives of time is that if we speak of something happening in Trudeau’s government or during a person’s youth, “that these expressions can also be rendered in dates, while most of those of many other societies cannot” (Hoskins 1993:79). In sum, the comparative literature in anthropology helps to remind us that the study of time in specific, cross-cultural contexts allows us to understand its various forms and permutations. One of the concerns of anthropology is to recognize and try to understand these variations in ways of seeing and accounting for time.

In addition to these general cross-cultural insights, there are specific concepts that emerge from the classical literature that are particularly useful for this discussion: time-reckoning; linear vs. cyclical time; ‘othering’ through time; and governance over time, and these will be briefly be introduced here, before turning to more contemporary approaches to the study of time.

Much of the scholarly work in the anthropology of time is about how different cultures measure or “reckon” time, beginning with Malinowski (Munn 1992). Malinowski applied a functionalist view to time, and described the “temporal representations” with which Trobriand
Islanders measured how long it was between two events, figured out when things happened, and coordinated their activities (Munn 1992). Munn demonstrates that in order to ‘tell’ time, there needs to be synchronization “between the reference point and the event to be located” (1992:103). So for example, if you tell someone to “meet at sunrise,” there is a temporal distance implied between the time-teller and the event that will happen (i.e., the meeting). The temporal distance is between now and sunrise (Munn 1992:103). Applying this concept to the context of advanced disease, the event that will happen (i.e., death) has been foretold, but there is no way for patients to “reckon time” – to account or measure the temporal distance between now and when death will occur. Using Munn’s example, it is as though one knows the sun will rise, but not when: hours from now? Weeks? Years? So patients’ abilities to ‘tell time’ in their own lives has been thrown off kilter. As Hoskins (1993:59) argues, systems of time-reckoning become especially important “when we come to realize that our days are numbered.”

Linear vs. cyclical time is the dichotomy that is often described to exist between ‘modern’ societies and ‘pre-literate’ ones. Linear time is seen as two-dimensional, progressive at a constant rate from past to future, irreversible, and capable of being “sold, saved, wasted” (Adam 1995:5), while cyclical time is seen as ‘static’ or repetitive, and associated with myth and ritual (Bloch 1977:282; Gell 1992:90). An example of linear time is Western time, which follows a linear progression model (Gell 1992:70). An example of non-durational or cyclical time is represented in Geertz’ famous quote on Balinese time as “a motionless present, a vectorless now” (1973:404). To make this argument, Geertz relied on the example of the Balinese “permutational” calendar, which is composed of 10 different cycles of day-names, running concurrently. Any given day has ten different ‘day-names’ associated with it – one for each of the 10 cycles. This calendar does not tell the Balinese what day it is, as it does not measure days, weeks or months, but rather what kind of day it is (i.e., if it is a holiday, a day for temple celebration, an appropriate day for marrying or harvesting crops) (Geertz 1973:392). Thus, this calendar helps the Balinese to coordinate their activities, but it is not quantitatively accounting for time’s passing. Patients with advanced cancer experience both linear and cyclical forms of time. As the most ‘modern’ of Western institutions, the hospital showcases the predominance of linear time, and the high value placed on the clock around which all staff and patient activities are organized. But cyclical time is also present, showcased through the repetitive motions that patients go through at every consultation, or at every chemotherapy at Lady Ann’s. In these days,
it almost seems as though time is ‘repeating’ itself, or at least is not ‘passing’ in the same way that we experience linear, clock time.

In 1983, Johannes Fabian published his renowned piece *Time and the Other*, making a critical and original argument at the time that the discipline of anthropology is founded upon situating people in different times and spaces. Fabian argued that this differentiation by time – by situating the ‘other’ in a frozen past – is part of how anthropology makes its object. Using the example of South Africa, he demonstrates that by situating native populations in a “different Time” (Fabian 1983:30) (i.e., by calling native populations “savages” or “tribal”) the expanding colonial power worked to lay claim to spaces that were not theirs to take. He names this phenomenon *chronopolitics* to show how people’s positions in time are used as a means of distancing them and denying them power. ‘Time othering’ is relevant in the context of advanced disease because patients with cancer are often advised to ‘live in the moment’ or to ‘take one day at a time.’ This directive asks them to live only in the present and ‘others’ them through time by confining them to a future-less condition, which is very different from the way the rest of us live.

Lastly, many anthropologists have pointed out that whoever controls time also controls a population, so time is a means of governance for both populations and individuals, through bodily control via at the rhythms of industrial work (Munn 1992). For example, “Standard Time” is not so standard after all, but reflects the prominence and dominance of the Western model of time across the globe (Fabian 1983:144). Through ‘timestamps’ and other features of industrial work, clocks reach in and control the body, showcasing that “clock time is quite alive, embodied in purposeful activity and experience” (Munn 1992:111). When patients enter the hospital, their bodies become the loci of control and the objects of timing (Frankenberg 1988). As they move through Lady Ann’s, it is their bodies that are taken through these particularly tough timely regimes, meaning the body is “part of the vital means of constant movement back and forth between the self and world time” (Munn 1992:112). For example, Murphy (1990:20) notes that when he was in hospital, he was woken and bathed every morning at 5:30 am before the nurses’ shift change, because the daytime nurses were too busy to do it. Thus, the bureaucratic clock of the hospital becomes embodied, but it is often set by an agenda that is not the patients’.

**Contemporary approaches**

More recently, Adams et al. (2009) have described the condition of “thinking and living towards the future” as an affective and temporal state of anticipation that governs contemporary
life. They argue that lives in the contemporary moment are lived towards the future, as if the future is what matters most. Importantly, Adams et al. (2009:248) argue that it is the regime of anticipation that allows for “the production of possible futures that are lived and felt as inevitable in the present”; providing examples such as global warming and oil crises, they demonstrate that we are pushed to prepare for these things now in order to be ready in the future. In their special issue After Progress: Time and Improbable Futures in Clinical Spaces (2011), Jain and Kaufman take up the anticipation approach and apply it to medical anthropology. They argue, “imaginings of the future constitute the present in terms of how medical treatment options are presented (and to whom), and how chronic and fatal illnesses are understood and lived” (Jain and Kaufman 2011:183). Importantly, both these works point to the politics of time, and to how anticipatory programs are always looking for new horizons and new territories for expansion (e.g., investing in young women as the “future”, increasing genetic technologies and testing (Adams et al. 2009), elderly adults receiving liver transplants where once they would have been denied (Kaufman and Fjord 2011)).

While both Adams et al. (2009) and Jain and Kaufman (2011) provide useful theorizing of how to conceptualize our relationship with the future and how it increasingly impinges on the present, the universality of one understanding of time is implicit. Time itself seems to be taken for granted; neither set of authors refers back to the classical anthropology of time literature. The focus on anticipation and speculative futures is a very broad idea, and can be usefully directed towards many areas of scholarship, but Adams et al. (2009) do not point their ideas towards an anthropology of time, but rather towards technology, capitalism and development. Similarly, Kaufman and Jain (2011) introduce a set of articles that are intended to be primarily about time, but they are really only focused on one aspect of time – the future. In this way, it seems as though these ideas about the future have emerged from a vacuum – a ‘timeless’ place – rather than represent one development of a long-standing anthropological interest in how people understand and mark time.

In this chapter, I combine the offerings of both of the classical and contemporary approaches to the study of time in order to consider an anthropology of time for advanced disease. Hoskins argues that in the English language, “we collapse a number of separate concepts to make our own category of “time,” whereas in many other cultures these notions may be kept more rigorously separate” (1993:58-59). She reasons that the separation into different aspects of time should not be used as evidence of these cultures’ “timelessness,” but rather that they
“distinguish different aspects of time more carefully than we do ourselves” (Hoskins 1993:58-59). Thus, I aim to add to the literature in anthropology by examining some of the “different aspects” of time or, as I call them, “temporal modalities,” that are experienced by cancer patients in one Canadian hospital, making the way for cross-cultural comparisons. An anthropological approach to time begins from a position that we can never be ‘out’ of time; as Nancy Munn argues, “we and our productions are in some sense always “in” time (the socioculturally/historically informed time of our activity and our wider world) and yet we make, through our acts, the time we are in” (1992:94). How do cancer patients make the time(s) they are in, and how do the larger time structures they operate within constrain their temporal possibilities? If futurist-thinking is the ethos of the day, how do we account for patients with advanced disease, whose futures have been denied? What is particularly political about temporality with respect to advanced disease? Given these questions, I now move forward to formulate an anthropology of time for advanced cancer.

**From Modalities of Personhood to Modalities of Temporality**

Considering the forms of time as elaborated in both the cancer and anthropology literatures, I suggest that a more nuanced way of looking at time is acknowledging that we all live in multiple and concurrent temporal modalities. The concept of “modality” comes from the anthropological literature on personhood in Melanesia, which examines the different ways that being a person is elicited. In the West we have an idea that personhood is located in the individual, and a society is plural because it brings together individuals. Melanesian scholars have advanced a more relational idea of personhood, where persons can be conceived not only as “individuals,” but also as “dividuals,” “the plural and composite site of the relationships that produced them” (Strathern 1988:13). In this view, an individual can be conceived of in plural terms, as a kind of “social microcosm,” and a group can be conceived of in singular terms because it represents collective life (i.e., the unity of “one”) (Strathern 1988:13). Strathern argues that in Melanesia the singular and the plural are “homologues” of one another, because when a person is individualized or a group is formed, both are based on the elimination of differentiation – in the former, of internal differentiation, and in the latter, of external differentiation (1988:13).
In considering these two forms of personhood, other scholars have suggested that rather than try to fit all people into the “dividual” or “individual” category of personhood, that it is more likely that most societies demonstrate elements of both. For example, Edward LiPuma (1998:56) argues that in all cultures “there exist both individual and dividual modalities or aspects of personhood.” Thus, the person emerges from the tension between these two forms, which are not “fixed categories” (Boddy 1998:256). Importantly, LiPuma suggests that different contexts elicit and accentuate different modalities of personhood, so that “the foregrounding and hence transparency of individual and dividual aspects of personhood will vary across contexts for action within a given culture” (1998:56). In adopting the language of modalities from the literature on personhood, it is this contextual aspect of temporality I am aiming to draw out. For example, many people have experienced the temporal modality of being at the mercy of hospital bureaucratic time, such as the experience of waiting for medical appointments. But for most people, this temporal modality does not come to dominate everyday life to the extent that it did for my participants, who sometimes spent the length of a typical 8-hour workday sitting and waiting for various appointments at Lady Ann’s.

This chapter focuses on foregrounding the various temporal modalities that are elicited for patients with advanced disease in daily life at Lady Ann’s. Janice Boddy argues that it is LiPuma’s attention to practice that allows him to make an important contribution to Strathern’s ideas on personhood (1998:256). Following Lipuma (1998), I aim to contribute to the scholarship in cancer and temporality by similarly focusing on practice. In 1988, Frankenberg published a now renowned piece on the “tragic temporal contradictions of biomedical practice,” which argued that the hospital takes over time, because patients’ own rhythms of time are replaced by those that run the bureaucracy. Patients’ bodies, in turn, are subjected to this bureaucratic time, and they are poked, prodded, and tested at time intervals that are convenient for doctors’ and nurses’ schedules, but not their own (Frankenberg 1988). However compelling Frankenberg’s ideas were at the time, his arguments were not based on original research, but rather on a review of secondary sources. Frankenberg’s lack of supporting data was made evident to Good and colleagues when they conducted interviews with oncologists in the early 1990s and found that temporality was actually “central to clinical work” (1994:861). They argue that while in Frankenberg’s work, illness was presented as a “timeless disembodied disease,” their interviews revealed the ways that oncologists “craft” therapeutic time in trying to keep patients focused on the present (Good et al. 1994:861, 856).
Good et al.’s article on “narrative time” is an important contribution to the cancer and temporality literature; however, the original data that they cite is in the form of quotes from interviews with oncologists, and, as such, they too evade what actually emerges in practice with respect to temporality. Interviews are in themselves scheduled activities that take place away from the busy, day-to-day practice of the clinic. The oncologists’ quotes are highly revealing of strategies oncologists use to limit the “time horizons” of patients while still promoting hope. However, as Chapter 3 revealed, what oncologists articulate in a research interview when they have time to reflect on their thoughts might be very different from what actually unfolds in practice in the clinic, when they are subject to the many timely demands of that environment. In my research, ethnographic data collection allowed me to see different temporal modalities as they emerged in everyday practice at Lady Ann’s. Thus, my contribution to this literature is to build on the work of previous scholars such as Frankenberg (1988) and Good et al. (1994), by demonstrating not only the kinds of temporal modalities that patients with advanced disease experience, but also the specific contexts that elicited those temporal modalities.

I propose that the different modalities of temporality are related to a person’s health status – whether or not she falls into a ‘sick’ or ‘patient’ role or a ‘not sick’ or ‘non-patient’ role. Both of these identities have associated temporalities: non-sick persons are assumed to be future-oriented, sick patients are assumed to be present-oriented (because their future has been denied). For example, Pascal et al. found that cancer survivors followed “the philosophy of taking one day at a time and being present in the moment” (2009:144). And yet living exclusively in the present is incredibly difficult, since we live in a contemporary world that is increasingly oriented towards the future (Adams et al. 2009). For example, Hagestad, a cancer survivor, describes how the future tends to dominate our everyday lives: “the frequency with which we ask about plans becomes painfully clear to you when you cannot make any” (1996:207). How does a person move forward in time from that position? How does the regime of anticipation apply to a person whose future has been denied?

The insistence that patients focus on the present commits two kinds of offences: 1) it separates cancer patients into a world that is different from the one the rest of us live in, implicitly communicating that not to dream or think of the future should be something they should get used to and is an acceptable way of living – in essence ‘othering’ them through time, as Fabian (1983) famously described; 2) it presumes that they have a lot more control over the timing of the major events of their day than they actually do, and ignores the very powerful
machine of hospital time that tends to dictate their daily lives. I argue that this is a form of chronopolitics, which is a denial of “coevalness,” in other words, a denial of a common “occupation” or “sharing” of time (Fabian 1983:31). Fabian (1983:143) used the term to argue that anthropology was an “allochronic” discourse, “a science of other men in another Time” articulating what he saw as a separation between anthropological author and informant. I employ the term here to examine the distancing of patients with advanced disease, to argue against the dichotomy of ‘present-oriented cancer patient’ vs. ‘future-oriented well person’.

I suggest that rather than try to separate out cancer patients and tell them that they live in a different kind of reality, we consider that for all of us there are many different modalities for experiencing or acting within time. What is of interest here is which modalities of time come out in practice, and what conditions allow for these different modalities to be perceived (LiPuma 1998). I develop Jain’s important concept of “living in prognosis,” which she described as “living in the fold of various representations of time” (2007:80), by specifying what those “representations of time” actually look like in everyday life at Lady Ann’s. This attention to the particular conditions that allow for these modalities to emerge builds on Nancy Munn’s view of time as “a symbolic process continually being produced in everyday practices” (1992:116). She says that people are “‘in’ a sociocultural time of multiple dimensions (sequencing, timing, past-present-future relations, etc.) that they are forming in their ‘projects’” (Munn 1992:116). For Munn, time is always connected to agency, and time-reckoning must be considered in light of the particular purposes people are working towards. I aim to demonstrate some of those multiple dimensions of time in advanced disease in relation to the different kinds of ‘temporality projects’ that patients might be engaged in (e.g., the project of living longer, the project of imagining a future, the project of getting through a long wait at the hospital). The four major temporal modalities I discuss include: life time; prognostic time; treatment time; and hospital time (Figure 5.1).

**Life Time** examines patients’ subjective experience of time. I employ Munn’s (1992) concept of time-reckoning to demonstrate how patients’ own perceptions of the life they have lived, are living, and will live are put in jeopardy because their own sense of time is thrown off and they have lost the ability to “reckon” or tell time in their own lives. I suggest that patients revise their pasts in order to make room for the onset of disease as a means of making it seem less like an abrupt intrusion in their lives, and more as something that had been growing for some time. I argue against the contemporary discourse encouraging patients to “live in the moment,”
and demonstrate that this directive confines patients to a time of cancer, cutting off the power to hope for or to imagine life beyond cancer. Lastly, I show that patients respond to the “contracted future” (Bell and Ristovski-Slijepcevic 2011) discourse of advanced disease not by giving up on the future, but by coming up with alternate plans for themselves.

**Figure 5.1. Temporal modalities in advanced cancer**

<table>
<thead>
<tr>
<th>LIFE TIME</th>
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<tbody>
<tr>
<td>• The subjective experience of time</td>
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<tr>
<td>• <em>Past time</em>: The past cannot rest and is revised to include missed symptoms, not caught disease</td>
</tr>
<tr>
<td>• <em>Present time</em>: The present is the only time that can be counted on, requiring patients to “live in the moment”</td>
</tr>
<tr>
<td>• <em>Future time</em>: The future has been taken away and must be reimagined as possible</td>
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<tr>
<th>PROGNOSTIC TIME</th>
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<tbody>
<tr>
<td>• The objective estimation of time</td>
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<tr>
<td>• The timeline of disease as determined by aggregate survival statistics</td>
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<tr>
<th>TEMPORAL MODALITIES IN ADVANCED CANCER</th>
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<tr>
<th>TREATMENT TIME</th>
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<tbody>
<tr>
<td>• The sense of time passing in the short term becomes defined by treatment schedule, with patients focusing on next dose, next chemo</td>
</tr>
<tr>
<td>• When patients are not on treatment, it becomes difficult to move forward without that schedule</td>
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<tr>
<th>HOSPITAL TIME</th>
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<tr>
<td>• Governed mostly by clock and calendar time, but some aspects of cyclical time present as well; often oriented around hospital hours and doctors’ and nurses’ time, not patients’</td>
</tr>
<tr>
<td>• <em>Waiting time</em>: The experience of waiting, often overlooked by the focus on ‘wait times’ in health care</td>
</tr>
<tr>
<td>• <em>Appointment time</em>: Patients’ very demanding schedules or itineraries at Lady Ann’s</td>
</tr>
<tr>
<td>• <em>Consult time</em>: Getting time with the doctor</td>
</tr>
<tr>
<td>• <em>Clinical record time</em>: Patients ‘invent’ time to satisfy the clinical record</td>
</tr>
</tbody>
</table>

**Prognostic Time** examines how survival statistics come to influence patients’ experiences, even when they have been avoided in conversations with their oncologists. Recall Elizabeth’s story from Chapter 3: she was the kind of patient who “wanted numbers” but who could not get any. In fact, she was offered some figures projecting her likelihood of recurrence, but the range was so great (“probably not 20 years, likely 3-5 years, but then again you could be cured”) that they were practically meaningless. I develop Jain’s (2007) concept of “living in prognosis” by demonstrating what Prognostic Time looks like at Lady Ann’s, where patients’ lifetimes became contained by aggregate statistics that they learned of outside the consultation room.
**Treatment Time** involves how time in the short term becomes defined by a patient’s treatment schedule, and this way of marking or measuring time persists even after treatments are finished or on hold. I reveal just how much of patients’ time treatments take up, and how patients struggle to fill the “dead” time that becomes available once they are on a break from treatment. Unlike other cancer patients, patients with advanced disease have insight into the reality that treatments for them are never “over,” so whether they are currently on or off treatment in no way negates that their future likely includes more treatment.

**Hospital Time** includes several kinds of temporalities, including those associated with waiting, appointments, physician consults and clinical record keeping. Although hospital time is highly governed by a linear model of time, where the clock and the calendar feature prominently, there are aspects of cyclical time that also persist, such as time that does not produce any outcome or climax, much like waiting. Hospital Time showcases both time governance (Fabian 1983) and time’s more flexible nature when it is ‘invented’ to satisfy record-keeping for clinical trials.

**Life Time: Invading Past, Present, and Future Temporalities**

As Jain (2007:84) has argued, “cancer is always about time.” Many people who have been given a diagnosis of life-threatening illness wonder, “How much time do I have left?” But it must be made clear that although living with advanced disease means living with a foreshortened lifespan, ‘time left’ is rarely an explicit topic of conversation. I observed multiple consultations in oncology, and noted that it was the very rare occasion that prognosis or a timeline was discussed openly, and if the subject was broached, it was always at the patient’s prodding, not the doctor’s. Yet despite this omission, the idea of time is caught up in any conversation that implicates the future. For example, when Pam asks, “When will I go back to work?” and Dr. Girard replies, “I wouldn’t worry about that right now,” or Elizabeth asks about implanting her frozen embryo and is told that it would be “a disservice to herself” to do that in the next 2 or 3 years. In other words, although doctors are not explicitly stating, “You do not have a future,” they are implicitly saying, “Please do not ask me about your future.” I observed that, in general, patients could talk about the future when it involved short-term, achievable goals or activities for themselves, but not when it involved more long-term plans. Although Pam frequently asked about returning to work early in her treatment, later in her care she seemed to accept Dr. Girard’s
response that work should not be her central concern for the moment. Thus, through these kinds of euphemistic replies, patients are subtly disciplined not to inquire about the future.

Advanced disease threatens not only a person’s lifespan, in the sense of the life not-yet-lived, but also his or her past and present temporalities. In considering the various fields of medicine, Frankenberg argues that general practice is oriented towards the present tense, but that the various specialties have “surprising and paradoxical tenses” (1998:142). For example, surgery “speaks to the future,” represented in the doctor’s invocation of the future, as in ‘you will be better when this body part is removed or fixed.’ Psychiatry conversely, “makes the extension of the present into the future bearable by permitting the restructuring of the past” (Frankenberg 1998:142). Where then, can we position oncology? As a medical specialty it is perhaps unique, as I would suggest that it captures, and even colonizes past, present and future equally. The regimes of treatment speak to a future of reduced or disappeared disease and the improvement of symptoms. The present is the only time that can be counted on. But even the past cannot rest, and patients feel pressured to reinterpret past behaviours as potentially carcinogenic (Frankenberg 1988:141). Seen in this light, advanced disease presents an invasion of all temporalities.

Munn’s (1992) elaboration of “time-reckoning” is particularly useful for understanding how the subjective experience of time – of past, present and future – gets taken over by the experience of cancer. According to Munn (1992:102), people use time-reckoning to figure out when the ‘right’ time for action is, to know when something has happened or will happen, and to measure how long an activity will take. Patients with advanced cancer lose the ability to “reckon time” in their own lives when their lifetimes becomes threatened. Melody, a woman with a strong sense of fashion, told me she struggled over whether or not to purchase a new coat that she was eyeing, unsure of whether she would get enough wear out of it to justify its purchase. Similarly, Pam told me that the first Christmas following her diagnosis had been very hard for her, as she was not sure whether it would be her last. Jennifer’s experience of planning her own funeral is perhaps the most telling. Given a diagnosis of metastatic endometrial cancer, and having lost her mom recently to cancer, she worried constantly that her cancer would be fatal. As a single woman with few social supports, she wanted to make sure things would be taken care of if she did die. So one day she walked into a funeral parlour and planned and paid for her own funeral. She did this preemptively – not because she had been told she was dying, but because she was worried that that would be the outcome for her in the not-so-distant future.
Using the language of time-reckoning helps to make patients’ struggles with time more obvious. We all live with the knowledge that we will someday die, but living with advanced disease transforms an abstract notion into a real event. Patients’ timeframes are thus different. Janet Hoskins, writing on Kodi perspectives of time in Indonesia, argues, “sequence, the possibility of ordering events and counting them, becomes relevant once our own duration becomes short-lived” (1993:59). Munn’s (1992) discussion of reckoning time implicitly has a future-oriented focus: events in the past or present become reference points – or means of reckoning – for events in the future – e.g., Melody’s coat, Pam’s next Christmas, Jennifer’s funeral. But cancer not only throws off people’s ability to reckon time in the future, it may also affect their ability to think about the past. Thus, Munn’s notion of time-reckoning can also be fruitfully used to examine how cancer revises a person’s past.

Past time: Revising the past and rationalizing the onset of disease

Neither patients nor their friends, relatives or doctors, hesitate to move the onset of their illness back in time beyond the incidence of their disease. They recall staying out in the rain, not wearing warm clothes, not being careful where they trod, eating, drinking and smoking inappropriately and in general neglecting to keep themselves healthy. They thereby date the origins of, and by implication responsibility for, their misfortunes in their own past misdemeanors (Frankenberg 1988:126).

Cancer certainly affects a person’s present and future, but it may be less obvious how it also becomes integrated with her past as well. Past physical symptoms and behaviours that might have been forgotten about or ignored are reinterpreted in the present as potential reasons for getting sick. As Frankenberg illuminates, patients feel pressured to revisit the past, but both their medical and social communities support these efforts. The patients I spoke with made room for cancer in their own pasts, and in doing so, they allowed it to inform even more of their lives.

A good example of how the past is always being brought into the present is found in lung cancer. I never asked the longitudinal patients I worked with whether or not they had smoked. But it came up in conversations with their doctors and nurses, to which I was a witness, or sometimes in casual conversations with me. For example, Paul told me that he thought that he had gotten lung cancer from smoking marijuana. He said that when he was in his 20s and 30s, he had smoked a fair amount; now in his early 60s, he believed that it was the cause of his current lung cancer. Similarly, Mary was an occasional smoker who smoked 5 cigarettes a day for 10-12
years. Although smoking was in her past, it came into her present when she was forced to wonder whether her previous actions had led to her current diagnosis of lung cancer.

I heard similar stories in speaking to women with gynecological cancers. Sitting over coffee one day, Melody, a woman with metastatic ovarian cancer, told me she was sure she knew what had caused her cancer: stress. She went back in her history and described her first diagnosis of breast cancer over 20 years prior. It came at a time in her life when she had moved with her two young children to a tropical country, in order to put distance between herself and her then husband. This was a very stressful time for her, because she was a single mother and had little means to support her children. She is positive that the undue stress she suffered caused her to get breast cancer. Elizabeth told me that after she turned thirty she found that her digestion weakened. Suddenly she could not eat certain foods, such as legumes, and as a result she had started taking a digestive supplement and eating more salads. When she was diagnosed with ovarian cancer at the age of 37, the doctors mentioned that the cancer had likely been present in her body for several years before she was diagnosed. She told me this story while she was waiting to go into chemo one day, sitting alongside her mother. I noted that both she and her mother subscribed to the idea that her digestion changes in her early 30s could now be attributed to the cancer; they saw those changes as early ‘signs’ of cancer that they had potentially misread.

In reinterpreting past behaviours, patients actually allow cancer to take up more of their lives and extend cancer’s timeframe into their pasts. Jain, who had cancer herself, argues that after cancer is discovered, “one realizes that it must have been there for a while, growing, dispersing, scattering, sending out feelers and fragments,” causing her to label cancer as inherently “creepy” (2007:80). The question is, what is the value in allowing cancer to ‘creep’ into the past? What is gained by permitting cancer to take up a greater chunk of the lifespan, as if present tense is not enough, that it must occupy the past as well? I believe it has something to do with trying to rationalize the illness – that by imposing a time structure to the disease’s origins it somehow makes it seem less like a random interruption to patients’ lives.

Kleinman (1988:29) demonstrates that in response to illness or misfortune, people in cultures around the world respond almost universally, by asking: 1) Why me? (the question of bafflement), and 2) What can be done? Biomedicine tends to focus only on the latter question, and often comes up short in explaining the onset of illness or trying to find a reason for it. Cancer is a type of “misfortune,” and like others, it “demands action and evaluation of consequences” (Whyte 1997:3). Because medical personnel often focus on actions and the response to cancer,
patients are left on their own to consider what may have lead to their cancer. Lung cancer is one type of cancer where a lifestyle choice (smoking) has been proven to be a known cause; for ovarian cancer, there exists no such clear disease etiology. Bell notes that some cancer patients reject the moralizing discourses of self-blame, and instead point to the “external and uncontrollable factors…such as genetics, stress and the environment” (2010:360). But rejecting the self-blame does not solve the mystery of why they have gotten sick, which is a very natural reaction to illness. For example, Hitchens (2012:6) wryly notes in response to his own ‘Why me?’ question, “the cosmos barely bothers to return the reply: why not?”

I suggest that, for patients, fitting cancer into their own past is a means of bringing cancer under their control, in order to see it as less fearful. Many of my participants had late-stage disease when diagnosed. This means that rather than suffering an early stage disease that had seen progression or had later recurred, they were all diagnosed with a life-threatening, incurable cancer. The diagnosis had a chaotic effect on their lives and on their time – it threw their timescales off balance in terms of their presents and their futures. By fitting the origin of disease to a time structure, and inserting it directly into their own pasts, perhaps they were trying to rationalize the onset of disease. By revising their pasts to include cancer, the diagnosis itself seems less abrupt, and therefore less scary and chaotic. In other words, at a time when very little is under their control, patients can and do control the story they want to tell with respect to cancer’s presence in their past. Paradoxically, it seems possible that this ability to fit cancer to their past brings patients some comfort and might actually reduce fears of the disease and its effects. In order to live in the present, and to move forward in the future, they must also make room for cancer in their pasts.

Present time: Living in the moment and the pressure of the present

To live in the present means that it is today I am here. It is today I can bicycle. It is today I may be able to go to work, or bake a scone. It is today I may read a little, if I am able. It is today I can go to church, or listen to some tapes that interest just me. I can call my children today. When someone telephones me, I have time for them, because I have today. That is how it is. Tomorrow has not been promised to me.

-a cancer survivor, Rasmussen and Elverdam (2007:619)

I’ve really learned to just deal with one day at a time – not a whole week or agenda – instead of getting overwhelmed.

-Melody
The current trope in cancer discourses encourages patients with serious illness to ‘live in the moment’ or to focus on ‘one day at a time.’ For example, in Pascal and colleagues’ (2009) study of cancer survivors in Australia, they identify that for their participants, survivorship “changed temporal proximity as present and future merged. This was expressed in the philosophy of taking one day at a time and being present in the moment” (2009:144). Similarly, Rasmussen and Elverdam found that cancer survivors expressed a “loss” of the future, and that life was about “living in the present” (2007:619). Although cancer survivors found living without a future frustrating, Rasmussen and Elverdam (2007:619) note that the future began to reappear in their narratives in the form of educational or work aspirations, or spending time with grandchildren, as the time since they completed treatment increased. Thus, for cancer survivors the unbearable situation of living only in the present is temporary. For people living with advanced disease, who never move beyond treatment, the pressure to live only in the present becomes permanent.

Living in the moment is an ideology that is particularly seductive in contemporary culture. With its promotion of neoliberal notions of changing your life and achieving your goals (e.g., Tolle 1998), and its nod towards new-age Spiritualism, the “living in the moment” mantra seems to advocate being grateful for what you have, appreciating the people around you and letting go of trying to control all aspects of your life. If we take our cues from the cancer survivor in the opening quote to this section, living in the present entails a great number of ‘choices’ about the possible ways that a person can divide up her time. The passage itself reads extremely slowly, allowing us to almost imagine each of these possibilities gradually presenting themselves to a woman over the day, and depending on her current sentiment, watching her choose whether it is the ‘right’ time to go to work or to call her children or to bake a scone.

Unfortunately, passages such as this one provide few clues to what living with advanced disease, day in and day out, actually looks like. It might be different if a person had only days or weeks to live, but this was not the case for my participants. They lived for months and sometimes years with advanced disease – sometimes with cancer being kept at bay by treatment, and sometimes with it growing and progressing. But of course within those months and years, they continued to live their lives – normal, time-conscious lives, where they must get to appointments on time, meet with family or friends on allotted days, and complete time-consuming activities of daily living such as laundry, cooking, and self care. Juxtaposed with the cancer survivor, Melody’s quote is immediately revealing of this difference. Her worry about becoming
“overwhelmed” and her reference to an “agenda” indicate that she still has many things to do. Thus, people with cancer may “tidy up time” (Rasmussen and Elverdam 2007:621) in some respects, such as letting go of people or things that they did not find rewarding in their lives, but they are still living in time, and in a world full of timely demands.

Living with cancer becomes patients’ new normal, but it is by no means the only aspect of their lives that still matters. It is unfair to place expectations on them that they should be grateful for each day they are alive or only use their time for ‘worthwhile’ people and activities. I call this phenomenon the pressure of the present to draw attention to the undue stress the ‘living in the moment’ discourse places on patients with advanced disease. My conversations with people living with life-threatening illness revealed that people actually live their lives with cancer much as they lived them before they had cancer. People who could no longer work found it difficult to fill the time that work used to occupy. But they were not sitting in their houses contemplating what time-worthy choices they would make for the day, which only served to remind them of the disease. In fact, people spent a lot of their time actively trying not to think about cancer.

On the first day I attended a chemotherapy session with Melody, she spoke explicitly about how she coped living with ovarian cancer. She said, “Life is a mental state.” She told me that she chose to actively deny her illness, and that this method helped her to get through her days. She talked about feeling low, and (unless it was really low), choosing to get dressed, and go out for a coffee, because she got energy from being out and being around people. She thinks of dying sometimes – “everyone dies” – but she cannot focus on it because she cannot live that way. She needs to focus on living her life, and enjoying what she can out of it. Several months later, this theme emerged again in a phone conversation, when she said that dealing with cancer “comes in waves.” When I asked her to clarify, she replied, “Knowing that I will be on chemo for the rest of my life and have this. It bothers me some days and other days I couldn’t give a shit.”

In these passages, Melody relates how she lives her everyday life with a life-threatening illness. She thinks about it sometimes, and blocks it out at others. She feels low at times, and manages it by getting out and being around others. Sometimes that is not enough. The phone conversation that prompted the “waves” comment occurred when I was worried about her ability to cope with everything, and tried to suggest that she speak to a psychosocial professional at Lady Ann’s. Interestingly, her reply to my suggestion showcased time as a barrier, because: 1) it would be yet another appointment she would have to be “running to and going out to,” indicating that she was already feeling quite busy with other time-consuming activities; and 2) it may not be
booked for the time when it could be most helpful to her. She said she could never guess in advance when it would be a good or a bad day, so booking an appointment to talk to a person in two weeks’ time might be futile. By the time the appointment came around, it could be a day when she was enjoying life, and not wanting to be pulled down with the reminder of her cancer.

Paul similarly worked at putting his lung cancer out of his mind. After a long interview in March of 2011, I turned off the recorder, but Paul continued to speak of how he managed every day. He told me that he had an appointment to speak with someone in the psychosocial department in April, and that he was worried that he or she was going to “force” him to think about it (‘it’ being his cancer), when actually, what he does is actively try to “put it out of his head”:

If I go to bed at night and I’m worrying about a medical appointment or something, I just think ‘How am I going to redo my friend’s basement?’ and I start to look at the details and then fall asleep. I’d like to say, ‘I live each day as my last,’ but I don’t do that. I’m not one of those people who say I always wanted to go to China – I’m going to China [he travelled a lot for work]. I’m not doing things on a bucket list.

Both before and after our interview, he joked with me about how he was very good at the “Scarlett O’Hara” thing. I laughed and asked, “What is that?” He replied, “You’ve never seen Gone with the Wind? She was famous for saying, ‘I’ll worry about that tomorrow.’” Paul’s efforts to focus his thoughts onto practical tasks, such as the basement renovation showcase: 1) his hope to continue his life with projects he was capable of before he was sick; and 2) his invocation of a future plan, revealing his hope that he will be around to complete that project. Thus, the basement renovation is in itself a kind of “time project” – a way to capture time and use it towards the fulfillment of his purposes (Munn 1992:116), which not only keeps him occupied in the present, but also allows him to cast a future for himself. The challenge of “liv[ing] each day as [his] last” is that it confines him to a time of cancer, and denies his very natural desire to hope for a future.

Importantly, “living in the moment” is not just a directive that patients internalize from contemporary culture, it is also reinforced implicitly through doctors’ actions and words. Both Pam and Elizabeth are subtly discouraged from pursuing actions that are about their futures – returning to work, and trying for a baby, respectively – in the opening examples to this section on Life Time. Good et al. (1994:856) also demonstrated that oncologists remained focused on the present, which they characterize as “an expression of time without horizons or of highly foreshortened horizons.” One of the oncologists they interviewed reported using Freud’s writing
on the fear of death as a primal drive to talk to his patients about their mortality. He said, “So I encourage them to take the benefit of this disease, which is to challenge them with their own mortality, and to evaluate their life in terms of enjoying their family and their friends and their job and the beauty of a Fall New England day in a richer way than they would have otherwise” (Good et al. 1994:858). He, like the cancer survivor quoting at the beginning, advocates that patients appreciate the present moment and feel gratitude for what they have been given. However, unlike the patients I worked with, he has the luxury of approaching death academically because he is not currently facing death himself. In my experience, it is only people who are not facing cancer or who have been fortunate to survive their cancers, who can speak of the “benefits” of the disease. Suggesting that people who have watched a loved one struggle and succumb to the disease, or who are facing end-of-life themselves, ought to think about cancer’s “benefits” seems cruel and heartless.

My point here is to argue against the literature that posits that once you have a serious diagnosis, all of your time is spent in this slow-moving period of the present. As Melody and Paul’s comments demonstrate, living daily with advanced disease is just living. They both experience difficult days and moments, and get through them by not thinking about their cancer. Murphy, who lived with a slow-growing neurological tumour for over 10 years, similarly noted that he lived day by day by “block[ing] from [his] consciousness any thoughts about the final outcome of the illness, to repress from awareness any vision of the unthinkable” (1990:25). To me, the oncologist’s encouragement to think about cancer’s “benefits” serve as a clear exhibition of the pressure of the present and the unfair relegation of people with advanced disease to their own separate domain. This is a modern form of chronopolitics (Fabian 1983), which serves primarily to establish and reinforce the dichotomy between the ‘present-oriented cancer patient’ and the ‘future-oriented well person,’ rather than to acknowledge that all human beings live in multiple pasts, presents and futures that they conceive of for themselves.

**Future time: Holding onto the dream and reimagining the future**

The reality is that future-oriented time persists even for people who are sick. This was expressed clearly to me one afternoon, sitting with Melody over coffee, where she was telling me about her small-scale plans for her near future. She described wanting to paint the outline of a window with a sky blue background onto the wall in her walk-in closet, so that she would have something nice to look at. Then she casually remarked, “Imagine what it’s like, to not have a
dream?” She continued by saying that it was the first time in her life where she did not have a dream or a plan. The painting of her closet was a very modest and small-scale plan in comparison with the way she had lived her life, embarking on many different careers and living in several countries while raising two children.

For people living with advanced disease, the sense of the future may become much more short-lived. There is a foreboding sense that the things they had hoped or planned for may no longer be possible. Bell and Ristovski-Slijepcevic (2011) found that mothers with metastatic illness shared in cancer support groups the feeling of needing to “cram parent.” Faced with the likelihood they would not see their children into adulthood, the mothers felt a responsibility to impart all their motherly knowledge in the time they still had left with their kids (Bell and Ristovski-Slijepcevic 2011). Living without a future is made all the more difficult to bear given the contemporary moment, when the majority of Canadians are assured of our futures. As Hagestad (1996) points out, not so long ago, especially during WWI and WWII, people were not so certain. Cancer thus presents a very modern way to take away that assurance. For cancer survivors, the future becomes something to be anticipated; “contrary to the cultural norm of fearfully anticipating old age, and its implication in death…[b]ecoming older was a way of imagining a future for oneself” (Pascal et al. 2009:144). Relationships with grandchildren and children become especially important, because they represent “the future, as well as present possibilities, thereby enhancing participants’ temporal identities” (Pascal et al. 2009:146).

The progressive nature of advanced disease provides an exception to the logic of anticipation that guides contemporary life, where the future “sets the conditions of possibility for action in the present” (Adams et al. 2009:255). The context of advanced disease presents a case that is definitely not about the future, but rather about the present. For example, why should one prepare for global warming or biosecurity threats, if one will not be alive to see those days? Adams et al. (2009) adopt the term “abduction” to demonstrate what they call “tacking back and forth” between the present and the future. But for patients living with the “contracted” future of advanced disease (Bell and Ristovski-Slijepcevic 2011), there is nothing to tack back and forth between: only the present has been offered to them. Thus, in order to conceive of a future, they must reimagine it. That afternoon over coffee, Melody implored me to see what it would be like to live in her shoes, to live a life where she feels that dreams have been prohibited. But rather than stop dreaming or planning, she revises the scale of her plans.
Elizabeth similarly had to work to imagine a different future for herself than the one she had been hoping for. She had undergone the first step of in vitro fertilization – egg removal and fertilization with sperm – prior to starting chemotherapy for ovarian cancer. This process had produced only “one measly embryo” (as she commonly referred to it), which was frozen at the IVF clinic in hopes that it might be implanted after she finished chemo. Throughout her first round of chemo how soon she would be able to try for implantation was the main question Elizabeth carried with her. It was implicit in any question she asked about the future, and sometimes made explicit in the consultation room, when she got up enough guts to ask. She was told that “from a fertility point of view,” “[she] would be doing [herself] a disservice” to consider implantation before 3 years, because they tended to see recurrence within 3-5 years. This news was devastating to Elizabeth, who watched her personal dream of becoming a mother be dissipated by the impersonal language of recurrence statistics.

In the spring of 2014, she told me that the IVF clinic had consulted her about what to do with her frozen embryo: continue to store it, donate it or destroy it? She recounted to me what seemed like a very difficult decision to donate the embryo, rather than to continue storing it, since no one on her health care team had supported her goal of going forward with implantation in the next few years. Given her age, and her insistence that she would not bring a child into the world if she was not sure she would be around to raise it, she had asked the IVF clinic to donate it, saying “I liked the idea of a little Lizzy running around.” Her motivation could be viewed as self-interested and altruistic at the same time; through the donated embryo, she was trying to forge a future for herself even if she would be absent from it, and she was giving another couple a chance at having the family she was denied.

After deciding to donate, Elizabeth’s story took yet another heartbreaking turn. She was informed that her embryo did not qualify for donation, for reasons having to do with the way it had been extracted or preserved. Thus, rather than donate her embryo to a couple, her only remaining option was to donate it to “science.” This meant that the embryo could be used in practice training for staff learning the techniques of implantation. Throughout this long process, beginning with egg extraction in 2011 before the start of chemotherapy, and ending with the donation to science in 2014, Elizabeth’s embryo is symbolically transformed from a representation of her dream of bearing her own child, to a “little Lizzy” being parented by others, to an object of value to be used in medical training. Thus, her embryo too, was denied a future and would never be transformed into a person. That Elizabeth could consider IVF at all is itself a
“success of biomedicine,” a representation of “the seduction and danger of future thinking” (Jain and Kaufman 2011:183). The technology’s power to “seduce” is through belief in its promises, and people in trying circumstances, such as those with cancer or those who cannot conceive, want so much to believe it will deliver (Franklin 1997). Yet in Elizabeth’s case, the technology’s existence produced yet another loss; not only does she have to accept her own uncertain future, but also that of her embryo as well.

Patients see the future that has been forecast for them by grim odds or evidence, and work to reject it by crafting other, alternate options. These are perhaps not the options they hoped or desired for – Melody’s window to the outside rather than her next trip or career, and Elizabeth’s future without motherhood – but they are still futures. Neither woman says, “I have no future.” Even while the disease carves away more pieces of their hopes and dreams, both women try to hold onto their dreams by continually scaling back their plans.

... In this section, I have demonstrated patients’ subjective experiences of time, what I have called the temporal modality of Life Time. I attended a public talk at Lady Ann’s, where one of the physician presenters remarked, “If your mind is constantly in the uncertain future or the regretful past, you cannot live in the moment.” This presenter failed to recognize that all patients reckon past, present and future simultaneously, and that “living in the moment” cuts them off from both coming to terms with their illness through incorporating it into their past, and seeing their way out of it by dreaming for a future. Patients with advanced disease are told to be grateful and appreciative of the time they have left, advice that emerges from the growing literature on post-traumatic growth after illness (Bell 2010; Lewis 2013). One problem with this discourse is that it views cancer as a “gift” or a “learning opportunity”; patients are thus expected to respond to their illness with gratitude and appreciation, not anger and sadness (Bell 2010; Conway 2007). This discourse contributes to a naïve, misleading view of cancer, and ignores its profound power to disrupt people’s Life Times. In the next section, I examine what happens when people’s personal chronologies of time come up against the objective neutrality of survival statistics.

**Prognostic Time: Feeling the Bars of a Numbers’ Cage**

*March 27/12. On our way down the elevator, Jennifer says, “I looked up my disease on the Mayo clinic and wasn’t too happy with it.” She mentions something about 67%, which I clarify by*
asking, “67% recurrence?” “Yes,” she replies, “in 3 years. I didn’t look at 5 years – I didn’t want to see it.”

Sarah Lochlann Jain (2007) has eloquently described the phenomenon of “living in prognosis” whereby survival statistics present the possibilities of one’s future. She calls prognosis one of cancer’s “materializing practices” and provides the useful imagery of a patient standing in “the firing squad” to describe how people’s remaining lifetimes become defined by the relative survival ratios (RSRs) regularly cited by the Canadian Cancer Society and the American Cancer Society (Jain 2007:78). Her words demonstrate how statistical averages enclose people and make it difficult for them break free of what I will call the ‘number’s cage’ – a cage which contains, through aggregate statistics, the quantity of life that remains for persons fitting certain categories of illness. These numbers seem ‘hard’ or ‘true,’ but of course, it is very difficult to translate these statistics into a prediction for one individual’s lifespan. The authors of a leading American textbook on end-of-life care recognize that “moving from a clinical diagnosis of a terminal or incurable illness expected to end in death to a prognosis – a prediction of the course of the illness and remaining life expectancy – is an exercise in uncertainty” (Field and Cassel 1997:30).

Furthermore, Jain argues that the numbers are offered “at a level of abstraction that is virtually impossible to grasp” (2007:81). For example, Person A, whose disease has a 5-year RSR of 5%, seems objectively much worse off than Person B, whose disease has an RSR of 80%. But whether Person A will fall into the 5% of people who survive 5 years, or the 95% of people who do not, is impossible to know (Jain 2007:81). Artist Carol Sibbett (2004) describes reading in her own medical chart that an expert had said her 5-year survival was 60%, and 10-year survival was 30-40%. Her oncologist told her, “Probability figures are one thing, but actually for you it will be either 0% or 100%” (Sibbett 2004:2). In other words, survival statistics are just that: statistic probabilities calculated for a group. The higher the probability of survival, the better it is for the patient, but it remains a probability: “once you enter the population, you will only die or not die; you will not 70 or 42, or 97 percent die” (Jain 2007:81). In this way, survival statistics mirror other uncertain concepts produced in medicine, such as the ‘partial pregnancy’ described by women who are undergoing IVF and hoping for its success: a woman cannot be “partially pregnant” but only pregnant or not pregnant (Franklin 1997). By focusing on what it means to live your life oriented around the timeline predicted by the disease, as opposed to your age or generation, Jain offers an important reminder that cancer changes the ways that
people orient themselves in time: “If you are going to die at 40, should you be able to get the senior discount at the movie when you’re 35? (is the discount a reward for long life or proximity to death?)” (2007:80; see also Hagestad 1997:211).

In this section, I rename Jain’s phenomenon of “living in prognosis” as “Prognostic Time” and aim to expand her frame of analysis, by discussing what that temporal modality looks like when specific prognoses are not offered to patients. For the participants in my study, living in “prognostic time” was less the result of living within specific ‘numbers’ cages,’ but rather living everyday with a disease they knew was incurable. For example, Mukherjee (2010:7) begins his book with the story of his patient Carla, who is suffering from acute lymphoblastic leukemia, a disease that, as he tells her, is 30% curable. In my research, I witnessed no comparable conversation in which any percentage of curability was so assured. Conversely, the potential of curability was actually bracketed off by the mention of the word *incurable*, which almost always came up in conversations about ovarian and lung cancers. So for the patients I worked with, predictions of “survival statistics” might be more appropriately renamed as “mortality statistics” since none of them were offered the likelihood that they would survive their cancers. The most that doctors would often say, for both lung cancer and ovarian cancer, is that the disease was incurable and its history demonstrates that it “almost always comes back.”

If people had ideas about prognosis, they most often came from the Internet, or from consultations outside of Lady Ann’s. For example, at one of my first informal interviews with Jennifer in early March of 2011, as we sat waiting for an appointment in the Gyne clinic, she brought up the subject of her prognosis, saying, “I don’t even know because I was too afraid to ask.” Several weeks later, I recorded the fieldnote at the beginning of this section, where she had looked up her disease online and found a recurrence statistic that made her fearful and unable to look further on the site to see the longer-term predictions of survival. Similarly, other participants told me that despite everyone’s best advice, one of the first things they had done after being diagnosed was to Google their illness. Predictably, they found varied results, but despite discrepancies in numbers, no site suggested that metastatic lung, ovarian or endometrial cancer was curable. Using outside sources to define Prognostic Time made this temporal modality seem more amorphous, or perhaps less ‘real’ (i.e., hard and true) since it was something not addressed in conversations with their oncologists. However, even though they used different sources to come at an understanding of their likelihood of survival, it still resulted in a numbers’ cage – just one where perhaps the contours were less rigidly defined. Thus, they could still feel
the trappings of the cage, and could articulate what it felt like to have their lives contained by statistical predictions of survival. Below I provide a few examples of how Prognostic Time materialized in patients’ lives.

I. Numbers are relative

I sat in on a consultation with Melody where a palliative care doctor (Dr. Kelly) explained very clearly that doctors avoided providing specific numbers because they are “often wrong”:

Melody: My big question is – I don’t know if you’ve seen, but judging by the fact… I’m cramming for finals here [i.e., she is asking if she is dying]

Dr. Kelly: We always defer to oncologists because it’s their area. Also, it would be a guesstimate. If I took the same cancer – in 10 bodies – it would be different. Often doctors say 1-2 years, 3-6 months, but they are often wrong. Do you know, a lot of patients are not sure they are interested in the number. We know it’s not fixable. (pause.) Ok, so here’s my doctor plug now. Forget about it. Enjoy your life.

Melody: And wait for the time to come?

Dr. Kelly tells her about another patient he had with lung cancer.

Dr. Kelly: People said, ‘Don’t buy a house.’ He had 9-10 months in that house being completely happy in that house. Numbers are relative.

Later in the conversation, he asked her directly again, “When you talked to your oncologist in the past, has prognosis ever come up?” Melody replied “Not really”, but then added, “She did say I would not get out of this. Alive.” In response to this comment, Dr. Kelly reiterated again that doctors often do not give prognosis because often they are wrong. At the end of this very long consultation (my notes indicate that we were in the room with either the doctor or nurse present for close to 2 hours), Dr. Kelly was encouraging Melody to push her oncologist a little more and to ask her specifically for the prognosis. This was Melody’s first meeting with Dr. Kelly and his palliative care team. She had asked Dr. Girard to be referred because, after her scary incident during her last chemo where she almost died with the IV in her arm from Carboplatin toxicity, she was not sure that she wanted to take more chemo. Dr. Kelly encouraged her to think about what she wanted:

Dr. Kelly: You need to say, ‘I need to know this.’ If you are going to go through that [i.e., chemo], you want to know: What I am I getting for it? What are the chances I’ll respond? For how much? For how long?
Melody:  But they don’t know

Dr. Kelly:  There will be an area of uncertainty…

What is interesting is that when he starts to push, she backs off a bit. By the end of the consultation, they have swapped positions – now he is pushing for numbers and she is concentrating on the “uncertainty.” Maybe she is exhibiting the comment he started with: that a lot of patients really do not want to know “the number.” The academic literature on prognosis supports Dr. Kelly’s claims. Christakis (1999) has shown that physicians in general do not prognosticate, which he attributes to its association with death, even though there are many more routine, less serious implications of prognostication. Studies on prognosis have shown that both patients and physicians tend to over-estimate prognosis (Christakis and Lamont 2000; Weeks et al. 1998; Glare et al. 2008, 2003), which perhaps is telling in that both parties are hoping for a better outcome than what actually occurs.\(^{148}\)

Paul’s last weeks of life showcase just how “wrong” the doctors can be sometimes. I spoke with his wife, Sue, several months after he had died and the trauma of the whole experience was still visible on her face as we sat in a restaurant and she told me about his last few months. He had been declining very rapidly and he kept saying, “If I can just get my chemo,” trying to convince himself that chemo would be able to help. As his primary caregiver, she knew that this was unlikely and so she tried to temper his hopes. When they finally got in to see Dr. Lawson, he was very, very sick. Sue recounted to me,

Dr. Lawson was really great. I have to say. She said, “In my heart of hearts, I can’t let you have chemo. There are sometimes when chemo helps. And sometimes when it hurts. And now it is just going to do a whole bunch of bad things.”

At that consultation, Dr. Lawson gave Paul 2-4 months to live. After their appointment in the lung clinic, they went on to an appointment with palliative care. After that consultation, Sue pulled their palliative care doctor into the hallway and asked if she could tell her how much longer Paul had to live (she did not want it discussed in front of him). Her palliative care physician replied, “I can say until the end of the week and after that I can’t say.” Paul died about 2 weeks later.

On the same day, in the same hospital, Paul is given two very disparate prognoses: 2-4 months by his oncology team (who, incidentally, was not planning on giving him more chemo, but who was planning on setting up some other sort of care for him in the next few months, suggesting they thought he would be alive to receive it), and 1 week by his palliative care team.
They both saw the same man, presenting with the same clinical symptoms. Paul’s days were limited, but just how limited depended on who Sue asked. Paul’s numbers were relative too, but in a different way than in Melody’s story, where Dr. Kelly uses this phrasing to refer to the quality of life that she has. In Paul’s case, the numbers are relative to the messenger: oncology had a much more optimistic prognosis than palliative care. This again underlines the temporal ambiguity of Prognostic Time.

II. Going to see God

Julia was diagnosed in Peru with ovarian cancer when she was 8 months pregnant. Her doctors told her the diagnosis was serious, “But they never said anything like, ‘you only have 3 months to live’ or something like that.” She told me after her baby was born, she and her cousin went to get a second opinion in Boston, Massachusetts. This doctor was very different:

So my cousin was making some of the more difficult questions that I was probably not ready to make, so she asked, “So what is survival rate with a cancer like this? Is it 20%?” The doctor said, “Oh no, it’s much less than that – it’s 5%.” Because it was stage 3 ovarian cancer and she said it’s 5%.

At the end of the consultation, the doctor told Julia to “go home and get custody of your child – take care of that” [she and her partner had split up].

Again, she wasn’t saying you are going to die in 3 months, but I think the clear implied message there, was ‘You’re going to die – I mean there’s no question about this.’ So I went back home and I really had a hard time dealing with what she said. I mean I think by far throughout my treatment and everything, this was the hardest thing to take. So I went back home and my doctor was very mad.

She recounted what her doctor in Peru said to her:

I never told you that you were going to die because I don’t know. Right? If I knew then I would tell you. But I don’t know. You may die, Julia, and you may survive, and I have no idea, so I’m not going to tell you anything like that…because I’m not God. But you went to see God and you got an answer.

Julia told me this story in an interview, and she disclosed that this experience with the doctor in Boston was by far the most alarming thing she had had to cope with – more difficult than being pregnant and knowing she had cancer – and that it had almost put her into a depression:

That was by far the most shocking experience throughout. And like I said, she was a very kind woman, I mean she was not meaning to hurt me or anything. It was just
like she was very (hand hitting hand sounds – chop, chop, chop) blunt about my chances of surviving this.

I include Julia’s story here, even though it happened outside of Lady Ann’s, because it formed part of her experience of illness, and of course continued to impact her after she had become a patient at Lady Ann’s. It also demonstrates two very different approaches to prognosis: the American approach, where giving specific numbers might be part of “fully informing” patients about the nature of their disease, and the Peruvian approach, where the numbers were avoided in recognition that doctors were not “Gods” and could not possibly predict what would happen for each patient. Hearing how “shocked” Julia was that this American doctor had been so blunt with her, and how difficult it was for her to live within a predicted survival rate of 5%, perhaps helps to see why doctors at Lady Ann’s are so reluctant to provide these specific numbers. It is worth noting here that in Julia’s case, the Prognostic Time forecast by the American doctor could not have been more wrong. When I met and interviewed Julia in 2011, she had survived 13 years since her original diagnosis.

One day early in my observations in the lung site, I overheard the doctors joking about a patient who “wanted to know exactly when he was going to die.” I noted it, because they were laughing and I thought it was a strange response to such a serious question. I was new to the site, so I asked the resident nearby, “Can you say that?” to which she replied, “No, of course not,” indicating with a look that I had asked a stupid question. At the time I thought they were making fun of this patient, and the notion that “he wanted to go home and plan his death.” Writing up my fieldnotes later on I wondered would they not want the same thing if they were in his position? In reflecting on Jennifer, Melody, Paul, and Julia’s stories of Prognostic Time here, I see now that those clinicians that day were not laughing at the patient. They were laughing because it is preposterous what we laypeople believe doctors might be able to tell us. A profession that has built up its own “God” complex, doctors are only too aware of the limits to their powers. As a culture, we have been misled to believe that doctors and nurses are capable of offering up these timelines and that they do so freely, without provocation, because characters in movies and on TV always seem to be offered up specific timelines. In fact, Julia made this direct link in our interview, in describing her initial diagnostic appointment in Peru. She said that although they were very clear that the diagnosis was serious, no one said anything about prognosis. When I probed further, asking if she had asked the question, she replied,
No…then you have like this I suppose…TV and movie images in your mind of doctors telling patients, ‘You only have 3 months to live’ and things like that, so you were kind of waiting for that to happen. But nobody was saying anything.

People who have little medical knowledge or background go into Lady Ann’s with nothing to compare their own experience to except for these cultural narratives, and then find them to be profoundly misleading.

However they came across the information, patients carried with them their ideas about their own Prognostic Time. Even though their oncologists had not often defined the ‘numbers’ cage,’ patients always felt the timeline of disease, and it continued to inform their experiences. Perhaps their cages’ bars were less visible, but living with advanced disease still felt very much like their lives and lifespans had been contained. In the next section, I discuss the extensive influence that being ‘on’ or ‘off’ treatment has on patients’ time.

**Treatment Time: A Way of Life Not Easily Left Behind**

Once people are initiated into life as a patient with advanced cancer, the routine of hospital life comes to replace the routine of work life, and the most dominant routine is that of treatment. Every longitudinal patient I followed was on some sort of treatment regimen. My focus here is not so much on how long treatment takes (the actual duration of chemotherapy or radiation), but rather on how the sense of time passing in the short term becomes defined by a patient’s treatment schedule. Medical staff often refer to the day patients are injected with or take the chemo drugs orally as “Day 1,” and thus the days after chemo come to be numbered in relation to when the drug was received. For example, in consultations, I often heard doctors and patients referring to “Days 5-7” as being the worst ones of each cycle, once the steroid drugs have worn off and the treatment is asserting itself. The predominance of the treatment schedule is reflected in most conversations between oncologists and their patients, such as this one:

*February 8/11: Doctor asks, “How was your last chemo?” Patient tries to answer, saying something about chest pain, but doctor cuts her off saying that “the only thing documented in the chart was chest pain that went away.” She asks the patient, “Next chemo is when?” Patient and family member answer that it is this week – last one. Doctor is looking down, reading the chart, and glancing at patient in between. She says that her bloods are ok to go for chemo, and then begins asking about specific symptoms (e.g., fever, nausea, vomiting; tingling, numbness; bowel, urine, vaginal bleeding).*
Patients focus on getting their next dose, next chemo, and look forward with anticipation to the end of a round of treatment, but contrary to what one might expect, several patients told me that the times when treatment stopped were actually more difficult. This comes somewhat as a surprise to most patients, as they seem unprepared to deal with the sudden amount of ‘free’ time they are faced with once treatment is over. So many efforts are aimed towards getting treatment, and then ticking off each subsequent cycle in the prescribed regimen, that when there is no longer the need to come to the hospital so regularly, patients are unsure of what to do with themselves to occupy the time that gearing up for, receiving, and then dealing with the after-effects of treatments used to take.

I. Being on treatment: “I just want to go home”

Once diagnosed, patients move quickly into the world of treatment, which involves coming to the hospital regularly for chemo, bloodwork and follow-up appointments. This world moves quickly and makes demands on them; not only are they faced with the physical changes brought on by treatment, but also with the logistical challenges of coming regularly (for chemo, often once every 3-4 weeks for anywhere from 1 to 8 hours, but with potentially more appointments such as bloodwork or scans in between; for radiation, often every day for a period of several weeks, for short, 10 minute doses). Patients turn over their bodies with few complaints to long chemotherapies, “the technologies through which the patient’s body must submit to the present through the promise of the future” (Stacey and Bryson 2012:12-13). In general, patients with advanced disease are very grateful to be receiving treatment at all, and thus they comply with treatment regimens, no matter how demanding.

Pam’s comment to me in August 2011, “If I could sleep until it was over…but that’s just not possible,” in response to finding out that her treatment would be put on hold for the second time, conveys just how hard being on chemo is for patients. Dealing with the physical side effects alone is challenging. But patients like Pam also had to deal with the emotional roller coaster of never knowing each month if they were physically well enough to get treatment, or if it would be delayed in order for their white blood cell counts or other blood levels to be deemed acceptable by their clinical team. Most people knew how much treatment they had signed up for, and were very conscious of the date they expected to be done. For example, an ovarian cancer patient is likely to receive 6 cycles of Carboplatin & Paclitaxel, given at 3-week intervals. Pam received this regimen, in addition to an extra trial drug she was given with the two standards. So
when she was delayed that day in August, it meant that the day she had forecast as her last chemo day would now be pushed forward another week (at least). Every time treatments are delayed it adds more weeks to people’s illness trajectories, and thus each delay delivers its own additional blow. Being “bumped” or delayed means that the treatment gets drawn out and actually takes up more of patients’ time than they had originally anticipated.

Even when patients receive treatments on schedule, it is surprising just how much of their time it takes up. For example, I went to visit Jennifer, who was receiving chemo for metastatic endometrial cancer, in chemo one afternoon. She told me she had arrived at 9 am and expected to be done around 4:30 pm – the equivalent of an entire day, spent in chemo. On another afternoon, I dropped in on Elizabeth around 1 pm, which was about halfway through her chemo, and ended up sitting with her for the remainder of it. Although she had only received a few cycles of chemo so far, she had quickly observed that her chemo lasted much longer than most patients’. As we sat there chatting, she pointed out to me, “That man is leaving, and that woman too, she’s finished,” revealing the severe strain of being the last one there. She said on her first day of chemo, she had been seated in a chair that was located next to two others. Over the course of her very long day, she watched many people sit down and get up from those two chairs (i.e., start and finish their chemo infusions, while hers continued). On the day I visited with her, she was sitting in a somewhat more private chair, but could easily see 6 other chairs in front of her, and told me she had seen at least four different people in one of the chairs since she arrived that morning. As the afternoon wore on and on, and the chemo nurses started to go off shift around 5:30 pm, she watched the nurse who had started her infusion that morning clean up her work area and leave for the day.151 She noted wryly, “It’s really bad when you start outlasting the nurses,” followed by, “I just want to go home.” As Pam, Jennifer, and Elizabeth’s stories show, being on treatment takes its toll on patients’ minds and bodies. And as the previous chapter showed, treatment for advanced disease is cyclical, not terminal, so ‘treatment time’ will continue to govern their time indefinitely for as long as treatments are still available. The challenge for patients is that once time has been defined by the treatment itinerary, it is difficult to move forward in time when treatment is on hold or is no longer an option.

II. Being off treatment: “It’s like being fired”

When treatment ends, it is often the first time the patient really has any time to stop and consider her situation. The difficulty of life after treatment was a central theme of the 2nd
interview I conducted with Jennifer, who was diagnosed with metastatic endometrial cancer. She said, “everything changed” in July of 2010 when she received a phone call; “when they said the word cancer,” “that’s when my whole life schedule changed.” When she started at Lady Ann’s and went in for surgery, Dr. Girard and her family physician were still thinking her cancer was “a good one” – early stage I cancer that might only require radiation, and maybe not even that. The pathology report from her surgery quickly dissipated any thoughts of a short-term treatment schedule. Instead, she spent 6 months in chemotherapy, which “kept getting dragged out because [she] couldn't take treatment because [her] white cells kept on going too low.” Chemotherapy was followed by 6 or 7 weeks of coming every weekday for radiation, which she likened to “her job” as it was what she did every day. After she finished radiation, she was put on 3-month follow-up, so she went through a period of not having to come to the hospital regularly. In describing how hard this time was for her, she said, “And suddenly I was kind of like, ‘What do I do?’ It’s like being fired.”

Jennifer: But, yeah it was weird to know – I didn’t know what to do

Alyson: Yeah, but it seems like you also didn’t really get a lot of help in sort of being prepared for that

Jennifer: For that sort of just – I don’t know – dead time, down time. And not knowing too, what – like the radiation is done, but you don’t know what that means

Jennifer’s description of life post-treatment as “dead” or “down” time is telling. After seven or eight months of receiving treatment and having her life scheduled out for her, she is suddenly not sure what she should be doing or what she is able to do. Before she had cancer, she was an avid runner, an equestrian who rode and trained horses, and an elementary school teacher. This is the life she is trying to return to. But when she was sick, she “went to bed for a year.” I reminded her that a lot of her time had been taken up by her hospital schedule and she replied, “I came here, but I stopped running and I stopped riding. And I stopped, you now...doing things that made me, that sort of defined me, I guess.” These are the routines she is trying to re-establish in her life, but she admitted in the interview how much she had struggled trying to do this: “I was trying to mimic what my life looked like before.” When we talked about what in particular made that time hard for her, she also admitted that it was hard for her to go so long without seeing Dr. Girard – “It was the longest I’d been away from her.”

Towards the end of this interview, Jennifer continued to bring up how she was still not sure what she was doing or was supposed to be doing. She was in the process of negotiating a back to
work agreement, which would have her return part-time rather than full-time so that she could get gradually reintegrated into teaching. But despite this, she said she still felt “lost in a crowd”:

Alyson: LOST IN A CROWD IN WHAT WAY?

Jennifer: JUST, SOMETIMES I JUST FEEL LIKE I DON’T KNOW WHERE I’M GOING, WHAT I’M SUPPOSED TO BE DOING. HOW TO GET THERE, WHAT STEPS TO TAKE TO GET TO THIS BIG END GOAL. I DON’T KNOW HOW TO MAKE LITTLE STEPS

Without a treatment schedule to dictate her life, Jennifer feels “lost.” This transition would be hard for anyone, but Jennifer has the added worry of feeling like it was not “over yet.” As a patient with metastatic cancer, she was sure she would have a recurrence. So, to what extent should she return to her previous life? If she resumes the activities that used to consume her time, such as teaching, riding, and running, how will she cope if she gets sick again and has to give them up once more?

Deo recounted a similar experience when I met with him in late September of 2011, several weeks after he had finished chemotherapy. At his first follow-up post treatment, he had been informed that he might qualify for a clinical trial, and now he was waiting with anticipation to see if he might be eligible to participate. He was returning to Lady Ann’s for a work-up – e.g., extra tests, MRI – as part of the required protocol for the clinical trial. On that morning as we spoke outside the hospital coffee shop, he asked me when we would conduct a formal interview (we had been discussing possible days for some time). He said that he liked to have “things planned,” hinting at the difficulties he was having in this period of time post-treatment as he waited to find out if he was going to get another treatment:

I DON'T LIKE BEING IN LIMBO. DR. LAWSON IS MY DOCTOR. I WANT TO SEE HER. I HAVE THESE QUESTIONS. WHEN WILL I SEE HER? WHAT HAPPENS IF I DON'T QUALIFY? I'M GUESSING I WILL END UP BACK WITH HER?

Similar to Jennifer, Deo is uncomfortable not seeing Dr. Lawson. His fears that he might not qualify for the trial are well founded; he has many other complicating health problems, such as diabetes, and a history of heart disease. He tells me, “I am confident I will get on the trial,” and then reasons that perhaps he is not seeing Dr. Lawson on these visits because “she too, is confident I will qualify, so knows she will be seeing me?” Deo tries to justify why Dr. Lawson would not want to see him as regularly as when he was on treatment. He is not ready to accept life “after treatment” because that life does not offer him much. When he was offered the clinical trial, the nurse specified that it was “for stage IV patients specifically” and situations where there
was “no cure.” I noticed at the time that he had been very quiet after she said that. Perhaps her words served as a harsh reminder that the time of treatment would eventually run out.

Deo had finished treatment, but right away had been offered the hope of another treatment; the promise of more biomedicine keeps him in Treatment Time, even when he is not actually on treatment. I spoke with other patients who had similar experiences with getting their hopes up for a treatment they would later be denied. On one visit to chemo, Isabelle and her husband recounted to me how they had been told about a trial, and then it had been taken away, only to become a possibility again the following week. Hitchens (2012:32), who similarly got excited about the possibility of a trial only to find out he did not qualify notes, “I can’t forget the feeling of flatness that I experienced when I received the news.” The prospect of treatment and the rollercoaster of emotions it causes for patients when it is offered and then soon retracted leaves a mark on patients, and makes it difficult for them to move forward in their lives.

Jennifer and Deo’s experiences support Hagestad’s (1996) argument that treatment protocols can provide a sense of comfort, and also accomplishment, as patients cross each one off their lists. But after finishing treatment, patients suffer from a loss of what to do with themselves and wonder what is coming next, resulting in anxious feelings or even a sense of failure (Roth in Hagestad 1996:213). They are charged with the additional burden that treatments for metastatic cancer are often not aimed at cure, but rather at control or shrinking of the disease. Thus, Treatment Time permeates life regardless of whether patients are on treatment or on break. By shaping their first six or seven months (maybe longer) at Lady Ann’s, treatment provides the foundational timeline for the experience of advanced cancer even long after treatments have stopped. Next, I present the last temporal modality, which examines how the powerful machine of hospital time dictates patients’ lives.

**Hospital Time: Governing Bodies and Temporalities**

In truth it is like this: You cannot imagine how time can be so still. It hangs. It weighs. And yet there is so little of it. It goes so slowly. And yet it is so scarce (Edson 1999)

In this quote from *Wit*, playwright Margaret Edson brilliantly captured the multi-faceted aspect of time through the voice of Vivian Bearing, a professor of English diagnosed with late-stage ovarian cancer. In the scene quoted above, she is speaking not only of her own lifetime,
which is increasingly threatened by a toxic clinical trial she is undertaking to combat her cancer, but also of the time of the hospital. When this play was made into a film starring Emma Thompson (Nichols 2001), the director chose to have her say the line from her hospital bed, and then showed scene after scene of tedious, still shots – the hospital room, in light and in dark, the view from the bed, the hallways – illustrating perfectly the quiet and isolation that patients endure when lying in a bed alone in a foreign place. Throughout the play, Vivian’s lifetime is elapsing (the play begins with the admission that she will die by its end), and yet her time is very much taken up by the time demands of the hospital: she is woken, sent for tests, poked and prodded all on someone else’s time.152

Frankenberg argues that time seems to “stop” when patients enter the hospital, and they are submitted to a new timeframe (1988). The recently deceased renowned film critic Roger Ebert, who had a very disfiguring head and neck cancer, had reviewed Wit before he had cancer. He admitted that he could not make himself watch the film again after going through treatment. He said, “I remembered it too clearly, perhaps, and dreaded re-living it. Since then, I have had cancer, and had all too many hours, days and weeks of hospital routine robbing me of my dignity” (Ebert 2008). Ebert’s comments demonstrate how the routine of the hospital tends to “take over” and come to dominate patients’ own lives. Murphy similarly notes, “what one loses in the hospital is not life but freedom of choice, for the patient must submit to the requirements and routines of the institution” (1990:20). Thus, the hospital becomes a “robber” of time, with patients surrendering themselves to recurring and tedious activities, such as the rituals of chemotherapy described in Chapter 4. Olivia told me that she found the regularity of these routines – their patterns and predictability – somewhat comforting, once she got used to them. She said that Lady Ann’s felt like its own “little world.” Spending the day there, she could “forget about everything else,” allowing her to leave her real life behind. These routines lend themselves to a cyclical notion of time, since it is that time which is said to repeat and be associated with ritualistic activities (Bloch 1977). Yet, the modern world is said to run on a linear notion of time, and a hospital is a prime example of a place that runs on the Western notion of clock and calendar.

Thus, advanced disease showcases both linear and cyclical aspects of time in the hospital. Although by and large, the hospital runs on a notion of linear time, made explicit in the clock times around which patient itineraries, doctors’ schedules, testing and treatment appointments are organized, cyclical aspects of time are pervasive as well, through the many activities, like
chemotherapy or waiting, where time almost seems to stop passing. At Lady Ann’s, there are many activities that take place throughout the day where the clock is not the main source of ‘telling time.’ Patients’ appointment times are a good example. Although each patient is given a specific time for a clinical appointment (e.g., 9:30 am), it is a rare and almost nonexistent occurrence that patients actually get called into the clinic at their given times. It is much more common for patients to wait anywhere between 1-2 hours to be seen. During this period, time does not stop – doctors are working, patients are sitting – but they are not being governed by the clock on the wall, but rather by the demands of the work that each patient requires. PFCs often ‘tell time’ by sharing with patients what ‘time’ they are on – e.g., if a patient at 11:30 am gets restless and goes up to ask the PFC what is going on, a common response would be, “Your appointment is at 11 am, but we are still working on the 10 am patients.” Oncologists similarly ‘tell time’ sometimes by asking how far behind they are.

Moreover, the hospital showcases how time control can be a form of governance, both at the level of the population, and at the level of the individual body (Munn 1992). The body has a particularly important role in this case, as both the locus of control and the object of timing (Frankenberg 1988; Munn 1992). Patients embody the purposeful activities of the hospital (Munn 1992:110), but even though they are the hospital’s primary users, Hospital Time is not oriented around their schedules. Rather, their bodies are moved through the bureaucracy at times that are convenient for the hospital and its workers. Frankenberg argues that it is actually the imposition of this new “temporal” framework that helps to ensure that the hospital has social order. The removal of patients’ own temporalities is seen not as a side effect of an efficient bureaucracy, but actually part and parcel of “the modus operandi of biomedicine as at present practiced” (Frankenberg 1988:148). There are particular concrete ways in which hospital time comes into view, which will be discussed below, including: waiting time, appointment time, consult time and clinical record time.

Waiting time: Questioning patients’ value

My problem is that all I seem to be doing is waiting. All I do is wait and wait. I wait for CTs. Then I wait for results. I wait for this and I wait for that. I can’t make a concrete plan in my life…I’m waiting to get older or I’m waiting to die.

-Melody

When I think about my fieldwork at Lady Ann’s, I think about the time that I spent there. The minutes, the hours, the days, the weeks, and months that I spent following patients through
the clinics. But my time was nothing compared to the minutes, hours, days, weeks, months, and sometimes years that patients themselves spent at Lady Ann’s. So much of that time is taken up with the act of waiting. A patient with advanced cancer often has to ‘suspend’ normal life in some important ways, such as working, and the productive hours of the day that used to be spent at work are spent sitting and waiting in the hospital. In this section, I examine the profound experience of time elapsing when patients are waiting for various appointments, treatments, and tests in the hospital. I focus on the act of “waiting” as opposed to the conjunctive noun “wait times” that is often used to denote official health care statistics. While there is much talk by provincial health care departments about decreasing official “wait times” for certain procedures like hip or knee replacements, there is practically no attention whatsoever given to patients’ experience of waiting on any given day they attend a clinical appointment at a hospital. Although it seems like a passive form of action, I demonstrate that waiting is not innocuous. As Melody’s comments reveal, she cannot reckon time, because all she seems to be doing is waiting – for both small, concrete things (CTs, results), as well as grander, more abstract things (getting older, dying).

For any person visiting a hospital, waiting to see the doctor is annoying and time-consuming, but for patients with advanced disease, for whom everyday life consists of waiting as they feel time slipping away, waiting is particularly complex. Even for a single activity, the experiences of waiting can vary. For example, waiting to be called into chemotherapy is different for a patient in cycle 1 (‘newbie,’ where a patient does not know what to expect because everything is new) than for a patient in cycle 6 (‘old hat,’ where a patient knows the routines and rhythms and can predict what the day will look like). Waiting is much more manageable if you know what you are waiting for and have a sense of about how long something will take. From my observations, it is the people who do not know the routines and are unprepared for the long waits that find them most frustrating.153

Melody, who has been coming to Lady Ann’s for years, explains her approach to waiting:

Compared to when I first came here in 1998 and you waited and waited for almost a day to have chemo, and then after waiting the whole day then at the end, you were still waiting and then you were told, ‘You have to go home and come back in the morning and we’ll try to get you in to chemo.’ So things have changed a lot since then, where yes, chemo I would say is pretty good. Well, we’ve waited sometimes 3 hours – 3 hours maybe, 4 hours. But once in…and bloodwork is pretty good. You get to know the good days and the bad days and what part of the day is good and compared to what’s going to be a long wait. It’s like everything – the restaurant
business – there are high times and low times. Bring a good book and be prepared to do the wait.

When I asked her if she didn’t mind the wait, she replied: “You’ve got to book it off. You can’t be leaving your job for lunch break and think you’re going to rush back.” Her friend Victoria, who always accompanied Melody, added, “You don’t make another plan.” Melody’s comments demonstrate that she has learned to wait – that her many years of treatment at Lady Ann’s have prepared her for what her time at the hospital will look like. She qualifies the 3- or 4-hour wait to get into chemotherapy as “pretty good” based on her own history of cancer treatment at Lady Ann’s. In 1998, she waited all day and was sent home without even receiving treatment.

But many patients I spoke with were not like Melody, and were encountering the hospital system for the first time. Their diagnosis of cancer was the first time they had to spend so much of their time in a hospital, and they resented the time they spent there, especially the ‘dead' time, where nothing happened. As Goffman (1971:256) famously wrote about the total institution, the hospital can be likened to a kind of “Dead Sea in which appear little islands of vivid, enrapturing activity.” There is a certain bitter irony to this – the irony of being told you have little time left and then having to waste so much of it waiting for the very people who informed you that you had little time left and that you should be “living in the present” or “for the moment.” Patients experienced various kinds of waiting: they wait to get referred to Lady Ann’s, often enduring months of work-ups and tests to confirm the cancer diagnosis; at Lady Ann’s, they wait for doctors and nurses, for drugs, for procedures and tests, and then the results of those tests to find out whether treatments are working; if treatments are not working, they wait to find out what options are left to them. Isabelle’s story showcases how these various kinds of waiting time often overlap and compound each other.

I. Waiting to see the outcome of your life

*Thursday, November 3, 2011*

Today, on my way out of the hospital, I remember that Isabelle is scheduled for chemo. I have not told her I am coming, but decide to go and see if she is there anyway, since I am not sure when I will see her next. I go up to chemo and find her sitting alone. She is wearing a pink scarf with a grey sweater and looks nicely dressed and put together. I notice that her hair is getting longer but very grey – I can’t remember if it was before as well. I tell her that I wanted to see how she was doing and she says, “If you have something else to do, you can do that.” I plan to only stay a few minutes and catch up but I end up staying with her for most of the chemo, as her husband Derek has not come today. We chat the whole time, but mostly about non-cancer things – her lifelong problem of putting on weight (more serious now that she has cancer), her
kids and grandchildren, her appreciation for the chemo nurses (‘they are so nice here!’). As we are nearing the end of the visit, I ask her what is next in terms of her next consultation since she is now on a clinical trial and I am unfamiliar with the protocol. She makes sure I understand that she is on a phase III clinical trial, and tells me that in 8 weeks she will see the doctor with a CT scan result and then “hopefully” will continue on the drug. When she says “hopefully” her hands are clasped in front of her, almost in prayer. This is a weighty moment; it is visually obvious how much she has invested in this trial drug. I have a tight smile and just stare for a second. I say something simple like ‘yes’ in reply.

Wednesday, December 7, 2011

I looked up Isabelle in the scheduling system this morning because she is supposed to be in chemo today, but found out that that she has actually been admitted to the hospital. I walk over around 11:45 am. I stop at the nursing station and ask if it is okay to visit with them. The nurse says, “Yes, fine” and directs me to their room. The door is slightly ajar so I knock lightly. I hear Derek’s voice, so I call out “Hello,” and poke my head around. I see that Isabelle is in the first bed, and that there is a second bed behind the curtain. Derek sees me and looks confused for a moment and then says, “Haven’t seen you in a while” or something like that. I say that yes, I didn’t see him last time I visited with Isabelle. She is lying in bed and does not look good. She’s wearing a hospital gown and pajama pants and her dark frame glasses that look even darker because she is so pale. She looks very thin and pale – not like last time I saw her where she looked thin, but not so pale. She says hello. I say I don’t need to stay, just came over because I saw she was admitted.

I ask, “How are you doing?” She replies, “Waiting, waiting.” I ask, “Waiting for what?” I ask her if she was admitted for pain or for something else. She said she went into [other local hospital] last week because of her stomach, and then was transferred to Lady Ann’s on Sunday. Since then they have been waiting to see a doctor to see what is going on. They mention something about being here for the bowel. She is waiting to go to the bathroom. She has had 2 bowel movements already, but she thinks she needs to have another one.

A nurse enters the room, sees me and says, “Sorry” and turns to leave, but I say “No, if you need to do something please do – I will step out,” and step into little anteroom for a second. I overhear the nurse telling them that the floor doctor will be coming to see them, and how she has told him about the laxatives. I hear them ask, “When is he coming?” She says he is on until 5 pm and so anytime. Isabelle asks if they have told Dr. Campbell (her doctor in gyne) that she is here – she is her real doctor – as she points out. The nurse responds, “Ok, but she is not a part of our team up here.” Isabelle tries to push a little more and the nurse says, “It’s [the floor doctor’s name] who talks with your doctor in gyne.” She leaves, saying “Sorry” to me again on her way out.

As I settle back in, Derek says, “5 o’clock is a long time” and starts to fill me in on what has been happening. He says that since Sunday, they have seen the floor doctor once. They saw Dr. Campbell twice – once on Monday, and once on Tuesday morning. Now they are waiting to find out what is happening. I ask if they are waiting for a bowel movement or one that is more regular? Isabelle replies that yes, she thinks so, but she is not sure. I ask, “Have they told you?” She says they haven’t really explained much since she has been admitted. Dr. Campbell came find to out why she had been admitted to [other local hospital] and to get updated on that, but no one seems to be telling them what the outcome is here.
I relate to them that I had had a friend admitted to a different floor and who had also found it very frustrating to be seeing the ‘floor’ doctor, as opposed to his oncology team. Isabelle says, “I don’t understand why it works like this. He doesn’t know me. Doesn’t know my history.”

They tell me that one of the things they are waiting to hear about are the results of her most recent CT scan, which had been taken at the other hospital. Since that hospital is not connected to Lady Ann’s, Derek had learned enough about the hospital system to be proactive and to bring a copy of the scan to Lady Ann’s for Isabelle’s doctors to review. They had told Dr. Campbell about it when they saw her last, but since then had not seen her again. They guessed that no radiologist at Lady Ann’s would look at it until Dr. Campbell told someone to look at it. So while they knew that the scan itself was physically at Lady Ann’s, they did not know what it said.

At the end of this long explanation, Isabelle says, “I am waiting to find out. I don’t know what is happening, I don’t know if I am still on this treatment or if there is something else or the results of the scan or if there is nothing left for me or what?” I clarify that the treatment she is referring to is the same one she had been on the last time I had seen her in November – the phase III clinical trial – and she says yes.

I notice that she looks very tired and worn. I ask her if they have told her what she can do – can she get up and walk around? Or is there anything to do to help the bowels to move? They say not really. That Dr. Campbell said she needed a laxative, but then didn’t prescribe one. And that the floor doctor hadn’t said anything about a laxative.

This is a hard conversation. Going back and forth with all they don’t know and my few contributions about how it “must be very frustrating for you” and how all this waiting is “not easy.” I say something like, “I wish it were different for you,” meaning right now, but I’m not sure how that is received. Neither they nor I mention the palliative care appointment she has scheduled for tomorrow.

As I get ready to leave, I mention that I could come back and see them, but Isabelle says she hopes she will be home soon. Her husband adds that they have a lot of visitors and have to turn people away, and I take the hint that all these visitors can be burdensome. Especially when, like me, they all want to know how she is doing and she is not sure how to answer. She says, “Thanks for coming.” I say, “Good to see you and take care” and tell her I will be thinking of her.

As I leave the hospital, I have a bad feeling that it will be the last time I see Isabelle. And I am right. Isabelle died the following month.

As Isabelle’s story demonstrates, there are several kinds of waiting going on at once: she is waiting to have a bowel movement, she is waiting to be prescribed a laxative to speed up that process, she is waiting to see a “floor” doctor, she is waiting to see her own gyne doctor, Dr. Campbell, to hear about her scan results and to see if her cancer is progressing, and lastly she is waiting to see if she can remain on her clinical trial drug, and if not, what will be “left for her” in terms of treatment options. The proximate, concrete kinds of waiting, such as the laxative, are
compounded by the more over-arching questions pertaining to her treatment and disease course. Her long quote inclusive of all she is waiting for seems to increase in desperation as she moves towards the thing she is ultimately most fearful of: that there will be no more treatment for her. The questions pertaining to her lifespan are made more acute by the clock time that is elapsing as she waits for even a treatable problem, such as bowel obstruction, to be resolved. I arrived at the room around 11 am that morning. The nurse says that the floor doctor will be in sometime before he leaves at 5 pm. This leaves a 6-hour window, and it is obvious why that news would not be comforting to them both. So there is no definite end to that problem either. On top of this, Isabelle is not sure when her CT scans will be read by a radiologist at Lady Ann’s (or if they have been read yet) and when Dr. Campbell will return to give them the results. So they are in limbo, waiting for a number of things, all of which are out of their control. Similar to what Melody articulates in the quote that began this section, Isabelle cannot “make a plan” for her life – in the short term, in terms of what to expect for that day, or in the long term, in terms of what to expect in the days and weeks ahead – when there are so many questions left unanswered.

II. ‘Doing time’: A typical treatment day for Elizabeth

**Figure 5.2. Time study with Elizabeth**

<table>
<thead>
<tr>
<th>Time</th>
<th>Location</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:30</td>
<td>Front lobby</td>
<td>Elizabeth and her mom arrive at Lady Ann’s and go straight to the Blood lab.</td>
</tr>
<tr>
<td>7:30</td>
<td>Blood lab</td>
<td>Elizabeth checks in at bloodwork. They are calling #10 when she arrives. Elizabeth gets #22.</td>
</tr>
<tr>
<td>7:50</td>
<td>Blood lab</td>
<td>Elizabeth is called in for bloodwork. She emerges 5 minutes later.</td>
</tr>
<tr>
<td>8:00</td>
<td>Gyne waiting room</td>
<td>She arrives at the Gyne clinic. No staff present yet.</td>
</tr>
<tr>
<td>8:30</td>
<td>Gyne waiting room</td>
<td>Louise (the PFC) arrives, and starts to check people in.</td>
</tr>
<tr>
<td>8:50</td>
<td>Gyne waiting room</td>
<td>Shelley (the clinical trials nurse) arrives.</td>
</tr>
<tr>
<td>9:00</td>
<td>Gyne Clinic</td>
<td>Shelley calls Elizabeth into a consult room. (Her mother and I go as well.) In the consult room, Elizabeth speaks to Shelley 1st, then to a doctor (not Dr. Girard).</td>
</tr>
<tr>
<td>9:25</td>
<td>Chemo waiting room</td>
<td>Elizabeth arrives at chemo to check in. She drops her hospital card in the slot and waits to be called to the desk to complete her registration.</td>
</tr>
<tr>
<td>9:40</td>
<td>Chemo waiting room</td>
<td>She is called to register. She goes up to the desk and returns with her pager.</td>
</tr>
<tr>
<td>10:35</td>
<td>Chemo waiting room</td>
<td>Still waiting.</td>
</tr>
<tr>
<td>11:30</td>
<td>Chemo waiting room</td>
<td>Still waiting.</td>
</tr>
</tbody>
</table>
On this typical treatment day for Elizabeth, which occurred in late January of 2012, she and her mom spent just shy of 6 hours at the hospital. Including Elizabeth’s travel time to and from Lady Ann’s (she commutes from a nearby suburb, about 1 hour each way, meaning she left her house at 6:30 am and will arrive home after 3 pm, due to afternoon traffic), this adds up to over an 8-hour day. Elizabeth has been coming to Lady Ann’s for 1 day every 3 weeks, since she completed standard chemotherapy for ovarian cancer in December of 2011. That means that this schedule has been her life for over 4 years now. Even being liberal with the contact times (allowing 5 minutes for bloodwork; 2 minutes to register in Gyne; 20 minutes for her consultation; 2 minutes to register in Chemo; 15 minutes for her Chemo nurse to set her up; and 10 minutes for the Chemo nurse to start the trial drug, and another 10 minutes when she stops the drug), that adds up to 64 minutes or just over 1 hour spent in contact with a staff person at Lady Ann’s over what is an 8-hour day for Elizabeth. No matter which time variable we use (1 visit every 3 weeks = 17 days a year, or roughly 136 hours (8 hours x 17 days) of time spent to receive 17 hours of care), it comes out to a good amount of time, a substantial chunk of which is spent waiting to receive care. Elizabeth’s waiting time is similar to the non-durational time that

<table>
<thead>
<tr>
<th>Time</th>
<th>Location</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>11:35</td>
<td>Chemo waiting room</td>
<td>Elizabeth’s pager starts blinking and vibrating, indicating that she has been assigned a chemo chair. She returns the pager and finds out her chair number and colour (designating 1 of 4 possible chemo zones) and we proceed into the chemo unit.</td>
</tr>
<tr>
<td>11:45</td>
<td>Chemo</td>
<td>She is in her assigned chair, but her drug has not arrived yet. Her nurse comes to start the chemo procedures (i.e., takes her vitals, inserts the IV and starts a saline drip) so Elizabeth will be ready when the drug arrives.</td>
</tr>
<tr>
<td>12:30</td>
<td>Chemo</td>
<td>Still waiting for the drug. Another chemo nurse who we know wanders by and tells us that there are 130 patients scheduled for chemo at Lady Ann’s that day. And of those 130 patients, 32 are on study drugs, like Elizabeth. He says it takes the pharmacists 1-2 hours to make 1 study drug because for each study they must follow strict protocols.</td>
</tr>
<tr>
<td>12:45</td>
<td>Chemo</td>
<td>Still waiting.</td>
</tr>
<tr>
<td>12:55</td>
<td>Chemo</td>
<td>Elizabeth’s drug arrives. Chemo nurse says she must check Elizabeth’s blood pressure again before starting.</td>
</tr>
<tr>
<td>1:00</td>
<td>Chemo</td>
<td>Trial drug infusion begins.</td>
</tr>
<tr>
<td>1:40</td>
<td>Chemo</td>
<td>Trial drug infusion is finished. The nurse runs a saline flush and takes out Elizabeth’s IV.</td>
</tr>
<tr>
<td>1:45</td>
<td>Front lobby</td>
<td>Elizabeth and her mom leave the hospital.</td>
</tr>
</tbody>
</table>
Geertz (1973) describes for the Balinese. He describes how on social occasions, there is often an “absence of climax”; “ritual often seems, as in the temple celebrations, to consist largely of getting ready and cleaning up” (Geertz 1973:403). Similarly, Elizabeth’s waiting time for a typical treatment day demonstrates that most of her time is spent getting ready for and finishing up the infusion; comparatively, the “event” or “climax” – the infusion of the trial drug itself – hardly occupies any time at all.

Given the amount of time and energy that is spent waiting in the hospital, perhaps it is useful to think of waiting as akin to “doing time,” the idiomatic expression we use to speak of the time of incarceration. Goffman’s (1971) analysis of the prison as a kind of “total institution” seems especially relevant. He says for prisoners, “there is a strong feeling that time spent in the establishment is time wasted or destroyed or taken from one's life; it is time that must be written off” (Goffman 1971:255). There are some interesting parallels, given that like prisoners, patients are in very little control of their circumstances and their bodily rhythms are controlled by a larger power and purpose. A common tattoo for prisoners is a clock with no hands, indicating the time lost while serving time in prison (Ferrari 2013). In Elizabeth’s typical day, there is so much of her time that is spent just waiting where nothing at all is happening, that it also conveys this sense of time that is being “taken” from her life. Or perhaps it is that the time that she spends waiting is not accounted for. I similarly tracked a few other patients’ movement trajectories and times at Lady Ann’s, and found that they too spent a great amount of time waiting in different locations around the hospital. Because a hospital is a highly bureaucratic centre, sub-divided into clinics and treatment areas, each service likely keeps track of its own ‘wait times’ (i.e., the time from check in to being assigned a chair in chemo). But to my knowledge, no one tracks in ‘real time’ how long it takes for patients to move through the various services at the hospital, as they must do, in order to receive care.

III. Waiting and ethnography

Week of September 6-9, 2011. This week I spent lots of time with Pam – probably close to 6 or 7 hours in total. I didn’t realize just how much until she introduced me to her friend as the research student who was doing a study of the ‘culture of the hospital’ and said I had spent many hours with her – especially this week, sitting and waiting, carrying her bag.

Sitting with patients during their ‘waiting times’ illustrated the strengths of the ethnographic method. While most qualitative cancer research takes the form of the interview, the ethnographic approach meant that I experienced the tedium of waiting, alongside the patients, but
of course without the added stress of wondering what the appointment would hold for my future. Hearing about someone’s waiting in a formal, 60 minute, scheduled interview is very different from experiencing someone’s waiting, as you sit alongside them in the chemotherapy waiting area, with your stomach growling as lunch hour passes and your bladder almost bursting, as you fear going to the washroom in case patients are called in during your absence. Livingston (2012:22) captures well the duplicitous character of hospital life – while a hospital is a dramatic place, full of important conversations and pressing existential concerns, it is equally a “tedious and boring place.” In her research, she observed that there was very little to occupy patients’ time and so they waited for hours “simultaneously bored, anxious, and hungry” (Livingston 2012:22). Importantly, she adds this reminder:

> It is very difficult to appropriately convey this tedium in writing. In the pages that follow, I spend more time describing moments of crisis and action, than those of tedium and loneliness. But as you read I ask you to remember the many hours you yourself have no doubt spent waiting, sometimes for unpleasant or worrisome experiences, in highly bureaucratic and uncomfortable government institutions. Recall your own boredom in repeatedly performing the same monotonous tasks. Or think about the nights you have spent away from home knowing that life there was going on without you. And know that these kinds of experiences, too, are fundamental to cancer everywhere in the world (Livingston 2012:23).

Although waiting is a central occupation of patients, there is very little research that examines the profound experience of waiting. Only recently has it been argued that a body of literature on the experience of waiting is warranted (Sabo 2014). Waiting time in a hospital showcases a “cyclical” or non-durational form of time. Geertz (1973:402) describes how in Balinese culture, social occasions do not often build towards “consummations” but are running continuously and are often directionless. For example, the cycles of days outlined in the permutational calendar do not accumulate or build (Geertz 1973:393). Similarly, waiting time in the hospital is ‘all for naught’ in some respects: it does not add up to anything, but seems to just repeat itself the next time the patient comes to Lady Ann’s.

Time in the hospital ultimately is a question of value. No one likes to feel that his or her time is being wasted. But what makes it seem especially unpalatable for patients with advanced disease is that their time is no longer a limitless horizon – suddenly it has become limited and irretrievable. In a recent documentary of his last months of life, the late palliative care physician, Dr. Larry Librach, described his experience of “time wasted” while sitting in chemo for up to three hours, only to find out he would not get treatment that day (CTV News 2013). He said
there was “no respect for [patients’] time.”\(^{156}\) His interviewer comments, “Given that time is limited, clock is ticking.” To this, Dr. Librach replies, “You need to make people feel they are still valuable” (CTV News 2013). As Isabelle’s and Elizabeth’s stories show, being made to wait long hours makes them start to question if they are still persons of value – whether people care about their time, and by extension, about them.

**Appointment time: Keeping track of hospital life**

My life is pretty much appointments right now.

-Pam

Now that’s my life – it’s booking rides to go to the hospital. I’m telling you, I need a frigging secretary. I’ve got to hire someone to keep track of my hospital life.

-Melody

Pam and I are sitting in the Gyne waiting room. We are discussing the fact that her mother has just arrived for a 6-week visit from England. Rather than bring her to the hospital with her that day, Pam encouraged her to stay home, as she is wary of telling her mom too much about the nature of her illness. When I asked her what plans they had for her mom’s time in Canada, she gave the above response, outlining that life was pretty much taken up with being at the hospital right now, followed up by, “I’m not doing anything fun.” She then conceded that she had done a few fun things recently, but, overall, the routine of coming to Lady Ann’s for regularly scheduled appointments was weighing on her.

What is interesting is that this conversation took place after she had completed standard chemotherapy for metastatic ovarian cancer. She was enrolled in a clinical trial, and the trial drug continued on after standard treatment stopped, so it was no surprise that she would still have some attachment to Lady Ann’s. But the trial drug was in oral form, so she took that everyday at home. When we met up that morning, I asked her “Are you getting a break from here?” assuming the answer would be yes, but she replied, “Not really” and explained she had come in for a mammogram, and had also seen her rheumatologist outside of Lady Ann’s. She had endured a difficult time with this first round of chemo, which had been “held back” at least three times because of low platelets or low Hemoglobin. She had received several blood transfusions to help address this problem. The irony was that now that she had finished up the standard treatment, and was continuing only on the trial drug, she was still enduring the same problems as before: low platelets, low Magnesium, and low Hemoglobin, all of which resulted in delayed treatment.
In fact, this was the exact problem on the day we met in Gyne. In the morning, she described her plans with her mom for the next few days. But by the afternoon, those plans needed to be revised. She was told that she could not leave the hospital that day without a Magnesium infusion. Tomorrow, she would have to return for a platelet infusion, which would take several hours. So even though she had completed the most time-consuming part of her treatment regimen, she was still tethered to the hospital.

At every visit to Lady Ann’s, patients are given up-to-date “itineraries,” which outline all of their upcoming appointments (e.g., follow-up visits, bloodwork, chemos, CT scans, MRIs) within the hospital network. The patient’s itinerary provides a paper representation of just how much of her time is going to be spent at the hospital in the upcoming weeks and months. I have seen itineraries scan several pages. When Pam says, “So much of my life is appointments right now,” she is figuratively referring to this itinerary and how it contains her life plans for the immediate future. Sometimes itineraries can be made to accommodate patients. For example, Elizabeth, who continued to work as an elementary school teacher while she underwent chemotherapy, told me that she had asked to be seen earlier in the mornings because she only took half days off and wanted to be back in school after lunch. The Gyne clinic had accommodated her and she was always seen first thing in the morning, and was able to leave after her appointment since chemotherapy took up the entire next day.

Other times, itineraries map out schedules that cannot, in practice, work. On one of her appointment days, Jennifer’s schedule outlined that she: 1) go to Gyne clinic for a follow-up visit; 2) go to a different hospital in Lady Ann’s network to get an ultrasound; 3) come back to the Gyne clinic to get her ultrasound results. Louise, the Gyne PFC, explained to me that it was very challenging to fit all of this in during the space of a 3-hour clinic. She told me that in fact there was no reason that the patient had to do all three things in the same day; the desire to cram it all into one day was initiated by Dr. Girard, who was thinking of her patients, and figured they would rather have one busy day, than have to come back to Lady Ann’s on a different day for their ultrasound results.

I accompanied Jennifer on this visit and observed just how hard it was to try to stay on time. Her itinerary for the day outlined a 9:00 am visit in Gyne, a 9:45 am ultrasound in another hospital, and an 11:00 am return visit in Gyne. She was seen at 9:30 in Gyne, and Dr. Girard spent extra time with her, discussing her concerns that Jennifer was not getting back to work quickly enough and was struggling to adjust to her life after-treatment. This consultation lasted
between 15 and 20 minutes – much longer than Dr. Girard would be able to give to her other patients that day. Upon leaving that consultation, Jennifer was told in reception to “high-tale” it over to the other hospital for the ultrasound. We ended up being driven by a friend of Jennifer’s, which took 10 minutes; had we taken the free hospital shuttle, we would have been even later, because it only departs from Lady Ann’s every 15 minutes. We arrived at the ultrasound reception at 10 am, and a very unfriendly technologist said, “She missed her appointment.” Jennifer tried to explain that she was at Lady Ann’s, but the technologist only shook her head like she did not believe her, replying, “Doctor’s appointment or something – you are just late so we will have to fit you in.” I pointed out that Jennifer had not scheduled it this way – someone else was responsible for planning her itinerary. But the technologist did not want to listen. She stuck to her story about “missing her appointment time,” and reassured us that Jennifer would be seen, but not in the timeframe expected. “You won’t be back at Lady Ann’s by 11,” she said, explaining that the ultrasound took 45 minutes and it was already 10 am at this point.

Jennifer’s example demonstrates how scheduling in a bureaucracy can sometimes work against patients, even when individuals, in this case Dr. Girard, try to intervene and orient it towards patients’ best interests. That Jennifer was blamed for being late demonstrates the hospital’s governance of time and the primacy of the scheduled itinerary: in this technologist’s mind it did not matter at all why she was late. What mattered was that the time on her itinerary had passed and she had not been present to attend her appointment.

Consult time: Getting time with the doctor

When I spoke to patients about the things they found frustrating about the hospital, one of the most frequent responses was the small amount of time they had with their doctors. Doctors’ time is viewed as a commodity, often in short supply. Patients may wait for several hours for a consultation that can last less than 5 minutes. If a patient is in the middle of treatment, and is present for a follow-up appointment where no test results are being given, the consultation goes especially quickly. The nurse and doctor will check in regarding symptoms experienced in the last chemo and will review the bloodwork they had drawn that day, and if all looks well, patients are often told they are “good to go” and are dismissed. The introduction of Hospital Time produces “a situation of enhanced power for the healers and reduced autonomy for the patients” (Frankenberg 1988:147). This loss of autonomy comes up in patients’ comments about how their time seems less “valuable” than that of doctors.
On several occasions, Dario said he found it frustrating that he could never get any time with the doctors. We were sitting in the radiation waiting area one day, where he was waiting to be called in. He had arrived a bit late for his appointment, and felt that the fact they had not called him in yet was a sign they were “punishing [him] for being late.” Here, he gives agency to Hospital Time, giving it a kind of power to “punish;” in reality, it was likely that radiation was just behind schedule. He felt that the doctors “think they are Gods,” and was frustrated for being made to wait. He told me that he was back again for radiation, because although his lung cancer was doing okay, the cancers in his back, brain and adrenal gland were growing. He did not understand how this could be the case. He said, “It would be nice if someone took 5 minutes with me – doesn't make sense to me – they say it’s the same cancer but I can’t see how.”

Earlier that year, in a formal interview, he said he found it “annoying” that he always saw doctors “running around.” He did not understand why they were not taking “a couple extra minutes and explaining and sitting down with you and asking you exactly, you know what the hell’s wrong.” He thought it must have something to do with “the almighty dollar” – thinking that the more patients they saw, the more money they made. When I expressed doubt about this – mentioning that doctors all had “big lists,” he countered with, “Yeah, you figure if that’s the case, they’d hire another doctor, right? Like if a doctor feels they are overworked.” When I commented that it sounded like he would appreciate a bit more time with the doctor, he replied, “Yeah, I think so. A little bit more where you actually… even if you don’t care – pretend to. Like take that extra minute and say, pretend to care and offer options, offer alternatives…” For Dario, not getting time with doctors, made him feel like they did not care about him. “No one cares,” he said, that day sitting in radiation, “Why are they in this profession? If they don’t care should get out – I presume that’s why they are in this line of work.” He said that watching the doctors run all the time made him feel, as a patient, that he was “just being put through the process,” and not getting any quality time with the people who actually could explain to him what was going on.

Other patients I spoke with saw the “running” in a less personal light, but did adjust their expectations for their consultations if they saw their doctors were especially busy. For example, one day in March 2012 I met up with Elizabeth after she had already seen Dr. Girard. In fact, she had been seen so quickly and on time, that I had missed the consultation entirely. When Elizabeth saw me, she started by saying “You didn’t miss anything. I could hear Shelley [her clinical trials’ nurse] in the hallway trying to get Dr. Girard to come in – saying that she had Elizabeth here and could she just come in. I heard Dr. Girard ask, ‘Is it going to be long?’ and
Shelley said ‘No.’” She said Dr. Girard had done a quick exam and “she was out of there.” I asked Elizabeth, “Did you have anything to ask her?” I knew that there was an ongoing discussion about whether or not she was going to have a colonoscopy. She replied, “I had a few things I wanted to know, but didn’t want to keep her as she was in a rush.” Clearly, she had overhead the conversation outside the room between her nurse and Dr. Girard and she felt badly about keeping the doctor, when it was promised she would be “quick,” and as a result she did not get any of her questions answered. Since she sees the doctor every 3 weeks, this means she had to now “save” her questions for the next meeting. What if her questions had been time-sensitive? Would that delay impact her care?

In Hospital Time, time with the doctor is the most valuable commodity. Patients are sometimes satisfied with the very little time they receive, such as Elizabeth, and sometimes interpret it as a lack of caring, such as Dario. It seems assumed that doctors are in control of their time and are “running” because of poor time management. However, from my observations, doctors and nurses are also subject to Hospital Time and a bureaucracy that is much larger than any individual personality. At Lady Ann’s, there are many patients to be seen, and a morning or afternoon clinic almost always has 20-30 patients, with several patients being booked into the same timeslot. But a doctor or nurse can only be in one place at one time; thus, the schedule as it exists on paper, can never work, even before individual actors are introduced.157

**Clinical record time: Inventing time for trial reporting**

In the world of cancer treatment and follow-up care, patients must keep track of dates and significant events that relate to their illness experience. Patients are regularly asked during consultations to produce a date and a time that a new symptom arose, a medication was started, or a test was taken. These dates are often accounted for in personal calendars, kept by patients. The need to produce specific dates and times is especially apparent when a patient is on a clinical trial. In every consultation, the clinical trials’ nurses will ask specific, standard questions and complete tasks that are outlined by the trial protocol. Often these questions concern dates and times, as in Elizabeth’s following interactions about recent symptoms she had experienced:

Elizabeth is telling Dr. Girard about a recent bladder infection.

**Dr. Girard:** What days? Is it burning?
**Elizabeth:** Let me get my calendar (pulls it out). Days 8, 9, 10.
Later, on when just Shelley, the clinical trials’ nurse, is present:

Shelley: Do you have headache? Dizziness?
Elizabeth: Yes, headache
Shelley: When did that start?
Elizabeth: (checking chart) the 19th and 20th

Both Shelley and Dr. Girard’s questions require Elizabeth to produce an exact date. This interaction took place about 3 months into Elizabeth’s treatment, so she anticipated these questions and was able to produce a desired response (not “Oh, last Tuesday…or maybe a few days ago”) but exact calendar dates because she had started to keep a calendar. The following day, I sat with her in chemo for several hours and brought up the issue of the calendar because I had noted how precise her answers had been. I asked her if Shelley had given her a calendar to keep track of things, and she replied no. I told her that another patient of mine was given calendars by this same nurse, since she takes her clinical trial drugs at home, and must record the dates and times. She returns these completed calendars to Shelley at the end of each chemo cycle. Elizabeth said that she did not remember anyone telling her to keep one. She just started to write it down because she has a “horrible” memory so she would forget the dates if she did not write them down. I remarked that it was surprising that no one told her, saying “Imagine if you had not kept a calendar. Do you think you would be able to remember all those details?” She laughed and said no, she would never remember – especially when they want “specific dates.”

I asked a few people informally about this, after I witnessed what seemed like real inquisitions in the consulting room, especially for patients on clinical trials. I had observed several consultations where it seemed patients were possibly just providing a date because they were asked for one. The general response confirmed my suspicion: patients said that they invented exact dates, when they were prompted and could not remember them. For example, many patients suffered from chronic diarrhea, which was a side effect of their chemo drugs. To them, whether diarrhea started 10 or 12 days ago made no significance – they could hardly remember the date, unless of course they had written it down. But they learned very quickly that what the nurse was looking for was something to enter into the box on her form that goes back to the drug company and that the date provided would not itself be questioned. Thus, it did not need to relate to ‘reality’ in any firm sense.

In a similar vein, Melody told me about completing paperwork for BRCA genetic testing and complained that the forms she was sending in asked “ridiculous” questions. When I said, “Oh really?” She replied, “Like asking 100 years ago when I was on the [birth control] pill? Like
I am supposed to remember that? I wrote in ‘too long ago!’” I laughed when she recounted this to me and told her I thought that was reasonable. Melody was 70 years old when she was completing this paperwork. The birth control pill was something she could hardly remember, and her reaction – refusing to provide a date, and pointing out that for her, the question was ridiculous – pokes fun at the fixation Western society and, by extension, its institutions (e.g., the modern hospital, drug companies), have on the need for specific dates and times.

Here, the clinical record and the drug company record demonstrate another means by which the hospital “marks” time. Time is constructed by clinical trials, as objective dates and times that can be fixed on a clock or calendar, but these representations are no more ‘real’ than other ways of constructing time. Patients’ ingenuity – just going with the flow and providing an acceptable answer – demonstrates that they are very much conscious that this kind of Hospital Time is in some ways not fully accurate.158 Elizabeth and Melody’s stories exemplify time as something that is ‘real’ and accounted for in the dates and calendars that patients provide. But they also exemplify time as a kind of “project” (Munn 1992) – something that can be worked on and ‘made up,’ and much more flexible than it at first seems. The clinical record logs that on this date in September, Elizabeth started experiencing this symptom, but whether it was this or that day does not really matter to Elizabeth. She knows that she is required to produce a day to fill the box and so she does, even if it comes from her imagination rather than from her experience.

**Conclusion**

May 14/2012. Pam called me today around 2:50 pm and left a message saying she was coming to Lady Ann’s because she had strange bruises on her arms and legs, and was going to see Shelley to have them checked out. Her message said, “If I wasn’t doing anything and wanted to come that would be ok.” I went over around 3:10 pm and found her sitting in the Gyne clinic, reading the paper. She seemed happy to see me. I sat down next to her and we waited quite a long time to be seen, chatting about various things. As Shelley came out and called Pam’s name, she apologized for the long wait. Pam replied that she didn’t mind, that she called me to “fill the time.” I laughed as we went into the room and said, “Oh, I see, I’m just a time filler!” Shelley said she was “really grateful” I was there, because if not, Pam would have been “up in arms about trying to get in.”

Thinking back about my fieldwork, I realize that the most valuable thing I had to offer participants was my time – the one currency in the hospital that everyone else was short of. As Pam articulates here, and other patients said to me as well, I helped to “fill” what was often very long and sometimes boring time, by sitting beside them, asking them questions, getting them a
drink or a snack, and sticking around so that their family and friends could take a break. Patients often thanked me when I had come to sit with them over chemotherapy, and I often had to remind them that it was me who was grateful and indebted to them, for sharing their stories and their time with me. Perhaps because I made it clear that understanding their experience was my ultimate goal, and, as a researcher, that was my sole occupation, having me there to witness what they went through made a difference. If long waits in the hospital and short visits with their doctors rushing off to see other patients were de-humanizing and made them feel that their time was disrespected, perhaps my continual presence helped to re-humanize their hospital experience and make them feel that their stories and their time mattered.

In this chapter, I have given primacy to patients’ various experiences with time, and have shown that patients with advanced disease actually move through multiple temporal modalities. I have demonstrated that although time is central to the everyday life of the hospital, the different modalities of time that are in play are often not made explicit. Beginning with how patients feel and experience their own Life Times, I have woven in other time structures that patients experience, such as Prognostic Time and Treatment Time. I have shown the very real limits put on them by Hospital Time, and how it tends to impose various temporal regimes (e.g., appointments, waiting, record keeping) that must be respected, regardless of patients’ aims for their time. Thus, there is not just one kind of present – a day plucked from the calendar – but rather it is possible for patients to experience many kinds of presents: e.g., in any given moment, patients could be simultaneously experiencing one, two, three or four temporal modalities. In this sense, the temporal modalities are similar to the day-name cycles that Geertz (1973:392) describes for the Balinese permutational calendar, where any given day has in theory ten different names associated with it, once from each of the ten cycles. Temporal modalities for advanced disease similarly run concurrently with one another. Although I have discussed the various modalities of time in turn, in order to demonstrate their unique aspects, my intention has been to argue that patients are never ‘in’ or ‘making’ one aspect of time, but rather that these modalities are always overlapping.

I have argued for the importance of recognizing these temporal aspects of patients’ lives, because current literature on temporality and cancer seems to take a very philosophical perspective on time by suggesting that after cancer, people learn to appreciate “the moment” and use time better towards the fulfillment of their purposes. Fundamentally, this seems like a way of telling patients with advanced disease, “You should live your life this way,” while we continue to
live ours a different way. This advice is neither helpful, nor realistic, since patients with
advanced disease for the most part live their lives much as they did before they had cancer. I
have framed this discussion using Fabian’s concept of “chronopolitics” (1983) to draw attention
to these politics of temporality (Adams et al. 2009:247) that are used to separate patients with
advanced disease into a present-oriented time, where the past and the future are denied. What
would be the motivation of such a distancing?

I do not wish to suggest this is an explicit and formulated plan, but rather to demonstrate
that this separation by time is the product of a contemporary culture of cancer that has no
vocabulary to include patients with advanced disease. Patients with advanced disease are offered
‘the present’ – e.g., discussions pertaining to treatment schedules, immediate side effects, the
latest therapy, daily activities (Good et al. 1994:585) – because these are the areas where
something can still be ‘done,’ and oncologists are very good at doing things and at acting. Thus
the politics of distancing have less to do with intentional exclusion than with collateral damage;
focusing on the present as a means of coping is what is offered to patients with advanced disease
because there is little else to offer.

But as I have shown, it is a small offering, and at times it may only serve to increase their
isolation, when their experiences do not match the discourses that surround them (Saillant 1990).
We would better serve patients with advanced disease by understanding that their struggles with
time are not exceptional, but rather indicative of the struggles of being human. If we are to help
patients with advanced disease better cope with the time they have left, then we need to better
understand the temporal modalities that are being elicited and the contexts in which they emerge.
It would be far better to have an open discussion acknowledging these different modalities of
time and how they are put to work, rather than using one catch all term – time – to account for
the complex varieties of experience that I have revealed here.

Notes

136 In general, the scholarship on time and cancer takes the form of interview-based research, and
thus is not very rich. (Although Rasmussen and Elverdam 2007 is an exception.) These studies
are revealing of some aspects of time that patients struggle with, but of course only those that are
at the conscious level. Additionally, data pulled from a one-hour interview at one time point does
not allow the researcher to capture how a participant’s perspective changes over time, and in
doing so, it ignores the very variable it aims to study. The resulting papers, mostly published in
nursing and health services research, highlight these gaps in the data. For a recent example, see
Robertson (2015), where the “thematic” categories do not even seem to result from patient
quotes and have so little data attached to them that they are essentially meaningless.
For example, in order for Elizabeth to attend her 9 am consultation at Lady Ann’s, she must arrive for bloodwork around 7:30 am if she hopes her results will be ready in time for clinic. Certainly, Elizabeth might prefer to have her blood drawn at a later time in the day, but this decision would have a direct consequence: her health care team would not be able to tell her whether or not she was ok to receive chemo that day. In fact, she could choose to come to the hospital on the day before her appointment and have her blood drawn then, as some doctors allow this. But for Elizabeth, who lives over 1 hour drive away and continues to work full-time, this would also be highly inconvenient for her, in addition to being costly (e.g., extra gas, parking and/or meal costs). So she submits herself to the time regime of the hospital, because she has few other options.

I am grateful to Holly Wardlow for drawing my attention to this literature and for suggesting it as a potential framework.

For a detailed review, see Munn (1992).

Here is a second example. Anne Fadiman’s *The Spirit Catches You and You Fall Down* (1998) outlines the challenges the Lees, a Hmong family of immigrants from Laos living in Merced, California encounter when trying to care for their daughter, Lia, who has epilepsy. The medical management of epilepsy requires ensuring that the patient receives adequate anti-seizure medication dosage at correct intervals. The Lee family was frequently seen as “noncompliant” by their Californian doctors because they never gave Lia enough medicine at the right times. Fadiman uncovers that one reason for this is that the time intervals indicated on the medications were meaningless to the Lees, because: 1) they were illiterate; and 2) they did not use the clock to tell time. Lia’s mom described the tasks related to particular activities of the day as their way of ‘telling time’ in Laos and Vietnam, where they had lived before: at one cock’s crow they rose, at two cock’s crow they fed the pigs, and so forth. Time was therefore not something to be decontextualized, symbolized entirely by a clock, but was rather immersed in the activities she had to complete in a regular day.

Fabian argues, “on the one hand we dogmatically insist that anthropology rests on ethnographic research involving personal, prolonged interaction with the Other. But then we pronounce upon the knowledge gained from such research a discourse which construes the Other in terms of distance, spatial and temporal. The Other’s empirical presence turns into his theoretical absence, a conjuring trick which is worked with the help of an array of devices that have the common intent and function to keep the Other outside the Time of anthropology” (1983:xii).

In terms of data on temporality in the clinic, Frankenberg relies almost exclusively on an article by Robert Hahn (1985), which examined in-depth the life of one internal medicine doctor.

It seemed to me a pointless and potentially cruel question, since my research was about the experience of cancer, not its prevention or etiology. People with lung cancer already suffer incredible stigma because their behaviours are seen to be the cause of their own disease. Being a smoker has no bearing on the suffering that he will endure; it only potentially adds to it, by further stigmatizing him.

Rasmussen and Elverdam (2007:619) take pains to point out that it is the time that has passed since finishing up treatment, not other factors, such as age or gender, that has allowed the future to come forward once more in people’s narratives.

There are of course, many exceptions to this point, since whether or not you have a future is highly dependent on your socioeconomic status. For example, Aboriginal Canadians in general have a much lower life expectancy than non-Aboriginal Canadians (Statistics Canada 2015).
Hagestad quotes Blythe as saying “we place dying in what we take to be its logical position, which is at the close of a long life, whereas our ancestors accepted the futility of placing it in any position at all” (1996:208). This quote requires contextualization, as they are many places around the world where preventable and treatable childhood diseases like diarrhea and wasting are responsible for high infant mortality rates, so that living into old age is certainly no guarantee. Because ovarian cancer attacks a woman’s reproductive organs, observing in the gynecology clinic I overhead many discussions about freezing eggs or embryos prior to treatment or ovary removal. Eggs or embryos represent the future for women and couples, and freezing them allows them to hold onto their future dreams. I attended an educational talk at Lady Ann’s on cancer’s impact on fertility, where this invocation of future potential was made clear, and contrasted with the majority of cancer care, where the focus on treatment attaches the patient to the present. A clinician audience member perceptively remarked that the role of health professionals in this case is to acknowledge that there is a loss of a dream, and to help patients cultivate new dreams.

Christakis and Lamont (2000) asked doctors of 500 terminally ill patients about prognosis, and found that 63% overestimated survival time, 17% underestimated it, and 20% were accurate. Doctors overestimated survival by a factor of 5.3. The better they knew the patient, the higher the likelihood of error in survival prediction.

Mary-Jo Good and her colleagues at Harvard point out that since the 1960s, oncologists practice full disclosure regarding prognosis and treatment options in the U.S. (1990).

For example, the whole premise of the film One Week (McGowan 2008) is that a young man is given only one week left to live.

Chemo is busiest from about 8:30 when it opens until mid afternoon, when most of the treatments are underway or finished. Accordingly, after 4 pm they have reduced staffing, with only a small number of nurses staying on for the ‘late shift’ that ends at 7:30 pm.

Murphy similarly notes that during his time in hospital his bodily functions, such as eating and bowel movements, were conformed to the “routine imposed by the establishment” (1990:20).

This point was made evident to me when I was still a volunteer. In that role, I would often approach patients in the waiting room who had been there for some time and were starting to look restless. I would ask if they would like me to check where they were in the queue. I found that relaying this information, “You are 2 people back – they are still working on people in the timeslot before you,” provided comfort, even when it did nothing to change their position in the queue or to decrease their actual waiting time. What it did seem to communicate was, “You are not forgotten” and “There will be an end to this waiting.”

As anyone who has waited for a doctor to round in the hospital knows, this indeterminate time would mean that Derek likely would never want to leave the room – to do practical things like get a snack, or feed the parking meter – lest the 5 minutes he stepped out of the room be the ones during which the doctor would appear.

When she was on standard chemo, her treatment days were actually much longer – closer to 8 hours of time spent in chemo, which took about 6.5 hours of IV infusion.

In a TV interview shortly before his death, renowned Canadian palliative care physician Dr. Larry Librach, revealed that experiencing things in the first person as a patient was very different from how he had perceived them as a professional. Dr. Librach had dedicated his whole career to palliative care, and had trained the next generation of doctors on how to care for dying patients. As a physician, he had helped many patients through their difficult times, and suddenly found himself in an uncomfortable position when he himself was diagnosed with pancreatic cancer. Even though he had had numerous end of life conversations, he reported that it was an entirely
different experience when he was on the other end of it, as a patient. If anyone in Canada should have known how challenging it is to move towards dying, it should have been Dr. Librach. But even he was grossly underprepared for it when it happened to him (CTV News 2013).

Doctors do not book patients into their clinics; this work is removed from them, and done at the level of the PFCs. I never asked PFCs who decided how many patients was an acceptable number for each clinic, but assume that there is some pressure at the level of administration put on doctors to see as many patients as possible, in order to keep wait times down, and to uphold Lady Ann’s status as a “premier” cancer center. It seems possible that people who do not perform the clinical work might determine appropriate numbers, since any witness to these clinics would note that both doctors and nurses are almost always running, and often skip meals in order to see the scheduled patients. If doctors were solely in charge of their numbers, I would question why they would submit themselves to such stressful working conditions, day after day.

Here is a different example of where “clinical record” time was inaccurate. One day I observed an interesting conversation between Dr. Girard and one of the associate doctors who helped in her clinic. This doctor was telling Dr. Girard about a patient she had seen, and recounting that she was ‘this much time since surgery,’ and ‘this much time since treatment.’ Dr. Girard said it did not matter about treatment – that you always count the time since surgery (the day you take the specimen to send to pathology) as Day 1. The other doctor replied, “Why didn’t I know that?” and said she had always been counting “time out” since the first day of treatment. Dr. Girard reiterated that the patient was now 2 years since her Day 1 (surgery) and so she would see her again in 4 months. She seemed to want to make sure this patient’s timeline for care was clear going forward.
Conclusion

My heart tells me to stop right here, to offer some quiet benediction and call it the end. But truth won’t allow it. Because there is no end, happy or otherwise. Nothing is fixed, nothing is solved. The facts, such as they are, finally spin off into the void of things missing, the inconclusiveness of conclusion (O’Brien 1995:301).

American writer Timothy O’Brien, trying to find an end to his superb fictionalized account of the 1968 massacre of My Lai during the Vietnam War, captures well the trouble in trying to adequately end a story. His thoughts on the futility of offering closure to experiences that have no end, but continue to live on in memory, provide fitting counsel here. For although the dissertation must have a conclusion, there can be no “quiet benediction” for patients with advanced cancer: they either continue to live with disease or they are no longer alive because of it. In this final chapter, I provide an update on some people whose voices have filled these pages, and I draw on questions raised by this research to point towards three areas of future scholarship.

I. Epilogue

In the time of my fieldwork, Laura, Mary, Paul, and Isabelle died. In the six months after I left the field, Dario and Deo died. I have since learned that Olivia passed away almost two years ago. For these patients, endings are no longer “in suspense” (Mattingly 2009:266). In 2014, Norma, Julia and Jennifer were still alive; I am unsure if today that remains the case. I did not follow patients right up until death. As a researcher, there was never a time I felt more superfluous as when I called a patient at home and found out she was in general decline. I found about their deaths in various ways – by reading obituaries, by being informed by their families, doctors or nurses, or other patients, or in one memorable incident, by looking up a patient in the scheduling system and seeing that I could no longer access his file due to his being “expired.”

I was able to speak to Paul’s wife, Sue, and Deo’s wife, Prisha, after both of their deaths. Although both men had been diagnosed with stage IV lung cancer – a disease with a life expectancy of two years or less – they both had what would generally be recognized as “bad” deaths. Paul spent his final days at home, with Sue struggling to support him and to manage the myriad problems that resulted from his late-stage cancer. One haunting memory she shared with me was that in his last weeks of life, his legs were so swollen with fluid and oedema that he kept
wondering aloud what would happen if they burst. And then they did – his skin split open and fluid leaked all over the bed, as Paul lay somewhat helpless and Sue worked at mopping it up and trying to stop the flood. The last time I saw him was about six weeks before he died. I met him in the waiting room of the palliative care outpatient clinic, where he was waiting to go in for his first consult with the palliative care team. He confided in me then that he was “a little scared” of what they were going to tell him. The previous month he had had a terrible time because his second primary cancer (colorectal) began to outpace his lung cancer, but the doctors had recently managed to get his symptoms under control. Sitting outside palliative care that day, he expressed hope, and told me that he felt that things were “looking up” for him.

Deo died in the ICU of a general hospital, where a confused physician insisted on treating him for pneumonia, rather than lung cancer. The doctor in the general hospital was, in a way, working blind – she was unable able to access any of his records from Lady Ann’s that detailed his cancer and various treatments. Prisha and her daughter fought desperately to get Deo moved to Lady Ann’s, where they thought he would be in better hands since they had all his records. Prisha had a family member who was a physician advocate on Deo’s behalf, and only then was a CT scan ordered and the doctor came to tell Prisha what she already knew: that the cancer was really bad. Deo was admitted to hospital in the week between Christmas and New Years, which is a quiet time in all hospitals, and there is often reduced staffing. Dr. Lawson was away from Lady Ann’s. When she returned, she asked to see a copy of Deo’s recent CT, which required that Prisha leave Deo’s side and drive across the city to Lady Ann’s, bearing in hand the CD holding what she knew was her husband’s final verdict. Dr. Lawson then took charge of his care from a distance (e.g., directing the ICU doctor in the general hospital what drugs to prescribe), but because Deo was already so sick, he was not moved. Prisha described how the physician treating Deo “gave [them] a lot of pain [they] didn’t need” because once the lung cancer had been confirmed, she kept insisted on pronouncing that he was dying almost every time she came in the room. Deo remained fully aware of all of this, and Prisha kept telling his doctor that they knew, and to leave it alone, but she would not. When I spoke with Prisha on the phone, several weeks after Deo’s death, she said that she found the whole experience “very disheartening all around,” and she continued to be “tormented” with how he had died. He was scheduled for his first meeting with the palliative care team early in the New Year. He died before his appointment.

Since the end of fieldwork, I have kept in touch with three patients – Pam, Elizabeth and Melody – and as of December 2015, they all continue to live with incurable cancer. They all
remain on various forms of cancer treatment. Melody and Pam are taking drugs that are part of clinical trials for ovarian cancer. Elizabeth continues on the same medication she has been taking since Day 1 of chemo. In July, she will mark 5 years on this same drug – 5 years of coming to Lady Ann’s every 3 weeks to be injected with this (possibly) life-saving drug. Elizabeth’s cancer has not recurred, but it is impossible to know whether it is the drug that is keeping it at bay, or if it has not come back on its own. She continues to work as a teacher, but has had to abandon her dream of becoming a mother. After 5 years without recurrence, other patients in her situation might consider themselves “survivors,” but Elizabeth generally frowns on labels. She just wants her life back.

Both Pam and Melody have experienced several kinds of ‘progression’ – indicating the disease is actively growing. If progression occurred while they were on treatment, they were taken off the medication and put on another one. If progression occurred while they were off-treatment, they were started on medication again. So the life of treatment continues, unabated, for all three women. It is difficult to convey in writing the alarming sensation I recently experienced in coming to the realization that so much time has passed, and so little has changed for them – that their lives mostly resemble what they did in 2011 and 2012. They are, of course, older. Many things in their personal lives could have changed as well (although, my understanding is, they have not). But their hospital lives have remained somewhat consistent.

On a recent visit with Pam, I met up with her at Lady Ann’s, and we sat in the empty chemo waiting room, wasting away a late afternoon in December. Pam was the only patient still waiting. The receptionist checked in with us every so often and reassured Pam that she “had not been forgotten,” which was comforting, and the cleaning crew began their afternoon shift, suggesting, “we might be more comfortable waiting somewhere else,” which was not. Pam was waiting to be infused with a drug she had only found out the day prior that she needed. As the clinical team had requested, she had arrived at Lady Ann’s around noon, and had a consult with a nurse. She had then been directed up to chemotherapy around 2:30 pm, to wait for the drug. I found her there around 4 pm. As the wait wore on and on, I was brought back to all ‘waiting time’ of fieldwork. Pam required no such reminder, because she has never really left Lady Ann’s. Since she was diagnosed in early 2011, dealing with cancer has been her main focus. She has been unable to return to the work with children that she loved, where she provided support to sick children in hospitals, classrooms, and at home. While she used to be the kind of patient who listened and did not ask too many questions of her health care providers, she has transformed
herself into a patient advocate, participating in several kinds of support groups (even coordinating one of them), and has become a wonderful resource for any woman newly diagnosed with ovarian cancer. But like Elizabeth, she too, would like nothing more than to leave behind her patient life, and go back to caring for sick children, rather than having to put so much focus on herself.

Melody is currently taking a clinical trial drug that takes her to Lady Ann’s more often than she would like. The drug is quite novel and is in its early stages of testing, which means she is monitored very closely by the clinical trials’ team. She takes the pills at home, but still must go to Lady Ann’s twice a week for bloodwork, various IV transfusions, and tests. She found this somewhat nonsensical, saying that they are giving her pills to take at home in order to be “freer from the hospital and I’m coming here all the time.” Provocatively, asked, “Should I pitch a tent at [Lady Ann’s]? Rent a broom closet? What are they thinking?” In a recent phone conversation, she seemed to increasingly resent the time that the trial takes away from her, saying that having to be “so dedicated” to the trial felt like she was “married to the hospital.” She continued, “This is not my life. This is not the way I want to go out.”

Elizabeth, Pam, and Melody’s experiences demonstrate the permanence of the liminal space of advanced cancer. Despite what they desire, patients’ general orientation towards life or way of living never goes back to a ‘pre-cancer’ time. Being unable to leave the liminal state has consequences on all their lives, both concrete and existential. For example, for Pam, being unable to work means that unlike fictional portrayals on TV and in film (e.g., The Big C, The Bucket List), she cannot spend lavishly and travel anywhere she desires to go; her treatment schedule does not allow it, nor do her finances. At work, Elizabeth finds it difficult to communicate that her treatments are not over, so simply agrees with people who expect her to feel relief at being done treatment. She manages her private reality – that for her, no conception of the future comes without a concern that there will be more cancer – with the support of a few close family members and friends. Melody is intimately aware of any treatment’s limitations. She could go off the trial and refuse further treatments at any time. But how is she to know when the time is right?

The alternative – no treatment – is also not ideal. Every patient I met was grateful to be offered treatment. Perhaps they did not understand how intricately it would become woven in with their futures, but they were glad to be offered something. Although it is patients’ choice to continue to take treatment, it must be remembered that taking treatment is the only choice that is
culturally sanctioned, unless a patient is very close to the end-of-life (Gawande 2010). Patients’ individual exercise of autonomy should not be the focus here, but rather how an exceedingly difficult task has become framed as individual choice, placed squarely on the patient’s shoulders (Mol 2008). We ask patients and oncologists to continue to push the limits of life so we can be satisfied that every option was considered, and everything that could be done, was done, so there will be no regrets. But in the process, all this eagerness for treatment, for cure, for life, further isolates the patient, and forces them to be the person responsible for saying when the time has come to move towards dying.

II. Future Research
Cancer’s Politics of Visibility

In the fall of 2015, the Canadian Broadcasting Corporation (CBC) began advertising for one of its new programs, a drama focusing on a woman who has terminal cancer. The promo material for the show included these lines: *This life. On CBC. A single mom. Diagnosed with terminal cancer. Life changes – for her, her kids and everyone she loves. Funny. Heartfelt. Deeply human.* I did not have the heart to watch it. Perhaps this time the true reality of living with terminal illness might be portrayed, but it seemed unlikely. Advanced cancer becomes entertainment only for those few who have been fortunate enough to have not come face-to-face with its heartbreaking disappointments.

I have argued that patients with advanced disease are invisible in contemporary culture in more ways than one. When Elizabeth tells me that not having her hair makes her never want to look in the mirror because it “erases the idea of me,” she expresses the loss of her former self. When Jennifer goes to a Canadian Drug Store chain that regularly runs a fundraiser for women’s cancers, and is asked at the till if she would like to “Donate $1 to women’s cancers?” her invisibility is explicit. When she told me this story, she said that her first response was, “Fuck, I have women’s cancer.” But she did not say that out loud. Rather, she said “Yes,” because saying yes was “easier.” At Paul’s funeral, I took a picture of him home that was placed on the side tables of the funeral parlour. I took it because I wanted to preserve a memory of him in a healthier time. In the photograph, Paul wears a white t-shirt, and smiles broadly for the camera. Sue later told me that the picture was taken just shy of two months before he died. What I had interpreted as signs of robust health – his round face and supple neck – were actually signs of the
tumours growing in his neck. As Elizabeth’s, Jennifer’s, and Paul’s stories show, incurable illness makes it sometimes difficult to recognize the self, and also to be recognized by others. The contradictions of having one of the most visible diseases today, and yet having at times, such an invisible illness presentation, warrants further research. This research would explore more fully not only its consequences on the self, but the forms of contemporary culture that directly contribute to visible and invisible illness experiences.

The politics of visibility also extends into the ways that patients with incurable illness are categorized, because not one discourse – survivorship, chronic illness, or palliative care – adequately accounts for what they experience. Although every patient I met wants to survive, the only option that is presented with any surety after diagnosis is that the cancer will likely cause her death, although not in the immediate future. Thus, trying to fit these patients into the survivorship model seems fundamentally disingenuous. Olivia confirms this in remarking, “I think this whole idea of survivorship just tries to homogenize the whole cancer experience and it’s not doing anybody any favours…Either people who have an easy time of it or those of us who have a worse time of it.”

In research and in clinical talk, cancer is increasingly framed as a disease that is becoming a chronic illness due to increasing numbers of survivors, but this assumption disregards the history of the appropriation of this label in the past (Weisz 2015). The following fieldnote suggests that some physicians may have difficulty rationalizing the ‘chronic’ label for patients with more advanced cancers.

I am sitting over lunch with two fellows who are sharing some of their experiences of working at Lady Ann’s compared to the hospitals in their home countries. They are talking about how cancer research has made much progress. He is giving me specific examples and seems very positive, but she is playing devil’s advocate. She says, “But look at what we are doing. I know I do this all the time. I say, “Your disease is like diabetes, cancer research has come a long way – now it is like another chronic disease.” But actually the prognosis isn’t that similar. A few months for some cancers.”

He seems to disagree, at least initially. But then he says he agrees that maybe it is not helpful to tell patients that their disease is like diabetes because if someone told him this he would think he was going to live 20-30 years. But this is not the reality. He says, “People are sometimes so blind to reality. You can ask a patient who is confined to a bed, and not ambulatory and they will say they think they will live another 20-30 years. But it is just not true.”

As this interchange demonstrates, the chronic illness label, when applied to advanced cancers, may inadvertently mislead patients into thinking that they will be able to live with cancer longer than is possible.
Lastly, the palliative care model seems like the most obvious and fitting choice for embracing the experiences and challenges of patients with advanced disease. The Canadian Cancer Society recently released a report arguing that palliative care is a right for all Canadians (2016). However, as the reader has likely noticed, palliative care was somewhat absent from the data I collected. Its relative absence from my research is perhaps due to the fact that I did not raise the issue of palliative care with participants in my study, unless they raised it first with me. For example, if a palliative care referral had been made, and I knew an appointment was forthcoming, I might ask to accompany them or ask them afterwards how the appointment went. Most patients that were referred benefitted greatly from the expert pain management and the emotional support that both the palliative care doctor and nurse provided. Some patients said they enjoyed the time they spent with the palliative care team (where appointments are much longer than oncology – 30 minutes for follow-up, and 60 minutes for a first consultation). For example, a few weeks before I left the field, I was able to attend Melody’s first palliative care consultation with Dr. Kelly, and afterwards I wrote in my notes:

*This is the first time in 17 months of fieldwork that I have heard death talked about so openly and candidly, and yet still with so much respect and care and tenderness for where the person is. When I spoke to [two colleagues who are well versed in palliative care issues], I said that it was ‘refreshing’ after so long to see it addressed so openly and rather than ‘skirt’ the issue.*

Melody has continued to see Dr. Kelly and she always reports that she enjoys his consultations, and benefits from their discussions where she is able to talk freely about things that never come up in her oncology sessions, such as preparing for the end of life. But she, like others who spoke about palliative care, seems to see what Dr. Kelly does as ‘secondary’. The Gyne oncology staff remain her primary caregivers, even as she approaches the end of life. It is the ‘secondary’ association that causes problems down the line. Rather than see palliative care come to gradually replace oncology as death approaches, as a dominant current model suggests (Hawley 2014), oncology continues to be very much involved in patients’ care. There is no magical time for weaning patients away from the ‘active treatment’ of oncology, and towards the ‘active treatment’ of palliative care. Furthermore, some patients and doctors are highly resistant to this transfer of care. But if it does not happen, and patients remain in oncology until they die, it leaves very little room to prepare for death (Anderson 2007). Neither Paul nor Deo, or their wives and families, truly benefitted from the expert palliative care that Lady Ann’s has to offer. Thus, valuable future research could focus explicitly on examining how advanced cancer fits into
current models of care, and how those models, in accommodating or not accommodating this patient population, contribute to a politics of visibility for advanced disease.

**Oncological Uncertainties**

This research has examined the narratives that patients and oncologists build inside and outside the consultation room that help them to move forward in their lives. One of my aims has been to show these narratives as “little plots” – what Mattingly describes as plots where there is “a) depiction of time as something still open to future revision, including moral revision; and b) the presence of multiple voices which offer different moral perspectives” (1998:116). Moral uncertainty is a key feature of any therapeutic plot (Mattingly 1998:116). I have shown that it is sometimes hard for clinicians to support or to forward the ‘hopeful plot’ of patients. This challenge could perhaps be attributed to the practice of oncology, where so much work and time are taken up with technical efficacies (Good 1994). For example, many treatment-related questions are necessary in each consultation in order to find out if the patient is ready and prepared for a next chemo cycle. These are often instrumental questions that have terminal answers – e.g., did you have this symptom or not? (Mattingly 1998:145) – making it difficult to get back to the larger issues of life and death, the meaning of illness, and how patients are coping with a difficult diagnosis. It is also perhaps related to the profession of oncology, where, similar to occupational therapy (Mattingly 1998:145), oncologists may downplay the importance of the “talking” aspects of their work, especially once the diagnosis of incurable cancer has been conveyed. But it is actually the little conversations that take place after that one monumental conversation that help patients to build narratives, and to feel that their providers see them as actors and agents, with lives and desires that matter (e.g., to go back to work, to have a baby, to plan a trip).

Research that takes seriously the work of oncology physicians and nurses, with the same depth and attention that I have given to patients’ lives here, could help to highlight these tensions of their profession. While certain “moral uncertainties” are found to be intolerable within oncology, such as the maintenance of the ‘hopeful plot’ without significant attention also given to the ‘realist plot,’ I observed that other uncertainties were tolerable. For example, I observed one consultation with Paul, where he kept worrying that the pain in his neck and his arm were new cancers spreading around his body. The doctor told him that she thought he was “worrying
too much about it,” and that if he continued to think this way, he would never allow himself to be okay. But later, during a debriefing of the consultation with her, she admitted to me that she could tell him that everything he was worrying about – his arm, his chest, his neck – “that’s cancer, and that may be cancer too.” “But,” she continued, “the truth is I don’t know so I don’t want to say that, and put the anxiety in his mind.” Here was an admission of uncertainty that could be tolerated. But she did not convey this news to Paul, because being told that your doctor “doesn’t know” is not reassuring.

Patients believe that medicine is a science that is always accumulating new knowledge, and growing exponentially in its powers and abilities to stave off death. As members of the public, they do not see or hear about the work of getting to research milestones – the slow, plodding steps towards progress, and the many miss-steps along the way. Although there are some important caveats (Aronowitz 2007, 2009), the science of cancer medicine is advancing, but it is a slow, gruelling and piecemeal process. In no way do I wish to deny the important progress that has been made in cancer research – made by scientists I saw everyday at Lady Ann’s, working tirelessly on a small piece of a very complicated problem. At a press conference announcing an important research development, one of the leading bench scientists at Lady Ann’s broke down at the end of a talk where he had painstakingly tried to explain his complex research program in words that would be understood by a layperson audience. His personal dedication and commitment to solving the problem of cancer was evident to anyone in attendance. The scientists know that the cure is indeed elusive, because it is multi-faceted – not one cure for cancer but many cures for many cancers – and yet they continue to prod away at the small piece of the puzzle they have carved out as their own.

Thus, further research examining how moral uncertainties arise in oncology and the means by which they are determined to be tolerable or intolerable would help to showcase that oncology does not have all the answers, and perhaps lead to a greater social acceptance of its limitations. This research would continue in the excellent tradition of social science studies of doctors begun by Renee Fox (1959) with her seminal work on how doctors learn to train for uncertainty, and more recent work on medical errors in surgery (Bosk 2003). In casual conversations about my research with other doctors (e.g., general practitioners, and other specialists), they almost unequivocally report that oncologists are “bad” at talking about death and dying. But criticism without comprehension is not helpful. An in-depth ethnography of the work of oncology would examine how difficult it is to be in the position of Dr. Lawson and Dr. Girard, who must raise the
subject of death and dying when a patient is busy emplotting for a different future. As Livingston notes, “it is a burden to be able to see someone’s future when they refuse it, even if they refuse it because this future is full of impossibilities” (2012:91). Everyone working in oncology deserves a little more compassion – not least of all the doctors and nurses who come face to face with cancer’s intractability day in and day out.

**Cancer Culture’s Affective Economy**

I recently saw an ad of women’s exercise clothing, entitled *Power in Pink*, by the athletics brand Under Armor. The clothing line seemed to be promoting breast cancer awareness, although as is common, there was no statement about where funds from the purchase of these ‘pink’ clothes went (Pool 2012). One particular tank top stood out, with its slogan, “Go! Fight! Cure!” As verbs that lack subjects, they leave the reader with a sense of confusion. It is unclear who exactly is being commanded to do these things. And, even if one might ‘go’ and ‘fight’ back against the disease, the juxtaposition of these achievable goals with the very unachievable imperative of ‘cure’ is profoundly misleading. These are exactly the kinds of slogans that do damage, because they falsely trivialize the complexity of the problem of cancer.

These are examples of what Sarah Ahmed (2004) calls “sticky words” that become attached to particular figures or objects. For example, she writes that fears of terrorism in Australia become “stuck” onto asylum seekers, when the asylum seeker or migrant is spoken about in the same news piece that mentioned terrorist threats to the Australian nation-state; “indeed, the slide of metonymy can function as an implicit argument about the causal relations between terms (such as *Islam* and *terrorism*) within the making of truths and worlds, but in such a way that it does not require an explicit statement” (Ahmed 2004:131). Similarly, in cancer discourses, ideas of cancer “hope”, “strength,” “optimism,” and “cure” get stuck onto cancer and because they have such salience and are invested with so much emotion, they are difficult to escape.

Rather than see emotions as contained within individual subjects or bodies, Ahmed posits that they actually gain their power from circulation, like an economy (2004:124). Within an affective economy, certain emotions “do things, and they align individuals with communities – or bodily space with social space – through the very intensity of their attachments;” thus, “they work, in concrete and particular ways, to mediate the relationship between the psychic and the
social, and between the individual and the collective” (Ahmed 2004:119). These “affective economies” are obvious in several forms of contemporary cancer culture, and help to showcase how the emotions associated with cancer actually accomplish things: they promote and circulate hope, they foster belief in the power of treatments, they suggest that there is one way to respond to cancer and it is to “fight, fight, fight” (Garmon 2008). The problem with this affective economy is that it leaves little room for other emotions or words to get stuck onto cancer. Patients who feel “angry” or “pissed off” or “scared” express emotions that have less traction. Because they circulate less freely and frequently, they are therefore of less value in cancer’s affective economy, for these are the very emotions that no one wants to acknowledge.

As I began in the Introduction, it is cancer’s culture, or what I have called its exoskeleton (Kleinman 1988), that has gotten out of control. While the disease itself may be difficult for scientists and clinicians to control and tame, its culture and representations is all of our responsibility. We unknowingly contribute to growing cancer’s exoskeleton, and thus the burdens placed on patients with advanced disease, every time we sign up for a race or an event, and do not question the cheerful atmosphere and feather boas, or the extensive presence of corporate logos advertising businesses that are gaining corporate social responsibility points indirectly off the backs of cancer patients. Each time we buy a Pink Ribbon product and do not examine how much money or profit is actually directed into cancer research, we risk reinforcing the corporate cause of cancer at a loss to the people who actually experience the disease (Pool 2012). Next time you attend a cancer fundraising event, try to ask yourself – where is the subject (not the object) of these interventions – the cancer patient herself? How is she being represented? What kinds of cancer personas are acceptable at this event? My experience from attending these events is that some patients who attend feel pressured to bury any uncertainties about their future, and to put on a ‘brave’ and smiling face. Olivia pointed out, “If we’re raising awareness, we’re raising it because this is a disease that kills people. And somehow that is being swept under the rug, in all of this happy cheery ‘Yeah survivors! Let’s raise money for this thing, let’s beat it!’”

A culture of cancer that makes a good name for business by attaching itself to cancer (King 2006), that promotes the idea of the individual, ‘responsible’ patient, that celebrates survivors and mourns the dead, but does not account for all the people who live with cancer and who get better at the same time as they get worse, is not a culture that is welcoming to all. Jennifer once remarked to me that having cancer closes down any “illusion you have of normalcy,” and that at
times you feel like “you don’t belong with the rest of the people.” Jennifer seemed to see her liminal status as a problem that was primarily individual, taking responsibility for her position as a good neoliberal citizen does (Rose 2001:6; Mol 2008). She imagined that if she were a stronger person, and had better coping skills and more supports, she might be doing better than she was. But this is patently not true. Her culture had failed her in not making room for her experiences.

Cancer’s most recent “frame” (Rosenberg 1989) or “sticky word” (Ahmed 2004) is genetics. The last ten years has seen a dramatic shift in the biomedical discourse of cancer, with new developments in genetics leading more towards cancer prevention and the hope for targeted, individualized therapy based not on cancer type, but rather on a person’s own genetic makeup. Personal genomics, we are increasingly told, will solve the problem of cancer. This frame penetrates further and further into the body, extending the “medical gaze” (Foucault 1973) to the level of the genes as both problem and solution to cancer, illustrating the phenomenon that Nikolas Rose (2001) has called the “molecularization of biopolitics.” But rather than provide a solution to the cancer problem, personalized genomics are likely to introduce even more uncertainties for patients and their doctors. As Rose argues, “while the calculation of risk seems to promise a technical way of resolving ethical questions, these new kinds of susceptibility offer no clear-cut algorithm for the decisions of doctors or their actual or potential patients” (2001:12). Once people have been placed in a cancer risk category, they will feel compelled to act on that information and to seek treatment (Aronowitz 2007; Timmermans and Buchbinder 2010), even if they have never been diagnosed with the condition. We are placing all our cards in the genetics box, in hopes that the clues to understanding our biomedical problems will be found within the body itself, but this perspective negates recognition of cancer’s cultural, societal and systematic factors that are this dissertation’s focus.

For while genetics may lead to a greater understanding of the cause, and more tailored solutions in treating cancer – much more discriminating than firing all weapons at the disease – it will not help people to live with the disease. As the science of cancer advances it is increasingly important that cancer’s subjects – the patients and the professionals dedicated to caring for them – are kept in focus. When we allow discourses to focus exclusively on the research successes, corporate philanthropy, and the search for the cure, any other message related to cancer is drowned out. This occlusion has an exclusionary effect. For it excludes the many, many people who die from cancer every day and every year in this country, and the many people, like the patients you have met here, who will live with a life-threatening cancer they will never survive.
Cancer tends to take over a person’s identity due to its extensive exoskeleton. Cancer, the disease, may be difficult to control, but cancer, the culture, can be contained with vigilance and hard work. We can and should commit to revising cancer’s exoskeleton, so that it better accommodates for the experiences of people with advanced disease.
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