

**IT STILL ISN'T OVER:
A MOTHER'S EXPERIENCES OF HEALING AFTER CHILDHOOD CANCER**

Natalie Carrière

THESIS SUBMITTED TO THE FACULTY OF GRADUATE
AND POSTDOCTORAL STUDIES

In Conformity with the Requirements for the Degree of Master of Arts Anthropology

Committee
Julie Laplante (Supervisor)
Karine Vanthuyne
Ari Gandsman

University of Ottawa
Faculty of Social Sciences
School of Sociological and Anthropological Studies

For Charlotte, Samuel and John. Every day you inspire me and make me proud.

And for Jeff. We share a story within the story.

ABSTRACT

This autoethnographic account explores my experiences of healing with my daughter and two sons after childhood cancer. My goal was to understand the disconnect between my experiences of persisting fear, grief and trauma and the contradictory messages we encountered during treatment that urged us to resume our ‘normal lives’ at the end of treatment. In analyzing my story, juxtaposed with other anthropologists’ narratives of their journey through cancer and beyond, I realized that my experiences were mediated by prevalent war metaphors in illness; the pervasive social and medical messages and expectations of restitution; as well as narrow biomedical understandings of illness and healing. I offer up my story with the intention of bridging the divide between patients, their family, and medical professionals.

Acknowledgements

I painstakingly wrote this thesis at my favourite coffee shop; with my feet propped up on the family room table in my parents' house with my parents, listening to them entertain the children with a game of Monopoly in the background; late at night huddled up in bed with the family dog on the floor next to me; and early in the morning hours in the dead of winter, at the dining room table, freezing despite my wool socks and heavy layers. The support, encouragement and love of the following people made this endeavour possible:

My supervisor Julie. You have long been a great source of encouragement and inspiration. During this project, your quiet but constant presence was what I needed, when I needed it. Merci.

My thesis committee. Your feedback, support and encouragement has been invaluable. Thank you.

Other professors in the department who have provided time, encouragement, feedback and much support, in particular Ari Gandsman and Victor Da Rosa, thank you.

My three children. Thank you for inspiring me every day. John, my jokester and affectionate boy, you make me laugh and your hugs warm my heart. Samuel, my sensitive kind boy, your strength of character impresses me every day. Charlotte, my resilient, bright girl, my old soul whose twinkle in her eye brightens my every day. Thank you, all of you, for being patient with me as I grow up with you. And, Charlotte, thank you for letting me share part of our story.

My parents. For looking after the children and giving me the gift of time. For providing love, encouragement and support, and for having faith in me. Thank you.

Jeff. At times sounding board, editor, best friend, partner. Thank you. Always.

Abstract	iii
Acknowledgements	iv
Prologue	vii
INTRODUCTION	1
The chapters	4
CHAPTER 1 - THEORETICAL CONSIDERATIONS	7
Medical anthropology	8
Illness, sickness and disease	9
Anthropologists, cancer and the military metaphor	10
Parents' experiences post treatment	19
Narrative, illness and medicine	26
Illness as a call for stories	26
Types of illness narratives	27
Types of narratives	28
The restitution narrative	28
The chaos narrative	29
The quest narrative	30
CHAPTER 2 - METHODOLOGY	33
Autoethnography	34
Data collected	37
Storytelling	39
Methodological reflections	40
Reflexivity	40
Vulnerability	41
Relational ethics	51
Participant Observation	43
CHAPTER 3 - LIFE DURING TREATMENT	44
Early attempts to bridge the divide	46
The first chemotherapy	47
13 days of morphine in a 22 day admission	48
Learning to live in a hospital	52

Adding a few doses of amphotericin B for good measure	55
Hematemesis, or Throwing Up Blood	57
Sleepless Nights	59
The End of Treatment	62
CHAPTER 4 - LIFE AFTER TREATMENT	64
So treatment is over, now what?	65
Camp Trillium	66
The First 3 month check-up	68
The second 3-month check-up	70
Dreaming while asleep	71
Dreaming while awake	73
Anniversaries	74
The rubble cancer leaves behind	75
Seeking meaning	76
Beyond PTS	77
CONCLUSION	81
Concluding thoughts	82
Limitations	84
Final thoughts — What medicine can learn	84
Looking to the Future	88
Epilogue	90
REFERENCES	93

Prologue

November 1, 2012

It is a Thursday morning, the day after Hallowe'en and I've entered my second week as a single mother to my six-year old triplets. Still reeling from my husband announcing his wish to separate after ten years together, and moving out of our home nine days before; and tired from having taken the kids' trick or treating the night before, I make my usual detour to my neighbourhood coffee shop after walking my kids to school for a much-needed caffeine injection.

Over the last couple of years, I've incorporated this ritual in my routine a few mornings a week. I'm not the only parent in the neighbourhood who has; it seems to be a comforting morning habit for a few of us before we resume our day and face our responsibilities. I must have stopped to chat with friends and acquaintances that morning, for I would not be home before ten.

As I returned, I must have turned my key in the lock, disarmed our alarm, hung my coat in the closet and my keys on the hook by the front door. I must have acknowledged our fluffy white old boy, our faithful family retriever greeting my return, patting him on the head as I walked up the steps on the landing. The flashing light on our answering machine must have caught my attention and I must have pressed play. Two and a half years later, I remember listening to the time stamp of the message and comparing it to my watch. Only minutes apart.

The voice recorded on the machine belongs to my daughter's plastic surgeon. She is asking me to call her back as soon as possible. Is it me or do I hear an urgency in her voice? I pick up the cordless phone, look up the last caller in the list and dial. Dr. D answers immediately, in the middle of the first ring and says "Hi Natalie". Wow I think to myself, she's good. Interrupting my thought, she says she's received some test results from Charlotte's biopsy and wanted to call

me right away.

Cradling the phone to my ear, I walk over to the kitchen, and instinctively place my hand on the counter to steady myself. She continues “I wanted to talk to you myself. I’m afraid the tumour is malignant.” I interrupt her. “Are you telling me my daughter has cancer?” I hear the sound of my own voice, as calm as I have ever been, as I ask her. But inside my head, I am screaming. No! No! No! And in my chest, it feels as if an icy hand has grabbed ahold of my heart and is going to yank it right out. Yet I manage to hear her say : “Yes, Natalie I’m sorry. We don’t know what type of cancer yet, we’ve sent the slides off to the Children’s Hospital of Philadelphia for further testing, and a second opinion. But I thought you should know right away.”

Suddenly my head is throbbing and there is a pen in my hand and I am furiously taking notes. I know the doctor is still talking to me, but it’s the sound of my own voice I hear in my head. “Charlotte has cancer. My daughter. My Charlotte. Cancer.”

INTRODUCTION

“Cancer has shifted my sense of priorities. I now believe that the anthropologist’s fundamental obligation is to use her or his repertoire of skills to bear witness. In so doing we are compelled to tell stories about kinship as well as cancer that shed light on social realities. As witnesses to social life, we are obliged to make our stories accessible so that a wide range of readers might discuss and debate what we have written.”

— Stoller 2004: 200

I knew nothing of the journey I was embarking on the day that phone call came. If little had prepared me to become the mother of triplets in August 2006, nothing could have prepared me to become the mother of a child who has cancer.

In October 2012, while I had just undertaken studies in my master's program, I already had a well defined research project in mind, one which I had been thinking about and working on for a while. I was going to look at infertility and how patients lived through their experiences with assisted reproduction. Then my daughter Charlotte fell ill. I was encouraged by my family and supervisor to continue, but I was so consumed by being Charlotte's mother through her illness and a newly single parent to all three of my children that I took a leave of absence for that academic year. Of course when I came back to my studies, the topic of infertility now seemed a lifetime away and completely foreign to me.

The impetus for this project on the experiences of being the mother of a childhood cancer survivor came when I realized that our journey with cancer had not ended, despite the fact that Charlotte's treatments were over and she was pronounced in remission. This came as somewhat of a surprise to me. During her illness, the only horizon I looked to was the end of treatment and Charlotte being well again. I was encouraged in this optimism not only by friends and family, but by our hospital care team: Charlotte's oncologist, nurses, case manager, child life workers and our social worker. In fact, I did such a great job of internalizing everyone's optimistic messages that I was completely blindsided when I realized after treatment had ended that I was still very much afraid, sad and angry. I was relieved and grateful for a positive outcome for Charlotte, but her illness had nonetheless left me grieving.

Thus, the question of why I have kept on experiencing persistent fear, grief and sadness marks the starting point for this thesis. As I've sought to understand my experiences, I've realized that I am not unique in what I have journeyed through. In fact, there is a large body of literature on psychological adjustment in the face of childhood cancer which suggests that many, if not most parents struggle with similar lingering trauma and feelings of fear, sadness, anger and loss. This has been reassuring, but nonetheless surprising given that during treatment the messages I received were messages of hope and encouragement to resume our 'normal lives' at the end of treatment. I felt as though there was a very clear disconnect between these messages and my experiences. Therefore, the first question I seek to answer in this thesis is, more broadly, how can biomedicine's narrow understanding of disease and consequently, of healing as solely physiological be thoroughly deceiving? More specifically, how are my experiences post-treatment influenced by the narratives we encountered while Charlotte was being treated and how do they mediate my task of "getting back to normal" after treatment, making it more arduous? And finally, how could different understandings of illness and healing have been more appropriate? My goal is to reflect on our story to understand the contrast between my experiences with persisting grief and trauma, and the contradictory medical and social messages we encountered throughout treatment that urged us to get back in the community and resume our 'normal lives' at the end of treatment. It is also to reflect on alternate understandings of illness and healing, beyond the physiological, which would have promoted the ability to move forward in my transformed life rather than foster the expectation of an illusory "normal life". It would seem then, that auto ethnography would be the best method to achieve this goal.

More than an autobiographical exercise, autoethnography, in simple terms, consists of writing about the self and connecting one's experience to a broader social context. In addition to wanting to understand why the end of the treatment is not the end where cancer is concerned, my desire is to explore the healing process after childhood cancer, beyond its biomedical definitions, and how it is mediated by social illness metaphors, messages of hope and social views on healing. It is an opportunity to offer up my story to other parents of childhood cancer and share in ways that I could not while Charlotte was ill. Finally, it will also be an opportunity to reach out to a medical team who was caring and competent, in the hopes that my story can be of clinical use to them, if only to encourage and assist them in offering a more nuanced story to other parents and patients as they undergo treatment. During Charlotte's treatment, it was clear to me that every single member of our medical team cared. They cared about Charlotte's health and recovery, as they cared for the wellbeing of our family. The manner in which they cared got us through many a difficult night, morning and day. Paradoxically, in their caring and wanting to get us through this difficult time, an opportunity was lost. An opportunity to prepare us for what came after treatment. Cancer doesn't end after it is cured physiologically. And children and families continue to heal physically, emotionally and socially, long after the disease has left the physical body. This is the story I shall seek to tell in the chapters that follow.

The chapters

In order to understand our story and the context in which it takes place, it is important to understand how illness metaphors, and narratives of illness are shaped socially and mediate the experience of being ill and accompanying loved ones through illness. The first chapter is built around exploring how we view and talk about illness in North American society and provides a

theoretical framework through which my story can be interpreted. I first make a distinction between illness, sickness and disease, before exploring how North American anthropologists such as Stoller (2004) and Jain (2013), who highlight the pervasiveness of the military metaphor, and Frank (1991) have lived through cancer and beyond as I examine their own personal understanding of what disease has meant for them and their family. I then outline the vast literature on parents' experiences post-treatment, a literature which mostly finds its roots in psychosocial adjustment, traumatological literature and psychopathology and I argue that while it is useful in validating my own experiences and reassures me regarding my own coping skills, it fails to explain the disconnect between the social and medical narratives we encountered throughout treatment and my current experiences. Finally I make the point that illness presents a call for stories. I outline Frank's (2013) narrative typology as it provides a useful frame not only for my own narrative, but also for the various social and medical narratives on cancer while Charlotte was in treatment.

In Chapter 2, I outline how my journey through illness with Charlotte presents a call to tell and analyze my own story. I discuss my choice of autoethnography and storytelling as methods, their usefulness for my project and some of the risks and pitfalls of this approach. I outline how I collected the data I analyze, and include some reflections on reflexivity, vulnerability and ethics.

Even though my narrative voice is present throughout each chapter of this thesis, Chapters 3 and 4 are most intensively narrative. In Chapter 3, I describe our life during Charlotte's treatment and present vignettes of events which have left their mark on me because of their intensity and the feelings of trauma they have elicited. I tell these events because they inform how

I have experienced life post-treatment. In Chapter 4, I describe life after chemo-therapy and endless hospital admission. A life that, despite what I had been led to believe, is not “normal again”. I describe nightmares, awake and asleep, and the anxiety and fear provoked by return visits for checkups. I talk about sad anniversaries and being troubled by the rubble, both literal and figurative, left behind by cancer and wanting to seek meaning beyond labels of psychosocial adjustment rooted in psychopathology. I draw on Kleinman (1995, 2006) to argue that finding meaning in my suffering, and making peace with what lies ahead is more important for me than finding another medical label for the trauma, grief, sadness and anger that still ail me.

Finally in the Conclusion, I offer up some closing thoughts and discuss the limitations of my study. I suggest that medicine can learn by listening to the stories of ill persons and their families. I also consider the direction in which this work has pushed me, and what I aspire to as I continue to journey, healing with my family and finding meaning.

CHAPTER 1 - THEORETICAL CONSIDERATIONS

Ethnography has commonly been summarized as description, albeit description in context, but not exactly theory. Yet theory is defined as the analysis of a set of facts in their relation to one another, or the general or abstract principles of any body of facts, which to my mind makes ethnography most definitely a theoretical endeavor, one that has had and still has worldly significance, as description and explanation.

— Nader 2011: 211

Medical anthropology

Medical anthropology is rich with autoethnographies and especially illness narratives. Many living with disease or with a loved one suffering through illness, have taken their journey and shared it, for these stories are always worthy of telling. For example, Ellis (1995) writes about caring for her partner through emphysema and until he passed away, and Ettore (2005) tells of becoming ill with thyrotoxicosis and then healthy again. Later in this chapter, I highlight Murphy (1990) and privilege the voices of Stoller (2004), Frank (1991) and Jain (2013), finding their personal accounts more powerful than research done from the 'outside'. Richards (2008), who has written about her experiences with chronic kidney disease points out that "the expert on the lived experience of disability or illness is not the clinician, but the person experiencing the disability or illness. (1717)" More importantly, as Richards (2008) emphasizes, using this approach, as long as it is bolstered by solid theoretical and ethical groundings, can allow "professional care providers access to the lived experience of illness, rather than just the data and symptoms (1725)", in addition to reaching a lay audience, and other sufferers of illness who can benefit from seeing "some of their experiences reflected. (ibid)"

However, perhaps one of the most glaring critique of autoethnography, after its too narrow focus on the self, is that it can be decidedly un-theoretical. Yet, as Nader (2011) argues, ethnography, and I would add, autoethnography, need not be. As such, three distinct but interrelated sets of ideas are particularly useful in understanding the narrative of my experiences as the mother of a childhood cancer survivor. The first has to do with how illness and cancer are viewed and experienced by physicians, families and patients. As mentioned, the work of three anthropologists and sociologists who have lived through cancer and beyond and provide autoethnographic

accounts of their experiences, Stoller (2005), Frank (1991) and Jain (2013) informs this discussion. The second looks at how illness narratives are constructed. Frank (2013) makes another contribution here with narrative typologies that anchor how I interpret my story. And the third, is how parents of childhood cancer patients experience the illness, and is informed by a comprehensive review of the literature. The chapter that follows then, is organized around these three themes. First however, I think it is important to disentangle the meanings of illness, sickness and disease; terms which in some instances can be mistakenly viewed as interchangeable.

Illness, sickness and disease

Like Kleinman (1988), I take these three terms to have very different meanings. In the narrative that follows, I understand illness to be what Kleinman (1988) explains as referring to

how the sick person and the members of the family or wider social network perceive, live with, and responds to symptoms of disability. Illness is the lived experience of monitoring bodily processes (...) The illness experience includes categorizing and explaining, in common-sense ways accessible to all lay persons in the social group, the forms of distress caused by those pathophysiological processes. And when we speak of illness, we must include the patient's judgements about how best to cope with the distress and with the practical problems in the daily living it creates (3-4).

Therefore, illness is the lived experience of suffering through, and coping with physical symptoms of sickness, physically, mentally and emotionally. Sickness, on the other hand, extends the meaning of illness to how it is lived socially. For example, "when we discuss the contribution of the tobacco industry and their political supporters to the epidemiological burden of lung cancer in North America, we are describing the sickness cancer" (Kleinman 1988: 6). In childhood cancer, we could talk about the chronic and serious underfunding of research (Kids Cancer Care Foundation of Alberta 2015), and lack of discoveries in comparison to 'adult' cancers such as breast, lung and prostate cancer as adding to the lived experience of illness, making it a "sick

ness”. Finally, and still following Kleinman (1988), I view disease as a biological disruption in the physical body which is attended to by medical practitioners. These are narrower definitions to be sure, but they are nonetheless critical for thinking through my experiences.

Anthropologists, cancer and the military metaphor

Through my own story, I weave three autoethnographic works because they meaningfully inform my experiences and have provided ways to write about them as well as make sense of how I have lived through cancer with Charlotte. While Stoller (2004) explores metaphors of cancer as being an illness against which we wage war, and remission as a liminal, demilitarized state, Frank (1991, 2013) includes close loved ones as ones who suffer greatly alongside the ill, whereas Jain (2013) echoes and similarly critiques the idea of cancer as a war. Most relevant to my story is Jain’s portrayal of the “rubble” cancer has left behind in her life.

Stoller, who has done extensive fieldwork among Songhay sorcerers of Niger who have the power to both inflict and cure illnesses, became a cancer patient in the US during mid-life. He contrasts between how Americans and the Songhay live through illness. He explains that because the standards and access to medical care are very different in Nigeria, the Songhay tend to accept illness as an inevitable reality. While they are limited to treatment from healers and sorcerers, they recognize both the power of illness and healing rituals and incorporate them into their lives. He highlights that this very different orientation “breeds considerable respect for the forces of the universe, including the ongoing presence of illness in the body (...) illness is accepted as an ongoing part of life” (2004:191). Thus, the Songhay, Stoller found, are humble in the face of illness. While the Songhay respect the inevitability of illness, Stoller (2004) argues that Ameri

cans are socialized to count on good news, value optimism and reward people with sunny dispositions and that this in particular extends to illness.

Stoller's experience largely echoes what I lived with Charlotte during her treatment. I was personally and repeatedly encouraged by our medical care team and family and friends to be strong, remain positive and look to the end of treatment and remission and a time when our lives would be "normal again". Stoller (2004) goes as far as saying that "we avoid discussion or acknowledgement of serious illness" (110). In a similar manner, we think of our bodies as "fortresses" (111) and assume that if our family members have enjoyed health into old age, we will too. We tend to think that cancer develops in other people, especially those with poor health habits (ibid). I would argue that childhood cancer, when it occurs, is all the more surprising because as parents we assume that we will outlive our children whose health and fitness we assume will be as good or better than ours. When Charlotte became ill, it was an incredible shock to me. During and after my pregnancy I had worked hard to avoid having my family be exposed to known cancerinogens, from clothes to cleaning products to food. I wondered what I could have done wrong as a mother to expose her to cancer. Was it because I had undergone in-vitro fertilization? Had I missed something else?

It follows then that cancer is viewed by many as an assault on our 'fortress', one against which we must wage a war. Stoller (2004) points out:

The world of cancer is particularly fraught with war metaphors. We are fighting the war on cancer. Cancer cells attack and overwhelm healthy cells. They slowly and inexorably grow and overwhelm the opposition -- our body's natural defenses. When cancer first appears technicians run reconnaissance tests that pinpoint the enemy's position and describe the enemy's internal arsenal of defenses. Oncologists then send a sortie of chemotherapy agents on search-and-destroy missions. These agents des

troy the enemy, but also kill healthy bystanders-- collateral damage. These missions often result in heavy casualties. If you live through this campaign, though, you become known as a veteran, a survivor. Survivors then tell 'war' stories to help other foot soldiers in the war effort (128).

He further explains that in illness, as in military culture, patients are taught to follow orders, and that non-compliance breeds weakness and disorder. Looking at how the immune system is constructed in scientific discourse, Haraway (1993) makes a similar point. She states that "disease is a process of misrecognition or transgression of the boundaries of a strategic assemblage called the self" (378), that "images of the immune system as battlefield abound in science sections of daily newspapers and popular magazines" (395), and further argues that these images of illness are powerful in how they mediate their experiences of being ill. She also makes a very interesting point regarding self-help practices in the healing process and discusses how patients are encouraged to enter states of relaxation and to visualize the processes of the disease and healing unfolding within the body (396). I remember Charlotte being encouraged to do just that by the attending oncologist during one of her longest hospitalizations.

It was in mid-December 2012, and Charlotte had been hospitalized for a few weeks, first for chemotherapy, then neutropenic and in isolation. We had been offered tickets to go see the Nutcracker at the National Arts Centre by a local charity organization. She so wanted to go. And I badly wanted to take her. I wanted to see her mesmerized for a few hours and I wanted us to forget that she was ill, if only just for that short time. The hospital had offered a 4-hour pass for us to attend, but I knew that we would not be allowed to go if she was feverish. One morning, about a day or two before the presentation, just after breakfast, we were sitting in her room and I had taken out her drawing materials. She loved drawing and I had splurged on a professional

grade drawing tablet and brought her school drawing blocks to the hospital. We were busy drawing animals, birds and landscapes (I'm a terrible artist!) when the attending oncologist walked in with her crew of residents for morning rounds. She asked what we were drawing and Charlotte proceeded to tell her the story we were putting on paper. Then the conversation shifted to how Charlotte was doing and we both mentioned that we really really wanted a day-pass to go the National Arts Center the next day to see the Nutcracker. She said she couldn't give us an answer and that it would depend on her counts and whether she continued to be fever-free. She then asked Charlotte if she knew what her neutrophils looked like and suggested that she draw some in her book. She said that maybe by seeing them and drawing them she would encourage her body to make more. Later Charlotte drew three large multi-coloured neutrophils.

Ultimately, I cannot help but acknowledge the prevalence war metaphors in the cancer world we live in. As in the military, as children we are taught at school to follow rules, to eat according to the Canadian Food Guide, to exercise and take care of our bodies. As patients we are taught and expected to follow treatment regimens to restore health when disease visits us. Like Stoller (2004), I was taught by our oncologists and nurses to administer the right doses, at the right times, to guard against germs and watch for fevers, and that not doing so placed my daughter at risk.

Similarly, it seems that everywhere I turn, there are fundraisers in the name of waging a war against every type of cancer. And while I have felt the need to resist the image of cancer as a war, I have been involved with the Sears Great Canadian Run, which bills itself as the 'Relay to End Kids Cancer'. Not quite a war, but if you ask a majority of participants why they are there, they will tell you unequivocally that they do it to *fight* kids' cancer. Similarly, I am on the email

distribution list for the International Society of Paediatric Oncology. Every year the organization hosts an annual conference, which brings together researchers, clinicians, nurses, allied professionals and survivors and their parents to share in the latest paediatric oncology research. The latest reminder I received in March, contained this line: “SIOP 2015 is giving you MORE time to send your research on a diverse list of topics connected to the fight against childhood cancer.”

So pervasive is the idea of a fight against cancer, that it permeates views at the individual, collective, medical and even corporate level. And not only is it ubiquitous, it actually shapes our response to the cancer itself. We spend months and years ‘fighting’ cancer. And then what happens when the fight is over? We’ve either won, by surviving, or lost, in dying. However, winning the fight against cancer is a strange kind of victory, for no one returns to their pre-cancer state. Instead they are in remission. Thus, like Stoller (2004) who resists the idea of fighting disease, I also contest the image and resist viewing cancer as a disease to be fought against, despite the fact that I actively participate in activities which seek to either raise awareness and/or raise funds to improve the lives of childhood cancer patients.

As Stoller (2004) points out, remission is not really a victory. After going through treatment, he realizes now “that my life would never return to normal. Cancer and chemotherapy would leave their mark on me” (158). He describes remission as an uncomfortable space where life as you knew it is gone, and an uncertain future remains. What’s more, you are no longer the person you used to be. Illness has changed you. He states “Seen in this light, remission is an example of what anthropologists have called *liminality*” (183, italics are Stoller’s). Later, he emphasizes: “Remission, though, is a trickier enterprise than treatment (...), how do you confront a life that cancer has complicated and perhaps shortened?” (190) That it is my daughter’s life

rather than my own in which I face remission, is nonetheless extremely daunting. How can I make sense of my own child having faced death at such a young age? What does our future hold? Will we be robbed the gift of children and grandchildren? I can't (and nor is it for me to) say exactly how my daughter continues to experience remission as she matures physically, emotionally and intellectually, but as her mother, it has been jarring, frightful and sorrowful. I share in Charlotte's remission, and have my own experience of it.

Stoller (2004), because of his initiation into Songhay sorcery, has a nuanced understanding of cancer. While he sees it as an "unspeakable evil" (195) inflicted on one's body (reminiscent of a war battle), and while he did submit to conventional chemotherapy to treat his Non-Hodgkin's lymphoma, he incorporated Songhay healing practices and rituals as part of his treatment regimen. This was his personal response to the American "unbridled optimism" (121), and instead, a way of "seeing things clearly" (114), a form of "tempered optimism" (ibid). I caught more than an occasional glimpse of this optimism as we journeyed through treatment and were told to look ahead to future remission. It seemed to me, that even as I was acknowledged and supported in our suffering, I was actively discouraged from faltering in my faith in a bright future. The liminal space of remission was not one which I had been prepared to face by our medical team.

Canadian sociologist Arthur W. Frank (1991, 2013) makes two similar points and important contributions to my work. The first is discussed here and lies in his argument of remission "as a kind of demilitarized zone, between health and illness" (9) and that the suffering that cancer brings forth extends to the ill person's loved ones. And the second is in the narrative typologies he outlines which I discuss later in this chapter.

Frank (1991) points out that living the experience of remission is not limited to the patients themselves, but extend to “the families that share the worries and daily triumph of staying well” (18). Spouses, brothers, sisters, anyone living in close proximity and playing the role of caregiver also suffer when their loved one has cancer. And while he reinforces what I know and have lived through, throughout a reading of his various works (1991, 2000, 2004, 2013), I saw a paradox emerge in my experience and understanding of childhood cancer. Indeed, I can see how he could argue that “medicine assumes that the person who has the disease is the only one who is ill. The assumption is shared by other institutions and even by family and friends (...)” (1991: 850). Having seen and supported as best I could my own father care for a spouse who was terminally ill with cancer many years ago in 1998, I remember well his own suffering as her caregiver. At the time, while his partner was well looked after by the medical team, I remember wondering who was looking after my father, and whether he was receiving enough care himself.

My experience while Charlotte was in treatment, was different than what Frank (1991) describes, and certainly different than what I remember my father living through. Without wanting to delve into an in-depth analysis of the social construction of childhood in Western society, I would observe that childhood cancers are viewed differently than adult cancers. Because we construct childhood as a time of innocence, vulnerability and promise (see for example Dixon-Woods et al. 2005), and because my family is fortunate enough to live in an urban centre, we have access to a children’s hospital. This has meant access to specialized care for Charlotte, and child-life workers and playrooms dedicated to improving Charlotte’s quality of life while in hospital. During treatment, it also meant additional support for our family, such as an Interlink Nurse, whose role was to liaise between the hospital, school and other community resources we

might have accessed in the context of Charlotte's treatment. It meant we were also connected to various community resources where we could turn to as needed for financial relief, and finally, it meant we had immediate access to a social worker when we were in the Day Unit, or hospitalized. In fact, our social worker often sought me out, regardless of whether I'd requested to see her, to check in with me and ask about how the boys were doing, and how I was coping. I came to expect and appreciate her visits, for she was one of the few with whom I could be completely open and honest, without worrying about placing the burden of sharing my suffering. Therefore, in this sense, I would argue that my suffering, alongside Charlotte's was very much recognized by all of our care providers.

The argument I wish to make regarding my own suffering then, and the needs of our care team, is more nuanced. That is, while our medical care team recognized my present suffering and provided great support, I think they were also cognizant of placing the additional burden of future fears on a mother who was already stretched to the maximum of her abilities in coping with the present. They could only acknowledge and allow for part of my suffering. Frank (1991) points out that "to live among others is to make deals. We have to decide what support we need and what we must give others to get that support. Then we make our 'best deal' of behaviour to get what we need"(68). Our medical team needed a mother who was able to cope to be efficient themselves in delivering the medical care that Charlotte needed. By focusing on the present, at the expense of educating me about our future, they were not only following Frank's (2013) restitution narrative which I discuss below, they were also making a deal with me. I just didn't know a deal was being made.

Finally, anthropologist S. Lochlann Jain (2013) reprises the idea of cancer as a war fought, one that is too often lost, but adds that it is paradoxically so financially lucrative in the United States that, she argues, finding a cure would be economically risky. Less than legal and economic arguments concerning the paradoxical centrality of cancer in North American society, and not surprisingly, what are most striking to me are some of Jain's personal musings. In particular, in Chapter 9, Jain reflects on the "rubble" left behind by cancer. She describes the "dreaded mounded accumulated in (my) closet (...) bottles of pills, a prosthesis, a used wig" (202), recalling how each of them came to be, and were now left in and "uncanny heap" (ibid). Reading those few pages, I felt as if I was stricken by a thunderbolt as images of Charlotte's leftover medications in the refrigerator, in the lunch cupboard and in the upstairs bathroom flashed before me. It wasn't that I hadn't known these were left behind, but it was how, amazingly, I was able to look at them every day without seeing them any longer, and wondering why on earth would I still be hanging on to these, nearly two years later. With just a few lines, Jain's seemingly banal account provoked the realization that I had been hanging on to those items for dear life, and caused me to reflect on why I had been unable to part with them, supporting once again my realization that even when cancer is over, it still isn't. They are another marker of the liminal space I inhabit.

Disease as war, and remission as a liminal and demilitarized zone. It is clear that cancer elicits rich and powerful metaphors which are shaped by and shape our views of illness and treatment, and colour our experiences. Thus, it is these views of health, cancer and healing which form the ongoing backdrop of my experiences. They permeate, shape and inform the story I tell.

Parents' experiences post treatment

While I couldn't find any anthropological accounts from parents of childhood cancer survivors, there is admittedly an abundant literature on the psychosocial impact of childhood cancer on parents and families. It would appear that as the number of diagnoses, improved prognoses and treatment successes have increased through the 1980s and 1990s, so too did research on the experiences of parents during and post-treatment. Most studies are published in nursing, oncology and social work journals and suggest that post-traumatic symptoms and stress (PTS) in both cancer survivors and their parents is a common response (see for example: Stuber et al. 1994, Goldenberg Libov et al. 2002, Norberg et al. 2012). Select others also look at costs to families and children (see for example Fletcher, 2010 and Tsimcalis et al. 2006), as well as, surprisingly, the hidden benefits of having a child with cancer to families (see for example Fletcher 2011). Interestingly, some of the benefits outlined include realizing and enjoying the presence of a strong support network, an enhanced appreciation and the opportunity to create special memories with the ill loved one, and finding joy in the opportunity to give back and help others.

Not surprisingly, from these studies, two broader themes emerge. They are: overall adjustment during and after cancer, and cancer as a life-changing event. The majority, if not all of the authors agree that parents, and in particular, mothers of childhood cancer patients experience high levels of distress, both during and after treatment has ended.

The first few studies I outline below are crucial to this project because they are among the first studies I read while exploring my topic. They spurred my thinking on the subject, and most importantly helped me interpret my own experiences and translate them into words. They also

helped me identify the contradictions in my expectations and what was actually happening, and in doing so, helped give shape to this project.

Indeed, it is an earlier study by Van Dongen-Melman et al. (1998) that specifically explores parents' experiences of childhood cancer after the treatment which has led me to want to explore this topic. Their study, which focusses on 85 parents of 8 to 13 year old children in the Netherlands who have survived cancer, was the first to make me aware that my own experience was not isolated. While I lived alongside parents and children undergoing chemotherapy and radiation for many months while we were hospitalized at the hospital, and I knew intellectually that I was not alone, I always felt removed from the situation, unable to truly connect with other parents at the time because my pain was too raw, the fears, sadness and especially disbelief were too real. I preferred to internalize my feelings and avoiding sharing in order to avoid 'breaking down'. Once we completed treatment, I realized I needed to pay attention to what had happened in the last year, and what it meant for my family and me. As I settled on the topic for this thesis and started searching for other parents' experiences far and wide, the study by Van Dongen-Melman (1998) was one of the first ones I came across. I found it compelling because it gives a comprehensive account of how parents live and cope through childhood cancer and, especially, beyond. Reading their research I found myself nodding my head and feeling weak, shaky and tearful. Especially when I read that they had found that for many if not most parents, despite the survival of their child and long after the end of treatment, parents remain deeply affected by their child's illness, and that emotional distress and a sense of loss and mourning persist. It was then that I realized that I wasn't the only one for whom 'normal life' had yet to resume, despite what I had been led to firmly believe.

In another similar earlier study that echoes some of what I have lived through, Stuber (1995) points out that not only are the cancer diagnosis and treatment stressful for a family, but that despite the traditional advice offered to parents when treatment ends which “has been to go out and live a normal life” (163), it can be assumed that putting such advice into practice is never as easy as it sounds and that for many, the experiences of fear and pain leave their imprint, which makes forgetting and living ‘normally’ impossible. Likewise, one of the key findings of Kelly et al. (2004), who produced an ethnographic study with adolescents in a hospital cancer unit in the UK, was that the end of treatment was a time of significant stress for many parents and a time of concern for health care professionals. Parents shared among each other their fears about the “challenges that would now face them in the outside world” (855) whereas the professionals caring for the families also recognized these fears about “leaving the security of the unit” (ibid). Whereas I initially had no such fears about leaving active treatment behind us, and was actually quite excited to be transitioning to this phase, this study was immensely validating in that it openly acknowledges the pervasiveness of the “go out and be normal again” message perpetuated by medical care providers.

Papaikonomou (2007) draws similar conclusions based on her case study of a couple, Marius and Mary, the parents of three boys, whose middle child was affected by childhood cancer (I have two boys and a girl, and because Charlotte is my “middle child” this is one of the reasons this study resonated with me). However, she pushes the argument further and insists on the need to understand the post-treatment experiences of parents and the meanings they attach to theirs and their child’s suffering. She comments directly on health professionals approaches regarding the end of treatment and states that “healthcare professionals should also not assume that

because the child has been disease-free for a certain period that the parents are no longer worrying about the child's future" (72) and suggests ongoing connection between healthcare professionals and the family.

Following a similar line of argument but using a more quantitative approach which entailed collecting medical and demographic statistics, using the Likert scale as measuring tool, and with larger sample size of 200 participants, Zebrack et al. (2002) likewise emphasize that parental distress remains post-treatment. What is notable about their research is that it leads them to make an interesting point about added suffering where mothers are concerned. They argue that even though both fathers and mothers worry about their children post-treatment, women may face additional distress and even suggest various reasons why this is the case. For example, they hypothesize that mothers' distress is mediated by their perception of their child's distress, and influenced by other factors such the presence of cancer after-effects, their own personal health and their relationship. In that sense, they also suggest that "mothers who are not married or partnered may worry more about their child's adjustment than do married mothers because of the extra burden they face in raising a child alone (...)" (18). In light of my recent separation, reading this study provided some measure of comfort that I wasn't alone with my fears and distress.

Conversely, highlighting the importance of providing a voice for parents' lived experiences, Dixon-Woods et al. (2005) have argued specifically for this approach in working with parents of childhood cancer survivors. Their work is particularly interesting in that they both sketch the clinical background of the illness in medical terms, and at the same time make use of, and argue the importance of using an interpretive approach to understand the lived experiences of families. They make several points which have been key in shaping my own project.

First they argue the necessity of locating social science research on childhood cancer within the family. Without diminishing the impact of life-threatening and debilitating illness on a child herself, they highlight that what happens to a child, in fact happens to the whole family. Childhood cancer has a very real impact on those who are “socially and emotionally adjacent” (13) to a child. Second, they are critical of psychological approaches which focus solely on parents’ ability to cope, psychosocial adaption and labeling residual trauma as mental illness. In their work, they “seek to move beyond approaches that endlessly catalogue families’ difficulties. (28)” This strikes me as particularly enlightened in that they aim to provide a deeper understanding of the multi-facetedness of childhood cancer, and to translate their research into theory about the experience of childhood cancer. In fact, a study by Maurice-Stam et al. (2007) likewise makes an argument concerning the need to look beyond maladjustment. They actually suggest that, overall, parents can be resilient in the face of childhood cancer and that distress levels will even out after the first few years post treatment. And like Papaikonomou (2007) and Zebrack et al. (2002) they make the case that parents should continue to be supported after treatment ends.

Third, Dixon-Woods et al. (2005) call on ethnography as a methodology to respond to this need to produce more reflexive accounts of experiences of childhood cancer. Nevertheless, whereas they insist on future directions for childhood cancer research which includes “fewer studies with uncontrolled designs, conducted using small sample sizes from single centres, and lacking in statistical power” (161), I feel there is a need and room for smaller studies, namely unique, thickly described autoethnographic accounts which provide a deep understanding of

what it is like to live with childhood cancer under particular circumstances. These should be powerful complements to the types of study they propose.

Dixon-Woods et al. (2005) make a final point which is critical to this project. They state that “Parenting a child with cancer needs to be recharacterized to draw attention to (...) show how becoming, and being, a parent of a child with cancer invites surveillance of parenthood. (ibid)”. This is not something that was particularly salient to me throughout treatment. But as I have reflected on our experiences, I have come to realize that as Charlotte’s mother, I was very much in the spotlight and my ability to provide adequate care was very much at stake and under observation. In urging, encouraging us through treatment by allowing only for success, and while keeping me unaware of what happens post-treatment, our caregivers were “building me up” to be a better caregiver to Charlotte. In other words, they needed me to do the absolute best job I could as a mother, in order to do their best job as physicians, nurses, and social workers. We all needed each other, in order to perform our own roles.

A more recent study by McKenzie and Curle (2012) largely echoes the ones discussed above, with some added nuances. The first one is that “families are often dubbed the silent sufferers because family members have their own and the patient’s emotions to deal with” (647). In our case I am not sure I would qualify as ‘silent sufferer’. The circumstance during Charlotte’s illness were such that our medical practitioners recognized the care “burden” (I do feel uncomfortable using that word since I never saw caring for Charlotte and her brothers as a burden) that I faced and provided support where and when they could to enable me to better support my daughter. The second point they make is regarding the need to place maladaptive reactions and medical models of adjustment in “the social context of caring with a child with cancer (ibid)”.

This would imply that parental coping mechanism who be directly influenced by medical care providers, among others and in our case would make sense in light of the interdependency that developed between our medical team and myself. Finally, these authors clearly argue that parents' experiences at the end of treatment continue to be mediated by the treatment process: "This account suggests that the EOT cannot be separated from the treatment process and post treatment experiences. The core theme of 'the end of treatment is to the end' reflects the continued process of role and identity changes that parents face (651)". This last statement could be used to describe my entire experience so far, as it will become apparent in the narrative that follows.

It is clear from the sample outlined above that most if not all of the literature on parents' experiences of childhood cancer describes distress, challenges in adapting to live after treatment. Given this abundant research, and evidence from a majority of other parents and families, why did my own experiences come as a surprise to me? Why, as a parent, was I not better prepared for what happens next? Were our medical professionals aware of something which I wasn't? To try and make sense of this, it seemed fruitful to look deeper into the kinds of narratives attempting to give meaning to such a disruptive life event. Therefore, I now turn to some theoretical approaches in anthropology that have attempted to provide a way to both understand and address illness narratives. As such, this anthropological literature provides both a theoretical and analytical lens as well as the beginning of a methodology to disentangle what is going on in people's lives as we try to find meaning with a cancer diagnosis in the family.

Narrative, illness and medicine

Illness as a call for stories

According to Frank (2013), illness presents a call for stories in two ways. First, as a matter of practicality. Ill people and their loved ones must tell stories of illness to other family members who call for news, to co-workers and employers who must be kept informed and to medical workers who need vital information to provide adequate care. Equally important, is the fact that the manner in which stories are told differs depending on the audience. Second, stories that are told help the teller make sense of what is happening to him, and to re-conceptualize and redraw the map of his life. Frank compares the disjuncture that illness presents in one's life to a shipwreck: "Almost every illness story I have read carries some sense of being shipwrecked by the storm of disease, and many use this metaphor explicitly. Extending this metaphor describes storytelling as repair on the wreck" (2013: 54).

Frank's metaphor is striking enough on its own. However, what strikes me is that on several occasions I have used a very similar metaphor myself. I have described repeatedly to friends and family that in November 2012 I felt as if I had just woken up after a train crash. And as I write this, I can still see myself in my mind's eye, standing amidst the smoke, mangled wreckage and rubble, in shock and deeply wounded, looking for my children, not remembering what has just happened or where I am. I feel desperately lost, the terror in realizing where I stand alone suddenly sinking in. In this sense, part of my attempt here in telling my story as a more coherent whole, rather than in disparate parts as I have been to myself, and others, is my attempt to rebuild after the wreck.

Telling my story is also an attempt to share. I have not been alone in my journey, many have shared it with me. Here again, I am inspired by Frank (2013) to explain the sense of responsibility I feel to others who have journeyed in various ways with me. He suggests the sharing of stories as an ethical gesture. Stories are for others as much as they are for ourselves. Drawing on the Levinasian ethic of living for the other, Frank argues that “Ill people’s storytelling is informed by a sense of responsibility to the commonsense world and represents one way of living *for* the other. (2013: 17, italics are Frank’s)” When Charlotte fell ill, our doctors provided me with a treatment roadmap. It was medicine’s unfinished story (if not a promise) of how they would heal my daughter’s body. We journeyed alongside one another, the members of our medical team and myself, united in our experience of caring for Charlotte. While they were scientifically and humanly competent (they knew biomedicine very well, and were, without exception, caring and compassionate individuals), there remains a gulf between our experiences that I feel important to try to bridge. It is in that spirit that I offer my story of illness. In Frank’s words again, it is my attempt, kindled by my daughter Charlotte’s “body’s disease to give a voice to an experience that medicine cannot describe. (2013: 18)”

Types of illness narratives

Frank (2013) poses that illness narratives are “one form of self-story” (69) and identifies three types of narratives: the restitution narrative, the chaos narrative and the quest narrative. While each type has a clear purpose, he issues two cautions. The first is that these narratives are “not presented as linguistic structures but as objectifications of the bodies that tell them” (52). In other words, different narratives are variously situated; they are means through which a particular person, at a particular time, is able to speak and tell their story. Secondly, he points out that

“no actual telling conforms exclusively to three narratives” and that “actual tellings combine all three.” (76) It is with that in mind, that I make use of Frank’s framework as a lense through which analyse my story.

Types of narratives

The restitution narrative

The first type of narrative that is outlined by Frank (2013) is the restitution narrative. In the same manner as Stoller (2004), he argues that we tend to view health “as the normal condition that people ought to have restored” (Frank 2013: 77). Consequently he explains a person anticipates becoming healthy again when he falls ill. This desire to have their health restored as soon as possible becomes amplified by the expectation of others around him who want restitution stories. As such, this type of narrative follows a basic plot in which a healthy person falls ill and then becomes well again. The message of restitution is powerful and pervasive. This type of narrative “not only reflects a ‘natural’ desire to get well and stay well. People learn this narrative from institutional stories that model how illness is to be told” (Frank 2013: 78). Such stories are found in drug company television commercials and magazine ads, hospital brochures, and more importantly are told over and over by medical professionals. Time and again, it is the discourse of restitution which I encountered during my journey through childhood cancer with Charlotte. The unified message which came from her oncologists, nurses, and hospital social workers was that we were going to get through this difficult time, Charlotte would become healthy again, and that we would go back out in our community to once again live a ‘normal life’.

While restitution stories shape personal and social expectations, and help us maintain hope, the shadow side of such narratives is that they offer no alternative should the plot develop

differently. If the ill person does not become well again, there is no model for how that story should be told. Or, in our case, now that Charlotte's health has been restored, life is still not 'normal' as was expected.

The chaos narrative

The second type of story told according to Frank (2013) stands in opposition to the restitution narrative. It is one of chaos, in which events are told without order or apparent causality, but rather as they are experienced by the narrator. The chaos narrative "imagines life never getting better." (97) These stories are difficult to hear, by family, friends, and clinicians alike because they threaten our sense of how life is meant to unfold. They are difficult to hear for close ones because they imply that our loved one may never get better. They are difficult to hear by clinicians because they imply failure and threaten their sense of professional selves. Frank (2013) argues that "clinical caregivers steer patients towards medical versions of liberation: treatment plans, rehabilitation, functional normality, lifestyle counselling, remission (...)" (112) but that in general we have "a hard time accepting, even provisionally, that life sometimes *is* horrible" (italics are Frank's) (112). This type of narrative is usually the one that more closely describes the disjuncture of illness in a person's life but is the least preferred. It is eschewed by medical professionals and even close ones since it does not conform to what Stoller (2004) has described as "the quintessentially American approach to disease" (196) or in our case, because it contradicts how we are expected to live through the experience of being ill. Not surprisingly, during our journey, our medical team repeatedly steered us away from chaos and towards restitution. From the moment Charlotte was diagnosed, we were assigned a case manager whose job was to oversee the coordination of Charlotte's care in an orderly fashion and as she told us, effectively take

us from the beginning of treatment, to the very end. She provided us with our treatment ‘road-map’, explained the milestones, timing of treatment and hospitalizations and made sure the right tests (for example ECGs to monitor her heart, and ultrasounds to monitor vital organs) at the right time. Margo was competent, efficient and caring and she was our point of contact for any treatment or care related question or issue. And while there was chaos in how Charlotte’s body responded to the chemotherapy and as a result in trying to manage our daily lives around endless hospitalizations, there was order in the medical responses to each of our crises.

The quest narrative

The final type of narrative identified by Frank (2013) is the quest narrative which presents illness as a journey in which the goal is to make the suffering engendered meaningful. These types of stories tend to be the ones that most get published. They can take the form of memoir, the “gentlest” types of quest story according to Frank, if they are told in conjunction with other life events (120). Both Stoller (2004) and Murphy’s (1990) account of their journeys through illness are written as memoirs, with illness presented as a disruption in their biographies, alongside other life events. In manifestos, they can be presented as a truth learned about suffering and become a rallying call for social action (122). Illness is presented as not only a personal journey, but as a social issue. Audre Lorde’s account of her journey through breast cancer is a resounding manifesto in various ways. She states:

But I believe that socially sanctioned prosthesis is merely another way of keeping women with breast cancer silent and separate from each other. For instance, what would happen if an army of one-breasted women descended upon Congress and demanded that the use of carcinogenic, fat-stored hormones on beef-feed be outlawed? (1980: 16)

Here Lorde not only decries the pressure imposed on women with breast cancer to “replace” their missing breast with a prosthesis, but implores the reader to recognize cancer-producing toxins in our food chain and suggests that social action needs to take place in order to remedy the situation. Quest narratives then, in their various subforms, seek to make illness useful and meaningful in a person’s life. They are ways in which we search for “alternative ways of being ill” (Frank 2013: 117).

To return to my opening statement, it is clear that autoethnography need not be anti-theoretical. The narrative of one’s story of illness is shaped by what we are told illness is and how we are expected to cope with it. Similarly, powerful socially originating metaphors also frame our experiences. The war on cancer is one that has steadily coloured the backdrop of my journey with Charlotte. During treatment we were “fighting cancer”, we were steered towards restitution in being told that once we had won the fight we would return into our community and resume our normal lives. But, as I have found, our lives are not ‘normal’, as Stoller (2004) and Frank (2013) I feel that I exist in a liminal space, even though personally my body has not lived through the illness in the way my daughter’s did. My Charlotte is well again, but the worries have not been erased. I am aware, every day, and in the small hours of the night when I sometimes lay awake, of the ongoing risks of relapse, and the continued threats of late-effects that the very chemotherapy which ‘cured’ her bone cancer, pose to her current and future health. This is the story I will tell. Frank’s narrative typologies frame at once my experiences during treatment, my story as it continues to unfold and as I tell it. During Charlotte’s treatment, our medical team’s restitution narrative coloured my days and shaped my hopeful view of our future. Howe

ver, now aware of post-treatment realities, similarly to Stoller (2004) my view is much-tempered.

As such, the story I tell is at once chaotic, questful and restitutive.

CHAPTER 2 - METHODOLOGY

The exposure of the self who is also a spectator has to take us somewhere we wouldn't otherwise go.

— Behar 1996: 14

Researcher involvement has been the hallmark of anthropological research since very early in the discipline, when Malinowski first visited the Trobriand Islands and set out to describe what he encountered. Similarly, using one's own personal experience in ethnography is also not new in the anthropological tradition. For example, Murphy (1990) describes his experiences with a degenerative illness of the spinal cord as "a kind of extended anthropological field trip" (xi). In their handbook of qualitative methods for health research, Green & Thorogood (2009) highlight the benefits of researcher involvement, and point out the importance of "reflexive 'insider accounts' written by professionals and patients drawing on their own experiences as data for understanding a particular issue. (150)" They also point out a "tradition of 'sociological autobiography' in which personal experiences are used to explore theoretical or conceptual issues. (ibid.)" In that manner, Nancarrow Clarke (1999) has detailed her experiences as a mother of a childhood cancer patient in Toronto and her writings are necessarily coloured by her training as medical sociologist, but nonetheless enlightening both as a poignant personal account, and as commentary on the Canadian medical enterprise in the 1990s. Without a doubt, placing the self at the center of an ethnographic project and telling our story can yield some powerful results.

Autoethnography

It will come as no surprise then that my method of inquiry for this MA project consists of autoethnography. Simply stated, I chose to use my personal experiences with my daughter's cancer and healing as a family after the end of treatment as the primary "data" to be analysed. It is a decision I struggled with at first, for I am well aware of the pitfalls and critiques made towards the method. For example, Chang (2008) cautions on excessive focus on the self at the expense of placing one's story within a broader context and sound analysis. While Gannon (2013) points out

that “autoethnography has at times been criticized for a relentless emotionality” (233), Anderson and Glass-Coffin (2013) highlight the personal risks of exposing oneself, and worse, that autoethnography has at times been charged as narcissistic. So like many researchers, I harboured my own suspicions about the quality of the method. Would it be seen as scientific enough? Academic enough? Would my own voice be sufficient and credible enough? Would the exercise be seen as too indulgent? Nonetheless, given that my goal for this study was to understand the contrast between my experiences with persisting grief and trauma, and how they contradict the medical and social messages I encountered throughout treatment that urged us to get back in the community and resume our ‘normal lives’ at the end of treatment it made perfect sense, as a starting point, to examine my own experience as a parent of a childhood cancer survivor. More than a purely autobiographic and therapeutic exercise, autoethnography is the ideal methodological tool to allow me to connect our story to a broader social context, and render a deeper understanding of what it is like to be the mother of a childhood cancer survivor.

I use the term autoethnography, in the manner defined by Chang (2008), as a mode of inquiry which “follows the anthropological and social inquiry approach rather than descriptive or performative storytelling” (46). Like Chang (2008), I reflect upon and analyze my personal story, one of journeying through, and beyond childhood cancer with my daughter while placing it in its broader sociocultural context. While Chang acknowledges that self-reflexivity and personal subjectivity continue to be critiqued, she argues that the following three characteristics of autoethnography make it as valuable as traditional ethnography: that it “uses the researcher’s personal experience as primary data” (as cited in Holman Jones et al. 2013: 108), it “intends to expand the understanding of social phenomena” (ibid) and its purpose “at least from the social sci

ence perspective, is not only to tell personal stories. It intends to expand understanding of social realities through the lens of the researcher's personal experience" (ibid). Thus in writing about healing after childhood cancer, I will be connecting my lived experience with that of others, while engaging in and contributing to a broader scholarly conversation on what it means to be the parent of a childhood cancer survivor after treatment has ended.

While Chang (2008) cautions that it is possible to place too great a focus on the Self at the expense of critical analysis, leaving the reader with a purely autobiographic story, Anderson (2006) similarly distinguishes between evocative or emotional and analytic autoethnography: "Unlike evocative autoethnography, which seeks narrative fidelity only to the researcher's subjective experience, analytic autoethnography is grounded in self-experience but reaches beyond it as well" (386). He cautions against a purely emotional autoethnography, and emphasizes the importance of an analytic agenda which engages and connect with broader social science theory. I very clearly side with Anderson (2006) and Chang (2008) in my commitment to an analysis which I weave withing my narrative, wanting to situate my story among stories of other parents, and medical providers, as well as alongside the stories of anthropologists living through cancer.

Finally, Chang (2008) cautions that the use of personal memories as the sole source of data can pose serious challenges to the researcher's subjectivity. She recommends using other sources of data such as interviews, documents and artifacts as "bases for triangulation" (55), which as I outline below, is what I have strived to do.

Data collected

As I have endeavoured to give shape to this project, in addition to recall techniques (Ellis 1995), I have made use of several material sources of data. First, I have reviewed field notes I

kept during Charlotte's hospitalization in which I described and commented on some interactions with medical personnel. I have also re-read, several times, electronic journal entries I made during Charlotte's illness. Many of them were about matters not directly-related to the illness but about other events occurring in parallel which nonetheless gave context to my thoughts and experiences; for example school issues with one of my boys, working out a divorce settlement with my children's father, and my hopes for the future in general. In the 18 months or so since Charlotte has been off-treatment, I have continued to keep an electronic journal. I have journaled about recurring nightmares, ongoing fears, successes, test results and more. This journal has proved invaluable as I have traced back our journey, through cancer and beyond.

Secondly, while I tend to journal extensively, I am not otherwise known as the "documenter" of the family. That title, along with the responsibility for photographing significant and mundane events was usually reserved for my former husband. These days my own parents tend to happily snap away at family events. I suppose I have always been too busy in the middle of the action, especially with three small children, to try to capture moments in images, preferring instead to reflect on my own and record my thoughts in a journal later when things are quiet again. It was no different during Charlotte's illness, I snapped very few pictures. Not only was I overwhelmed with caring for an ill child, it felt intrusive to be taking pictures of Charlotte while she was so vulnerable. The few images I did capture, I find haunting to this day. Even though I have revisited them several times for this project, I am still not able to look at them without feeling the air drain from my lungs and raw fear squeeze my heart. Even though I took few pictures of Charlotte in treatment, or our family during that time, I have an extensive collection of electronic images from November 1, 2012 to today. These are images exchanged by text message

with a dear long-time friend and partner. We've often exchanged funny or evocative pictures summarizing our days as means of staying in touch with each other. Going through these images I have found I could associate nearly each one of them with a precise moment in our journey. Some of them I have even been able to associate with a particular smell, usually of a chemotherapy drug. When Charlotte would sleep, I would check my messages and often there would be something from Jeff. These were invariably imprinted in my mind. My mother, ever an avid scrapbooker, has kept albums for each of the children since their birth. And where I lacked the ability to document our journey in pictures, my mother has had the courage to keep filling Charlotte's book. Although extremely painful to review, the pictures my mother has collected also tell a powerful story which has helped me in constructing this narrative.

Thirdly, I collected several material items during and after Charlotte's treatment; items such as appointment cards, countless hospital bracelets, discharge summaries, wound care instructions, information leaflets on various chemotherapy drugs, and even a special quilt that was donated during our first hospital stay after diagnosis. These items have proven powerful in helping me evoke memories and details of our experiences.

Finally, I have been fortunate to be able to validate some of my memories through conversations with others who have shared the journey with me. They include but are not limited to, my mother, close friends, special nurses and our oncologists upon many return visits.

All of these journals, artefacts and conversations have been useful as I have built my narrative and analysis. It should be mentioned that while the focus of this thesis are my experiences post-treatment, they are invariably informed by the events that occurred during treatment. Thus the narrative of this journey spans a period of approximately 28 months, from November 1,

2012, the date of Charlotte's cancer diagnosis, to mid-April 2015, when this thesis was completed.

Storytelling

Earlier in Chapter 1, as an affirmation of my commitment to analysis, I outline Frank's (2013) narrative typologies as part of a theoretical lense through which I tell and analyse my story. Here what I want to discuss is the importance of storytelling as an effective methodology. It is the work of Carolyn Ellis (1995, 2004, 2007) in particular that convinced me of the power of stories. Ellis combines sociological and anthropological methodology with the personal and the emotional, and fervently promotes narrative and the use of autoethnography in particular. She has written at length about her own various experiences, both on a personal level and in the world of academia. In particular, her work on her partner's chronic illness and death (1995) has had a significant influence on my choice of methodology. Ellis (2004) argues that, in academia, personal stories can be a powerful way of knowing:

Stories and theories have different purposes. Even so, I would argue that a story's generalizability is always being tested -- not in the traditional way through random samples of respondents, but by readers as they determine if a story speaks to them about their experience or about the lives of others they know. Readers provide theoretical validation by comparing their lives to ours, by thinking about how our lives are similar and different and the reasons why. Some stories inform readers about unfamiliar people or lives (...) The focus of generalizability moves from respondents to readers (194-195).

Thus, rather than being generalizable in a traditional sense, stories can be tested empirically by the reader against what they know, have experienced themselves, and can imagine possible. Similarly, while my life is one lived at a particular time and place and under specific circumstances, I do know, for having lived alongside them, that I share a similar story with other parents who

have journeyed through childhood cancer. Readers who have not experienced childhood cancer firsthand will still identify with my story or parts thereof by virtue of being a parent themselves or by knowing someone whose life has been touched by cancer. Therein lies the 'generalizability' of my work, if such a concern need to be addressed. In that sense, Charon (2006) states that "What distinguishes narrative knowledge from universal or scientific knowledge is its ability to capture the singular, irreplaceable, or incommensurable" (45) and that in particular narrative medicine "provides health care professionals with practical wisdom in comprehending what patients endure in illness and what they themselves undergo in the care of the sick" (vii). It is with this in mind that I wish to continue uncovering my story in the chapter that follows. However, before I proceed, a few reflections on my methodology bear mentioning.

Methodological reflections

Reflexivity

To position myself at the center of research is the ultimate exercise in reflexivity. Evidently there are limits to the claims to knowledge which I am able to make. My story is mine, and mine alone. There are as many stories out there as there are people, however similar experiences may be. Moreover, even within my own story, I will inevitably privilege certain interpretations over others. Certain memories will have been erased to the benefit, or at the expense of other recollections. And, to be sure, I will have been tempted at times, or even fallen into the trap of wanting to ignore my weaknesses and failings, and represent myself and my actions in too positive a light. Still, I hope to be able to negotiate the blending of the personal, the emotional and effective analysis with (at least) moderate success.

Vulnerability

Opening up my story will also necessarily leave me vulnerable in many ways. Behar (1996) argues that the only kind of anthropology worth doing is one that leaves both the observer and the reader vulnerable, an anthropology that breaks your heart. Certainly, vulnerability permeates this project. However, I hope I will have heeded Behar's caution that "Vulnerability doesn't mean that anything personal goes. The exposure of the self who is also a spectator has to take us somewhere we wouldn't otherwise go" (1996:14). I have intended on telling the relevant parts of my story through an analytic lens, one that looks past the labels of psychopathology and PTSD and understands the lived experience of a mother. Still, emotion can and should be a powerful tool for an anthropologist, despite the discomfort it may generate, I hope I have made good use of it. Like Behar, (1996) and Ellis (1995, 2004, 2007) I am convinced of the importance of moving my reader to create a shared space of knowing together. Finally, Rabinow (2007) makes an important point regarding vulnerability and answering difficult questions. He states "Rendering things visible and vulnerable, we often forget, is not the same as denunciation" (98). Therefore, while one of my goals is to understand the disconnect between my personal experience and the dominant medical discourse, it is not to denunciate or chastise a medicine and people who have practiced very competent medicine, but rather to comment on the divide which exists between patients and their loved ones and medical professional, in order to bridge it in some small way.

Relational ethics

If I was conducting interviews with other parents of childhood cancer survivors, our relationship would naturally be underpinned by the usual ethical considerations of the informed con

sent and bound by university guideline regulations. It should be noted in fact that this project was the subject of vigorous debate between myself, my thesis advisor, committee members and the University's Ethics Committee. Regardless of the fact that in the end it was decided that no official Committee approval was required, I feel it is still important to address certain ethical considerations which I have kept at the forefront of my mind throughout this process, especially in relation to the telling of a story that belongs in part to my daughter.

Ellis (2007) poses that in autoethnographic research, loved ones and others with whom we are involved in close, intimate relationships are inevitably drawn into our work. Since as (autoethnographic) researchers we write about ourselves, and they are inextricable parts of our lives, we inevitably write about them. She asks the very important question of how do we honour our "relational responsibilities" towards them while at the same time remaining true to our research? Because there is no 'one size fits all' approach in this case, she proposes a "relational ethics", one that "requires researchers to act from our hearts and minds, acknowledge our interpersonal bonds to others, and take responsibility for actions and their consequences" (3). In the same manner, I have been sensitive to the fact that some stories related to my own experience are just not mine to tell. Throughout the process of planning, and writing, I have had several conversations with Charlotte about including her in my narratives. I have explained, in a way that an 8 year old can understand, what I am writing and why, and asked her if she is comfortable being included in the stories. She has usually agreed, and where I felt certain details would violate her privacy, I have left them out. I have read to her the parts I have written that concern her and sought her approval.

Roth (2009) casts the ethics net even wider and states that by virtue of the fact that no life is lived in isolation from others, "all forms of auto/ethnography (...) are inherently ethical

acts” (section 1). That is, we as researchers, have an ethical obligation to all who participate in our research (and our lives), whether in centre-stage or on the periphery. It is for this reason that I include a section addressing participant observation below.

Participant Observation

While participant observation was not part of the ‘official’ design of this research, and thus not “ethically approved” by the University of Ottawa, it should be, at the very least, acknowledged to have taken and be taking place. While in the text that follows I do not quote directly specific individuals, I have been and continue to be a member of the local childhood cancer organization the Candlelighters, as well a member of an online childhood cancer community and discussion groups. My children and I have also been and continue to be involved in various Camp Trillium activities where we play and camp alongside other paediatric oncology families in Ontario. During Charlotte’s illness, I spent countless hours in our local children’s hospital, looking after my daughter, either in the Medical Day Unit or as a ward patient on 4 North, living, participating, and observing alongside other parents who were similarly caring for their sick child, as well as our nurses, oncologists, case managers, dieticians, social workers and many other key members of our care team. As such, my experiences are inextricably linked to these children, families, nurses, doctors and care teams whom we’ve journeyed with. I am part of their story, and they are part of mine. It is part of the “ethnographic imperative that calls for dialogue with ‘data’ or ‘others’” (Anderson 2006: 386) and what allows me to join my personal story to the broader story of childhood cancer.

CHAPTER 3 - LIFE DURING TREATMENT

Pathology was consistent with a peripheral primitive neuroectodermal tumour (PNET) arising within a preexisting cavernous hemangioma. PNET tumours belong to the Ewing's Sarcoma family of tumours and are treated as Ewing's Sarcoma.

— Dr. R, August 13, 2013, letter to our family doctor

Ewings Sarcoma gets its name from the physician who first described it in 1921, Dr. James Ewings. He noted that this bone cancer was different osteosarcoma because it was particularly sensitive to radiation. For several years, it was felt that Ewing's sarcoma occurred only within the bone; however, other tumors were found within soft tissues and determined to be similar under the microscope.

— Janes-Hodder & Keene (2002: 174)

I have triplets. And now a child with cancer.

I chose the stories I tell in this chapter because of the salience of these memories. They are the most salient because of the intense fear I felt in those moments, a haunting fear that usually recalls me far more than I'd like to recall it. The images they've left behind tend to catch me unaware, asleep and while dreaming, or elicited by a sight, sound or smell while awake. These stories are also significant because they are the ones I have told more than once and for different purposes. They illustrate that despite the chaos of illness, I have hung on to our medical team's narrative of restitution (Frank 2013) in trying to cope with fear and uncertainty. And of course, I tell of what happened during cancer treatment because it informs what comes after, and how I continue to cope in the aftermath.

Early attempts to bridge the divide

As I have written this thesis, I have become acutely aware, intellectually, of the divide which exists between ill persons and medical practitioners. However, long before I have been able to articulate it, I have felt it. This experiential divide between our medical team and myself is one I recall trying to bridge, instinctually, from the very beginning. An early conversation with our oncologist comes to mind. Just after Charlotte's diagnosis, while she was in surgery for a lung biopsy, Dr. R came to find us in the parents' waiting lounge near the recovery room on the surgery floor. She sat us down to explain how treatment would proceed, reviewed the roadmap they would be following and outlined some of drugs that would be administered. We'd had a meeting with her before in which she explained our roadmap, and although it wasn't made explicit, I understood the purpose of our meeting that day to be an opportunity for us to voice our fears and concerns and ask questions. Charlotte's father sat in on that particular meeting and asked ques

tions and took notes. Still reeling and not sure I could speak without falling apart, I sat quietly until the end. Finally I did manage to ask her the question that mattered to me most then and there. I asked her if she had any children of her own. She told that me she didn't but that she was no less committed to caring for the children of others and that she would work hard to cure Charlotte. She told us that she was optimistic about a good outcome for Charlotte, that the prognosis for her type of cancer was very good. As we spoke, my eyes bore into her. I believed what she was saying, I needed to. And I also trusted her medical competence. But in that moment, I didn't just want her to see my pain and fear. I wanted her to feel some of it. Right then, I wasn't interested in medical details, drug side effects and success rates, I wanted to connect with her in a way that would affirm her personal commitment to Charlotte not as a case, not as her patient, but as a child whose life mattered greatly to her.

The first chemotherapy

I will never forget the sheer terror I felt, the night Charlotte's first chemotherapy treatment started. Late at night, in the dark of mid-November, probably after midnight, and I had settled Charlotte in her hospital bed and was lying on the cot by the window in her double room. Her oncologist felt that she had recovered enough from her lung biopsy and was anxious to start aggressively treating her cancer.

Chemotherapy can be administered any time of day or night. On the day a patient is set to start a particular course of intravenous drugs, blood and urine samples are taken at regular intervals and sent down to the hospital laboratory for analysis. Once the patient is deemed to be hydrated enough, nurses are given the go ahead to start administering the drugs, not before. That night, we got the go ahead very late.

Charlotte, and the patient we were sharing the room with had gone to sleep, as had her mother on a cot on the other side of the room. The room was dark, except for the green glow of the lights on various IV pumps. A nurse walked in, her footsteps inaudible over the hum of the pumps, and the rustling of her uniform. Over her regular scrubs, she was wearing a full disposable gown and gloves, her face covered by a mask, and plastic shield protecting her eyes. She carried bags of liquid which also seemed to glow - one was red and had a large sticker with a skull-and-bone on it (in retrospect, I recognize that drug as doxorubicin). The other bag seemed to glow green (though again I recognize now that it was a saline solution). Various tubes were dangling from these bags. The nurse hooked the bag with the poison to Charlotte's IV pump and proceeded to attach the tube to Charlotte's central line, under her pajama top. I prayed silently that she would keep sleeping through this exercise and tried to control the terror that was overtaking me. They were going to pump my baby full of poison. My little girl. I wanted to wake up from this nightmare I was having. But I couldn't because it was real. I steeled myself and held on tight to the edge of the cot to contain my urge to scream as my blood ran cold.

13 days of morphine in a 22 day admission

After the first course of chemotherapy, before we were discharged to come home, we were instructed on the secondary effects we could expect in the weeks to come. They included hair loss, loss of appetite and energy, and weakening of her immune system. She would inevitably become neutropenic - meaning that her immune system would not be able to fight off infections because her marrow would stop producing blood cells, and her neutrophil counts would crash. We were under strict instructions to monitor her very closely for fevers. For any fever over 38

degrees celsius, I would need to alert the oncology team, and she would need to be brought straight to emergency, and placed in isolation, night or day.

Coming home that day, I felt more fear than the day, years ago, I had brought Charlotte and her two brothers home from the hospital as 9 day old babies. Though looking back, I'd been terrified then too. In the last days, I'd seen her be violently ill from the chemotherapy drugs in the hospital and already the smell of those drugs had imprinted itself in my mind. Over the next few days, Charlotte would become far more ill than anyone of us expected.

It started the next day with Charlotte complaining of stomach pain. I heated a bean bag, gave her acetaminophen since ibuprofen was strictly forbidden, and called the oncologist when it became clear after a few hours that it would not pass. In fact, Charlotte was describing pain which was increasing in intensity. Our oncologist Dr. R called me back in late afternoon and seemed to know immediately what was wrong. Charlotte was likely having another, more severe, secondary effect which she called mucositis. This is when the mucous membranes lining the digestive tract become inflamed and ulcerated. When I told her I was administering acetaminophen and it was providing no relief, she offered to call in a prescription for morphine in liquid form at our local pharmacy and instructed me on dosing. A day later, Charlotte lay on my bed, writhing and crying in pain, in late afternoon, having had several and increasingly large doses of morphine, as recommended by the oncologist who foresaw the need, with no effect. For the third time in two days I called our oncology team. This time I was told to bring her in to the emergency. As I brought her in, carrying her in my arms, already light as a feather with her gangly six-year old legs dangling against me, I scanned the corridor of the emergency to see if I could locate a triage nurse right away. There was no way I was going to let my daughter, whose blood

counts were rapidly crashing, stand in a waiting area full of potentially life-threatening germs. As I did this and walked past the lineup of other young patients and their parents waiting to be triaged, I was vaguely aware of a few burning stares. It didn't matter, I had stopped caring about what anyone might think.

By the next morning, we had been admitted to 4N (4th floor, North wing), the hospital's oncology ward, and several blood samples had been taken. Charlotte's counts were indeed rapidly plummeting and by the next day she would be neutropenic, feverish and placed in isolation as a precaution. A broad spectrum antibiotic would be administered over 48 hours to ward off any infections. On admittance to 4N, she had also been hooked up to a morphine pump which delivered larger doses of morphine than I could safely administer at home, into her blood stream every four hours. We could also request boluses, a single dose of medication administered all at once, when the pain became too great in between regular doses.

It would take 13 days of continuous morphine to keep Charlotte comfortable while she healed from the mucositis in her stomach. During those 13 days, her blood counts fell and rose again, and soon she was well enough for another round of chemo. Her protocol called for week on, week off for four weeks, to be repeated eight times. The first week were a cocktail of two drugs administered during a two-day hospital admission. The third week, a different cocktail of three drugs was administered over a five-day admission. So the next round of chemo took place over five days, during which time she kept receiving morphine as she hadn't yet recovered from the mucositis. I had asked that this second chemo be delayed to give her time to heal, but our oncology team felt that time was of the essence, her cancer was particularly aggressive and that she was well enough to face a second round. They did their best to reassure me of their decision, but

truth be told, I not only had doubts about whether Charlotte was well enough, I wondered how I would keep weathering this storm. When I asked her oncologist what the risks were in forging ahead, she told me the risks to her life would be greater if we didn't. She told me that over time bodies seemed to adapt to chemotherapy and although Charlotte was having an exceptionally difficult beginning of treatment, it was a good sign. That her body was reacting so violently to the chemotherapy meant that the poison was effective. She told me she was confident that Charlotte's body would adapt as the months wore on, and that our family would find a rhythm which would carry us through to the end of treatment and a bright future. Not knowing what the future held for us, I had to place my trust in her and focus on being Charlotte's mother.

This was also around the time that Charlotte started losing her hair. We were in her hospital bed one day watching a movie and she was curled up against me. When I moved to reposition us, I noticed my sweater was covered in baby fine blond hair, as were her blue flannel pyjamas. The next morning, as I was changing her clothes, her hair was all matted at the back of her head. I had the brush on the night table and I couldn't bring myself to brush her hair. Our nurse walked in. She took one look at me, saw my eyes full of water threatening to spill, and sent me to get a bowl of jello. I stood in the hallway and cried silently for a few minutes. When I came back in, Charlotte was dressed and her hair was brushed. What that nurse did for us in that moment was a blessing. She gave me a few minutes to gather my strength, and took the time to care for Charlotte as a mother would, moreso than a nurse. There would be time later to fall apart. This was not the right time.

This time, because of the longer infusion time for her chemo drugs, her blood counts started falling again before the five days were over. She was still in pain and still receiving regular

doses of morphine around the clock. The chemotherapy has also made her even sicker than the first time. She could keep no food down. And the only reason she wasn't dehydrated was because she was constantly receiving IV hydration. Her antiemetics were increased. In addition to Gravol, she received Ondansetron, Dexamethasone (a steroid), Nabilone (a cannabinoid) and Ativan, around the clock during chemotherapy. With the exception of the Nabilone, all could be administered intravenously through her central line. The Nabilone came in capsules which I would open up and mix with a spoonful of chocolate ice cream and pray it stayed down. The chemo ended, we were still admitted, and now her blood counts were falling again. Soon she would be neutropenic once more. We remained in isolation and our medical team slowly started weaning Charlotte off the morphine to ease withdrawal symptoms.

All in all, that particular admission lasted 22 days, well into the month of December 2012. By mid-December we were finally discharged, only to be re-admitted a few days later for a short two-day chemo cycle. We were then re-admitted again a few days later for febrile neutropenia. With the exception of a day-pass to take Charlotte to see the Nutcracker at the NAC with other patients, Charlotte was admitted until Christmas eve and spent maybe four days at home that month. We went home late that day, celebrated Christmas morning with our boys at home and then we were back at the hospital on Boxing Day for a five-day chemo admission. I looked forward to the New Year and prayed for better days ahead.

Learning to live in a hospital

Those first two months of Charlotte's illness, I felt like I ceased existing in the world outside the hospital. I went in survival mode. While I physically still belonged in the kingdom of the healthy, I felt like I existed more in the kingdom of the sick (Sontag, 1978) or at least someplace

in between. I coordinated care for the boys mostly because I could not be with them. I blessedly found meals left on our doorsteps when I would go home to have a shower. And I traded laundry baskets with my mother in the hospital parking lot. My mother took home dirty laundry to wash it, and I took home clean clothes and refilled drawers and bags for the hospital.

Life in a hospital with a sick child has an interesting rhythm. Isolation was difficult because Charlotte could not leave her room and visitors were not allowed with the exception of a caregiver to provide relief, which usually meant my mother who came to spell me off so that I could go home and shower, or occasionally her father. For me isolation meant peace, quiet and time to be alone with Charlotte without roommates or nurses coming and going at all hours of the night. It meant that when Charlotte slept during the day, I could grab a nap. It also meant I could curl up in bed with her whenever I wanted. Since she'd been born at the same time as her brothers, I'd hardly ever had her to myself and vice-versa.

When we weren't in isolation, we usually shared a double room with another oncology patient. The hospital did their best to pair us with a girl of similar age when possible. Charlotte liked this, not so much because we had roommates, but because it meant that she could spend time in the playroom. And what a blessing the playroom and child life specialists were. That they were able to distract and entertain Charlotte meant so much to me. I alone was not able to bring a smile to her face anymore. I was mom the caregiver, rather than mom the playmate. Sometimes when there were volunteers present, Nancy, the Child-Specialist, would take me aside and talk to me. She offered support, kindness, encouragement and hope. If Charlotte was busy in the playroom and didn't need me, I did not otherwise know what to occupy myself with. I didn't have the attention span to focus on any sort of work. I thought of bringing my running shoes and going for

a run, but it seemed wrong to be focusing on my health when I was so worried about Charlotte's, and frankly I couldn't muster the energy. I was drained. I also found it very difficult to connect with parents of other sick children. My own pain and fear were so raw that I found it difficult to welcome the pain and fear of other parents. I found that in sharing, my own suffering couldn't be lessened, at least at that time. And for these first few months, by refusing to acknowledge my pain and suffering, I could survive, numb in a quasi-denial that would enable me to keep functioning for Charlotte and her brothers. Half of me existed in the present and was busy taking care of the daily business of living, and the other half existed in that hopeful cancer-free future where I'd rebuild our lives.

As much as the world of cancer is rife with analogies of fights, battles and a war against the disease, through these months, I never thought of us as being engaged in a battle. The image of my daughter as a warrior was not one that resonated with me. And for myself, her mother, every ounce of energy I could muster was devoted to supporting my children through this, being strong for Charlotte and trying to find peace and meaning, rather than fighting. Frank (1991) argues that "thinking of tumours as enemies and the body as a battlefield is not a gentle attitude toward oneself and ill persons have only enough energy for gentleness. Aggression is misplaced energy" (85). At that point, I had not yet been exposed to Frank's (1991, 2000, 2004, 2013) writings, but if I had, I would certainly have agreed. It seemed to me that Charlotte needed to use the precious little energy she had to remain the playful child that she was and that likewise, I wanted to make peace with the disease rather than engage in a fight.

Adding a few doses of amphotericin B for good measure

During the diagnostic process Charlotte was x-rayed. The pictures revealed a small nodule on her right lung. There was fear that her cancer had metastasized. This led to surgery for a lung biopsy, before she could start chemotherapy. I remember being under the impression that this was a simple surgery where a small incision was made and a lung tissue sample taken via aspiration with a long needle. This is certainly how it was described to us and they mentioned that at the same time as they did this, they would install her port-a-cath (or central venous access device) while she was under general anaesthetic. A port-a-cath is a small medical appliance placed under the skin where a catheter connects the port to a vein. It is used to deliver drugs to a main artery, to take blood samples and to transfuse blood and plasma (Charlotte received a total of 10 blood transfusions and 4 platelet transfusions). Once the outside needles are in, they can remain in place several days. In cancer patients who take regular doses of drugs and antiemetics and whose blood must be sampled every day, it saves multiple skin pricks and avoids the risks of having veins collapse from the trauma of repeated procedures. Charlotte's was a double port and was installed in her upper right chest. It took me a long time to get used to seeing the protrusion on her little body, and the catheter line run below her skin into her neck. Once treatment was over, it took me as long to stop looking for it, though I was relieved that it was finally gone. Several scars remain on her chest, back and neck, visual reminders of her journey.

After that double surgery, she was wheeled out of the recovery room to a shared room on the orthopaedics floor for recovery. I was surprised and traumatized to see her slight and fragile body attached to chest drainage tubes connected to a drainage canister. I guessed we weren't going home that night for a reprieve before the first chemo. My guess was right. I did not sleep a

wink that night. But, as I listened to the IV pump hum and beep, I lay in the dark and watched the lights on the drainage canister intently, transfixed. Every so often a nurse would come in and note the level of liquid drained from her lungs. How could they have told me this was a simple procedure? For whom was it meant to be simple? Did they see me as fragile and my abilities to cope as limited, thus protecting me from the seriousness of the situation? Or were they simply viewing the procedure in surgical terms, relative to other more complicated procedures?

The lung biopsy in the end would reveal no traces of cancer, but instead residual chest infection caused by a fungus, histoplasmosis, which we suspected was caught playing in the soil to make a garden at our cottage. All of us had had bad colds that summer, which were likely the result of this same chest infection. Charlotte's infection could potentially become active again, and being immuno-suppressed posed a great risk. The Infectious Disease Team was consulted, and they prescribed an indeterminate course of amphotericin B, a potent antibiotic. She was to receive three massive doses a week, until further notice, and be re-evaluated in a few months. Each dose came in a large syringe approximately six inches long with a diameter of almost two inches, and was administered through IV over a period of three hours. This meant that we spent Mondays, Wednesdays and Friday in the hospital's Medical Day Unit, unless we were otherwise hospitalized on 4N in which case she would receive doses concurrently with her chemo. It also meant that Charlotte, even in between chemotherapies, always felt nauseous and unwell. I was now worried about the cancer, the chemotherapy, and the potentially serious side effects of the Ambisome, in particular on her heart and liver. One less serious effect was that it decreased potassium levels in individuals taking the drug. So in addition to all of the other drugs Charlotte

had to take, I had to find a way to get her to take very large potassium capsules. Potassium was added to the schedule of drugs and doses we had to keep track of.

Hematemesis, or Throwing Up Blood

A few months into Charlotte's treatment, just when I thought I was starting to get used to the rhythm of hospitalizations, chemos, febrile neutropenia and trying to settle in to a 'new normal', another event which has engraved itself in my memory occurred. It was on a cold January evening in 2013, not long after Christmas. Charlotte has just been discharged from the hospital after an admission for chemotherapy treatment. I brought her home and ordered a pizza to share. Throughout the duration of her treatment, even in between chemotherapies, it was always so difficult to get Charlotte to eat. The nausea never really went away. She had many food aversions, and found precious few other foods appealing. She went through phases of craving one particular food and would eat almost nothing else. During that particular period of time, she was only interested in pizza. It had to have green olives and bacon on it, the same way I like mine. So that particular night, I made sure to order the pizza just so and, again prayed she would eat some of it.

When it came, we sat down to eat. It was cold in the house and I turned up the heat. I sat with her. While I ate, my heart sank as I noticed her pushing her food around on her plate. I felt so desperate that I used my best persuasion skills and encouraged her. Sadly, I might have also laid a bit of guilt on her. A small child to begin with, by then she had lost more than ten percent of her body weight. She would lose a total of 18 percent during the course of treatment, and by the time it ended she weighed no more than a toddler would at 31 pounds. I was besides myself with worry and always trying to find new ways to get her to eat or absorb some form of nutrition.

That night, it was no use. I could not get her to eat. Tired from not having slept enough while in the hospital with her, and worried, I could feel myself grow more irritated. All of a sudden, she sprang up, pushed back her chair and ran to the bathroom. As I ran after her, I heard the seat hit the back to the toilet, and she promptly threw up. As I bent down to pat her back and flush the toilet, I noticed some red. Having eaten no pizza, there was no mistaking it for tomato sauce. Horror seized my mind and body as I realized she was throwing up blood. Unable to control my terror, and realizing I was scaring her with my reaction, I became angry with myself, which of course upset her even more.

Struggling to maintain composure, worrying that maybe all along the oncologist had missed a tumour in her digestive tract, trying to figure out what to do, a distant part of my mind was calling on me to comfort my child. Unable to be at once calm, nurturing and efficient, I let the anger, the flight or fight response, the instinct for survival take over. It pains me to write that I can't remember uttering any comforting words as I wiped her up, took her back to the dining room and sat down her frail body on her chair. Still angry, I picked up the phone and dialled our oncologist. Of course, she told me I had to return to the hospital. Not thinking rationally, I became more frustrated and angry. Being angry generated more energy to cope and prevented devastation from taking over. All I wanted was a quiet night at home with my daughter, safely tucked away in her bed. Why, for once, could I not have that?!

After unpacking our suitcase and re-packing it with clean pajamas and clothes, I did take her back to the hospital that night and she was re-admitted to the oncology ward. She underwent more imaging tests, which by then we had both become accustomed to. As it turns out, she had developed ulcers in the lining of her stomach from the potassium tablets she had to take. She was

prescribed a medication to heal and protect her stomach and weeks later, once her potassium levels neared normal again, the tablets were discontinued.

Fortunately, the outcome of this event did not confirm the worst fears that had formed in my mind that night. However, the horror and guilt have stayed with me. I can close my eyes and in an instant be transported back to that moment in time.

This is an event I have told and retold. First I remembered it for myself, without sharing, with great shame at having gotten angry at my daughter for being ill. Then I told it in a paper as part of coursework in one of my master's seminars, in the hopes that by putting it out there and owning my shame, I would be able to exorcise it from myself, perhaps forgive and free myself from the trauma. In May 2014, I again shared it in a paper I read at the Canadian Sociological Association conference. As I now tell it again, I realize that I have yet to let forgiveness visit to me. Cancer did not make me a better person in that moment and more than two years later, hot shame, and the pain of not having been able to comfort my daughter still wash over me when I recall that night.

Sleepless Nights

Having a child in chemotherapy is not unlike having a newborn, at least where sleep is concerned. While admitted in the hospital, my nights were sleepless for a variety of reasons. The noise: IV pumps beeping relentlessly; nurses who were unconcerned about the need for quiet; and patients using washrooms several times a night. Chemotherapy patients are given increased fluids during chemo drug infusions so that their kidneys will flush the medicine to avoid increased toxicity. For Charlotte, this was a challenge, in particular at night. Some of the antiemetics she was given made her drowsy or induced deep sleep, in particular the Gravol and Ativan. I

had to keep an eye out to make sure she woke up to use the washroom and then had to help her get out of bed, holding her steady, while making sure the IV lines did not tangle and making sure to drag the IV pole behind us. During chemo treatment, urine output had to be measured and reported to the nurse who would make sure that this corresponded to the level of hydration the patient was receiving. I had to wear gloves and mask to wash out the “nuns cap” (measuring container placed beneath the toilet seat which Charlotte urinated in), but before I could do that, I had to wash Charlotte and return her safely to bed. If I accidentally slept through (less likely to happen) and forgot to wake her, or if she had to go again soon after and we did not get up quickly enough (more likely to happen), one of two things would happen and did happen regularly: a nurse would wake us, or else Charlotte would wet the bed. This usually meant Charlotte had to be washed and changed from head to toe. Her urine with chemo drugs was very toxic (hence the gloves and mask I had to wear) and could quickly burn her skin. Once that was done, the nurse and I would temporarily settle her in my makeshift chair bed while we changed her bedding together. We would then resettle her, hopefully for the rest of the night. I always kept a fiction book with a tiny book light in my overnight bag. Nighttime was the only time I could read and maybe manage to focus on a few pages. There was a blessing in being able to keep the worry demons at bay during the hours they were most likely to torment me.

If Charlotte was well enough to be at home, nighttime provided little more respite. Discharge in between chemotherapy treatment meant that I got to take home a child who required 24 hour care. Her counts were rapidly falling and neutropenia for Charlotte inevitably meant a fever, regardless of whether she was actually fighting an infection. The fever would come on just as her counts were crashing and then remain for a few days. In the beginning, I would bring her to

emergency, as instructed and she would be admitted, isolated and treated with a broad spectrum antibiotic.

However, as treatment progressed, I discovered that her fevers did not necessarily mean serious infection as I'd been taught. I realized, giving her tylenol for pain relief after surgery to remove the tumour that it also brought her neutropenic fevers down. By then, Charlotte's morale was falling as rapidly as her blood counts did between chemos. She missed her brothers, her school and her friends. She was tired of living in the hospital. Frankly, living in the hospital was also taking its toll on me and I too missed the boys terribly. I also wanted to be able to take care of Charlotte at home, where at least we could be comfortable, in familiar surroundings. So when I knew her counts were falling and the telltale fever would appear, I would give her a dose of Tylenol and then monitor her every half hour to see if her temperature kept rising or for other signs of infections. If it did, I would take her to emergency, if not, I'd keep monitoring her. This meant that through the nights, I would get up regularly to check on her to make sure she wasn't febrile. These nights reminded me of when she and her brothers were small babies and I would be up all night feeding, changing and rocking them.

Low blood counts also meant daily injections of GCSF (granulocyte colony stimulating factor), a drug that stimulated her marrow to produce blood cells. In the beginning I categorically refused to do these at home. Not because I was afraid or squeamish (though I could be for other things), but because I wanted to be that person who only brought her comfort, not more pain or anxiety. Eventually, realizing that having a nurse visit everyday was too much of an intrusion on our already strained family life and that other patients probably needed this resource more than us, I relented when Charlotte assured me that she preferred me to do it.

These injections are meant to be given using small needles (the type used for insulin injections) in the fatty part of an arm, leg or even in the belly. For Charlotte this was problematic because at six years old she weighed less than a healthy toddler and was increasingly frail. All I could ever pinch was skin. Every day we'd go through the ritual of skin numbing with lidocaine cream, cleaning, dosing the medication carefully and injecting. She carried on bravely while I cried inside looking at her bruised and marked arms, willing the cancer to go away.

The End of Treatment

The end of cancer treatment is typically marked by the “ringing of the bell” tradition. In the Medical Day Unit at the hospital, once a child’s treatment is officially over, nurses, oncologists, child life specialists, secretaries and whoever else is present gather to watch the child ring the ceremonial bell and the moment is celebrated enthusiastically with cheers and applause. Child and parent are congratulated. For me, this moment was intensely anticipated, even more so than the moment I gave birth to my three children. Going into labour, I felt incredibly ill, tired, overwhelmed and scared. As Charlotte rang the bell, in contrast, I was overwhelmed by gratitude and excitement for a bright future. I had been told repeatedly through treatment that this moment was the moment we were all working towards and should keep our sights on. Now we were being congratulated and celebrating the end of treatment. We could finally have our lives back. I had taken our medical team’s restitution narrative (Frank 2013) and was incorporating it the story I was telling myself about our future.

On that gorgeous sunny early summer day, I made sure she wore her sunhat before we came out. Chemo makes the body ultra sensitive to sunlight and UV rays, she also had skin graft on her face which needed protection from the sun. I held her small hand, still smiling, as we

walked through the hospital parking lot. Her counts were still low, but given that we were now at the end of June, we had all summer at home together while she regained her strength. In the Fall she would head back to school, but before then, in August, we'd be going to Camp Trillium as a family, Charlotte, the boys and me for a bit of special vacation. During treatment, this was the horizon I had kept looking toward. And it was the horizon I was encouraged to focus on by our oncologist, by the social worker, by Nancy, the child life specialist on 4N whom we had befriended. She was very special to Charlotte, as was Molly Penny, the resident clown. Throughout Charlotte's hospitalizations they both would almost quite literally do hand stands and move heaven and earth just to get a smile from Charlotte. They made quite the pair and were essential to Charlotte's health and recovery throughout her many hospitalizations. As I buckled Charlotte in her booster seat that day, I knew that the next time we'd be back it would only be for a quick visit with Molly Penny and Nancy and, though we'd miss them and their antics, that thought was more sweet than bitter.

CHAPTER 4 - LIFE AFTER TREATMENT

We spent some time talking about the chemotherapy that Charlotte has received (...) With regards to ifosfamide and cyclophosphamide, the doses that Charlotte received may impair future fertility (...) With regards to etoposide, the major long-term complication is the small risk of a secondary leukaemia (...) With regards to doxorubicin, the main side effect is cardiomyopathy, which can occur many years after treatment. Charlotte received a relatively high dose of doxorubicin (...)

— Dr. R, August 13, 2013, letter to our family doctor

So treatment is over, now what?

The first month after Charlotte was home for good was a busy but blissful one. The chaos of treatment and hospitalizations gave way to the busyness of rebuilding family life. In mid-July, she returned for day surgery at the hospital to remove her port-a-cath, and the boys were on summer holidays and involved in various camps. Charlotte's appetite and enthusiasm for food was slowly returning, and I was enjoying having her all to myself while the boys played at camp. Charlotte and I read books, gardened, crafted, visited grand-parents and shopped for groceries where she delighted in picking new foods to try. I also started entertaining the idea of returning to my studies and reworking my thesis project.

On August 2, 2013, we met with Dr. R for our 'end of treatment' meeting. While Charlotte was present at that meeting, it was a very different occasion than the ceremonial ringing of the bell. It was at this moment that my unbridled optimism started to crack. Dr. R went over each of the drugs Charlotte received during treatment and their long-term effects. To be fair, I was very aware during treatment of all the drugs and doses being administered and their side effects but during that time my focus, encouraged by our care team, was getting through treatment. I knew also of other risks as Charlotte's heart and kidneys were regularly monitored for damage. And I knew of the potential impairment of her future fertility. Our medical team had always been very frank in discussing treatment and effects and were always willing and available to answer questions and concerns. Still, perhaps through my own failing, and because perhaps I had been far too willing to hang on to our medical team's message that we would get through this and face a bright future at the expense of a more balanced view, I missed performing the mental task of

aligning future risks and possibilities alongside the excitement and relief that our suffering was finally ending. In the end, although both messages were presented by the care team, my sense is that the message of optimism and the importance of looking to the end was dominant in our ongoing discussions, and thus very powerful in offering me something to cling to amidst the chaos of illness. It offered relief from the daily worries and Charlotte's suffering which I found difficult to bear.

At the end of that meeting, Dr. R handed me a letter which contained all of the details we had just discussed. This 3-page letter was addressed to our family doctor and I was to keep a copy for our files. We would need to provide this letter to any new family doctor that would see Charlotte in the future. There in black and white, were the details of diagnosis, procedures performed, treatment protocol followed and hospital admissions for febrile neutropenia and adverse reactions. It contained information on future risks of leukaemias, kidney, heart and fertility impairment. And so it was, that my daughter was becoming well again, but it was not over.

Camp Trillium

Our experience at Camp Trillium a few weeks later provided me with a short reprieve in facing the return of some of my fears and having to face the emotional effects of cancer. The Camp is a registered charity which operates at two main sites in Ontario and brings current and former oncology patients and their parents, as well as bereaved families together for a camp experience. When I made the decision to attend with my children, I thought it would be a great way to celebrate the end of Charlotte's treatment and provide a fun, safe vacation for all three kids. With Charlotte still recovering, I felt comfort in knowing that the camp has medical staff on site

and that she wouldn't be exposed to any illnesses, since anyone with even a common cold is turned away to protect patients. My expectations were met, and beyond.

When we arrived by boat on the island with other families, our very own three 'special friends' singled us out of the crowd, introduced themselves, picked up our bags and took us to our cabin. When we arrived to our room, our door was adorned with a huge poster welcoming each of us by name. For the next five days, our three 'special friend' camp counsellors quickly taught me how to let go. They took charge of the children, entertained them and got them involved in activities. In the beginning my instinct was always to make sure I was looking after the kids, but our special friends made sure that I understood their job and passion was my kids and their wellbeing, and my job was to have fun myself and watch my kids have fun without worry. Most of the time I was free to join in the games or take some time for myself to read, go for a run, socialize with others or even have a nap. Towards the end, I was so relaxed that I managed to forget Charlotte's dose of Septra (she remained on antibiotics for 6 months after treatment to protect her fragile immune system) one day. When I remembered in the early evening, I went to find her in the activity hall and she told me that the camp nurse had already been there a little earlier to give it to her.

The gift that Camp Trillium gave me was the best one I could have received that summer and frankly, that I have ever received. To be able to watch my children laugh, play and be themselves, without the distraction of organizing, putting on sunscreen, drying their clothes, brushing their teeth and getting them ready for bed, making and cleaning up meals or doing any kind of work at all gave me such joy. For the first time in their lives, I was completely focussed on enjoying them enjoying themselves, something I had never been able to do before. When they were

babies as small children, I had always been too focussed on (and most times overwhelmed by) making sure all of their needs were met to be fully present in the moment. As we returned home from Camp Trillium, I still wasn't completely aware of what was to come.

The First 3 month check-up

The following month, Charlotte was already due for her first three-month checkup. This meant a CT scan, an MRI, blood counts, urine sample and an afternoon at the hospital with our time split between the imaging department and Medical Day Unit. Early September was busy with all of us returning to school. It seemed like I barely had the time to blink and it was already time for Charlotte's first checkup.

When we headed into the hospital that day, I already knew my way around too well. We checked in in MDU first, then went to imaging for her CT scan. We recognized the technicians and they were happy to see Charlotte looking much healthier already, but the procedure was otherwise uneventful. Then we headed to the MRI department. Again, we recognized a few of the staff as we checked in. I changed Charlotte in a gown, took off my watch, bracelet and earrings and locked them in a locker with our bags. We then waited patiently in the adjacent hallway and I recalled with mixed emotions all of the previous times we'd been there, the trauma of finding out her MRI a year earlier was abnormal and subsequent cancer news. I was becoming uneasy.

When it was our turn we were called in and as always, I went in with her. I helped her on to the sliding table outside the machine. The technician placed a warm blanket on her and adjusted a mask and earphones so that she could watch her movie while inside the machine. Charlotte's MRIs usually lasted about 45-50 minutes. One time, around the time of her diagnosis, it lasted over an hour and half because the radiologist requested a second set of pictures after seeing the

first ones. That time, I stood by the outside of the machine motionless, holding Charlotte's foot so that she would know that I had not left her. It is only since she has been off treatment that she is comfortable with me sitting in a chair at her feet, without touching her. Usually I always had to keep my hand on her foot or leg for the duration to keep her calm.

On the day of her first 3-month appointment, the technician gave me the usual pair of hearing protection headphones to wear and left the room, closing the heavy door behind her. From the next room she would operate the machine and watch the images being taken on a screen. While the headphones help protect our hearing, the sound an MRI machine makes is incredibly loud and remains audible despite being muffled. MRI machines bang, groan, hum and at times squeek as though they have a large bird trapped inside. The sounds patterns alternate and quite often will be interspersed with a distressing sound resembling a very loud alarm. Though they have since been renovated and relocated, at the time the hospital had two MRI rooms. One of them was smaller, cold, dark and windowless. It was there that Charlotte's MRI was taking place that day.

As soon as the door closed behind the technician, I felt like the air drained from my lungs. The machine's humming and chirping became louder. Gasping for breath and chilled to the bone, I suddenly panicked as I thought to myself, "oh God, please, please don't let there be anything on those pictures." The book I had brought with me lay in my lap. My eyes closed, tears threatening to spill, I tried focussing on the sound of the machine, willing my consciousness to be lulled and dulled, instead of being terrified. I bargained with the universe. "No more cancer please. We can't take any more of it. Please let me have this time to gather up my children and find peace again, please. And, if anyone has to be sick, please let it be me."

The second 3-month check-up

Needless to say, this time, after that experience, I saw our second 3-month checkup coming from a mile away. It was scheduled for mid-December 2013 and by late November, I was having regular nightmares or else just waking up in the middle of the night, cold, sweaty, terrified and unable to fall asleep again. The bargaining started again. This time I asked the universe the gift of my daughter's health for Christmas.

By the time our appointment rolled around, I was a nervous wreck. I was dreading the appointment, and at the same time it couldn't come soon enough. I tried to prepare myself for the MRI machine. Still. Same effect. Same terrorizing fear. I tried to tell myself that it was just anxiety. And that I could manage it. Breathe. Be still. Find calm. I couldn't. Weeks later I would find great comfort in Audrey Lorde's (1984) words:

But fear and anxiety are not the same at all. One is an appropriate response to a real situation which I can accept and learn to work through just as I work through semi-blindness. But the other, anxiety, is an immobilizing yield to things that go bump in the night, a surrender to the namelessness, formlessness, voicelessness, and silence (14).

But for now I had to get through this. And find a way to get through many more. Because it wasn't over. And it wasn't about to be.

After the MRI that day, when we saw the oncologist and she asked us how things were going, I decided, impulsively, to be very honest. I told her that Charlotte, despite my heightened awareness of her every bruise, scratch or little cough, was doing great. But that I had been a major wreck these last weeks and that frankly I hadn't anticipated feeling this anxious, sad and even angry. I told her about the nightmares, the fears that never really went away. And she told me that I was experiencing what many, if not most parents experience post-treatment. She said that some

parents were even diagnosed with post-traumatic stress disorder and that I shouldn't be afraid to seek help, that what I was going through was normal. As I looked at her, searching for clues of if and how I could have missed any of this before, what I wanted to say was: "Wait a minute, why didn't anyone tell me about this?! Is that what you meant when you said our lives would be normal again?" What I did instead, was sit quietly and take it in, so that I could go away and think about it.

Over the next weeks, I needed to get to the bottom of this. I read study upon study on familial and parental adjustment after childhood cancer. I felt somewhat better. My fears were validated and I wasn't alone in my experience. Great. However, if what I was experiencing alongside other parents was "normal" and not uncommon, then why label this a stress disorder? And what was 'normal'? How we lived life before cancer? Or how we were having to adjust to a new life now? And did I really need to seek more medical attention to learn to cope with what was happening?

Dreaming while asleep

Fast forward to April 2014, just after Charlotte's third three-month checkup and another clean bill of health. I was in the bathroom upstairs getting ready. Kayla, our babysitter and piano teacher extraordinaire who came a few mornings a week to help out, was downstairs giving the boys breakfast and packing their lunches before giving them their piano lesson. I was distractedly running through a mental list of things to do that week — get the winter tires changed on our car, meeting at the bank, a doctor's appointment for Charlotte, a progress report for the university, a poster to prepare for the Canadian Anthropology Society conference and a paper to submit for the Congress at Brock in a few weeks-- while becoming irritated overhearing the boys'

shenanigans at the table downstairs. This layer of irritation was adding to a distress that had been brewing since I woke up. Why was I so bothered I wondered? I took a breath to steady myself. As I was leaning into the mirror getting ready, I suddenly realized it wasn't myself I was seeing. It had come back to me. A flash of the dream I had woken from an hour earlier.

In the dream, I was standing just inside the doorway of a hospital room in the oncology ward at the hospital. Charlotte was standing next to me and we were holding hands. Lying in each of the beds was one of my boys. They were both undergoing chemotherapy and they had been there for a couple of days. While my heart was heavy and the familiar fear squeezing my rib cage, I manage to marvel to myself how well they were both doing. Neither of them had thrown up so far. But I felt torn looking at them from the outside. I wanted to sit with each of them and take care of them. But how could I stay here at the hospital when I also had Charlotte to look after? How was I going to manage this time?

Preoccupied with visions of the hospital room still in my head and trying to make sense of them, I walked out of my bathroom. Suddenly, Charlotte jumped out from hiding behind the doorframe, terrifying me. I shouted at her: “Don’t you EVER scare me like that EVER again, do you understand me?!” The look of glee on Charlotte’s face quickly turned to surprise and then dismay, and she ran to her room. My heart felt like it was going to beat out of my chest, and I could hardly breathe. Just a few days before, Charlotte pulled the same trick on me and we all had a good chuckle together when I jumped back, startled. Now she was in her room crying and I was trying to catch my breath and calm the fear.

I went in, sat on her bed and pulled her close to me. How was I going to explain my reaction this time when we had such fun together a few days before? “Charlotte, I’m sorry. I’m not

angry at you. I just got scared. I already had scary thoughts in my head and you startled me” I said to her. “What were the scary thoughts mommy?” she asked. Unable to tell her the truth, I said the first thing that came to my mind: “Oh, just that some burglars tried to break in our house”. A terrified look came over her face. “But don’t worry Miss Boots. That would never happen. We have an alarm system, remember? And you know our pup Stella would protect us.”

Dreaming while awake

In the last 20 months or so, I have had more than my fair share of nightmares, all variations on the theme of cancer, illness, danger of harm to Charlotte and her brothers. But not all nightmarish visions have taken place asleep. One late evening last fall, as I was getting ready for bed, I walked across the upstairs hall to go into the boys’ bedroom, before going into Charlotte’s, for a final kiss goodnight. I knew the kids were all sound asleep but it didn’t matter, that good-night kiss was for me. I still don’t know the reason why I stopped dead in my tracks just outside the bathroom before making it to the boys’ room, and instead looked into Charlotte’s room first. Maybe some familiar sounds caught my attention; a sigh and some rustling of blankets. Maybe it was a smell, toothpaste and Biotene. Or a familiar movement, caught from the corner of my eye. Maybe it was an electric current in the air, caused by a convergence of all three.

In that moment, I stood there, and I was transported back to a time when Charlotte was very ill. I was seeing her frail little body, a tiny, fragile mound under the blankets. I saw the pale almost translucent skin on her head, her soft cheeks and delicate features. I stood rooted there, feeling the need to wake her to take her temperature but unable to move.

“Mom, mom.” A gentle whisper. “Mom!” The voice, still whispering, grows louder. A hand takes mine. Startled, I looked down. My son John, who had gotten up to use the bathroom,

asked me what I was doing. I told him I was coming to give everyone a last kiss and he asked me if I was OK. "Yes I am John, I promise."

Anniversaries

Hallowe'en and November 1st have become sad and conflicted anniversaries. That they are sad, is perhaps not such a difficult thing to understand. They are conflicted in that I've wondered and struggled with whether I am allowed to feel grief and sadness on those days, and whether I should instead be celebrating on those days, as we celebrated that day in June when Charlotte's treatment officially ended. After all we have been incredibly blessed that Charlotte is well again. I have not lost a child as others have. While I have not marked those anniversaries openly, so far, each year those dates have still filled me with sadness and a sense of loss.

October 31st, 2012 was the first holiday the children and I spent without their dad, and I took them out to Trick or Treat with some dear friends. I remember that night, the children were so excited to see Hannah and Sarah, my friends' teenaged daughters. We had pizza at their place before going out and the girls helped me get my kids ready. I was so glad for their help. Charlotte, having had her biopsy a few days before, still had a bandage covering part of her cheek. At that point however, the tumour had grown so much in size that its mass was unmistakable behind the bandage. Towards the end of our evening, just before heading back, we knocked on a door. As all three children stood in a row in front of the door with the older girls behind them, my friend Kathy and I stood back a few feet. A man opened the door and greeted the children. His gaze settled on Charlotte's face for what seemed a long time. Becoming aware of the presence of adults and perhaps made uncomfortable by realizing that he was staring, the gentleman said jokingly "poor child! Does your mother beat you?". I stood there, wordless, feeling like I had been

sucker punched. I am grateful to this day to my friend Kathy for having had the presence of mind to say “No, she just had a biopsy”, after which the man apologetically gave us his best wishes. In retrospect, I have enormous empathy for that gentleman who made the mistake that most, if not all of us make at one time or other, of saying the wrong thing at the wrong time. But that moment has become engraved in my memory because it holds so much symbolism and because of the gravity of the news we would get the next day. Now, October 31st and November 1st represent clear fault lines in my life as an adult, and as a mother.

The rubble cancer leaves behind

One marker of the before and after of cancer, is the rubble that it leaves behind, both figurative and literal. Emotionally, I am left with some rubble to clear away and some experiences to make peace with, made all the more salient by the unexpectedness of my experiences. And quite literally, there remains, to this day, physical rubble to clear in our home. Earlier I refer to Jain (2013) and how the description of her own rubble prompted me to realize that I was still hanging on to a collection of Charlotte’s drugs, both in the refrigerator. In the beginning, I resisted throwing away, or returning to the pharmacy some very expensive drugs, telling myself that I would check with the hospital to see if another patient who needed them could use them. We were lucky that most of Charlotte’s drugs were covered under a medical insurance plan. Had they not, we would have faced costs of at least \$2,000-\$3,000 every month. Thus I wanted to make sure that what was left, unopened and unexpired could still be put to good use. When I couldn’t find any recipients, I told myself that I would return the drugs to the pharmacy. However, for every trip I made to the pharmacy to have Charlotte’s antibiotics refilled for the first six-months of remission, I left the drugs behind. I had GCSF in the refrigerator. And in our lunch container cupboard

under the counter, I had on the top shelf a Rubbermaid tote containing: 2 (full) biohazard safe needle containers, Prevacid tablets, Ondansetron oral solution and tablets, bag full of unused 3ml syringes, Nabilone tablets, box of alcohol sterilizing pads, potassium chloride tablets, ClearLax powder, bag of insulin syringes, liquid acetaminophen, morphine (both liquid and tablet form), Emla lidocaine cream, instant protein powder and a drug calendar. In fact, for the first time in almost two years, I removed this tote to inventory the contents for the above list. As I did, the memories flooded back.

Why have I been hanging on to those items? When will I be ready to let them go? I know that regardless of the answers to these questions, I can't wait until I stop being afraid of relapse, otherwise the medications will keep gathering dust forever. I can accept now that life isn't what it was, and won't ever be the same.

Seeking meaning

Hanging on to rubble. Terrifying dreams. Haunting memories. Reliving traumatic moments. Ongoing fear, grief and sadness. And then the label of post-traumatic stress. What should I make of it?

As I've kept trying to make sense of what we've lived through these last few years, the literature on parents' experiences post-treatment has been enormously validating. For one, I've never been overly confident as a mother, and I've had far too many moments where I've second guessed decisions I've made and wondered if they were 'good enough'. From talking with friends of mine who are also mothers, I understand that feeling of not being 'enough' is likely a common one during motherhood. However, from birth there are unique challenges to raising three small children who are the same age. Thus, my feelings of not having enough, being

enough, giving enough, have been a steady presence since their birth. Finding out that other parents have experienced the same distress and challenges in coping in the face of childhood cancer has at least reassured me that my coping skills were and are adequate. However, the label of PTS or even PTSD, in this particular instance, is not one that I am willing to embrace, or even willing to accept. To accept this label would imply that I am problematizing, and pathologizing my suffering in the face of Charlotte's illness. Instead, I consider my suffering, and my experiences post-treatment to be reactions to an extraordinary set of circumstances. Problematizing this very human experience would not lead me to make sense of our journey or make peace with how the disease has changed our lives.

Beyond PTS

The work of Arthur Kleinman has been instrumental in helping me articulate my thoughts on why the label of PTS makes no sense to me. Kleinman (1995) examines how biomedicine is practiced, and distinguishes between disease and suffering, and treatment and healing. He argues that, in biomedicine, the goal of treating disordered biological processes leaves little space for physicians to recognize, or at least acknowledge in a truly meaningful way, the human suffering engendered by the disease. He outlines cases where patients' psychological and moral suffering becomes "euphemized" (35) and reinterpreted as a psychiatric condition to be medicalized, and how "an existential experience of tragedy and loss is reconstructed as a professionally managed experience of major depressive disorder (ibid)". In this instance, Kleinman makes an important distinction between necessary intervention with a patient who is in deep distress and whose condition can and should be medically treated in instances of clear diagnosis. But more importantly, what he does is

call into question the practice through which the suffering that is part of a serious medical disorder is reinterpreted as depressive disease so that an institutionally efficient fix (a drug) can be applied in the place of a humanly significant relationship of witnessing; affirming, and engaging the patient's and the family's existential experience. That the professional transmogrification of suffering is problematic is seen when virtually all seriously ill medical inpatients can be made to fit the American Psychiatric Association's official diagnostic criteria for major depressive disorder on account of the psychophysiological effects of their heart disease or cancer or their treatment. That is, the suffering of patients has been medicalized, inappropriately, into a psychiatric disease (36).

I wholeheartedly agree with Kleinman's assertions, and in light of the extensive literature on parents' traumatic experiences during and after childhood cancer treatment, I would extend his arguments to these parents. Suffering in the face of an illness, should not be considered an illness itself. I could accept a diagnosis of cancer, and the need for immediate and aggressive medicine for Charlotte on the basis of very tangible images and laboratory results indicating the presence of cancer cells. Similarly, under very different circumstances, I might be inclined to accept a diagnosis of mental illness depending on the evidence presented to me. But in this instance, what I could not accept was another medical label for a such a fundamentally human kind of suffering. The kind brought on by witnessing my own child suffer through cancer and illness.

Kleinman (2006) is similarly emphatic. He recognizes more broadly our human suffering in the face of illness as he states:

Perhaps the most devastating example for human values is the process of medicalization through which ordinary unhappiness and normal bereavement have been transformed into clinical depression (...) That is, suffering is redefined as mental illness and treated by professional experts, typically with medication (9).

Schweitzer et al. (2012), who have used interpretive phenomenological analysis of parental experiences of childhood cancer would also agree. They critique studies on parents' experiences post-

treatment which draw on traumatological literature. They make two points: the first is that they fail to “recognise the fundamental differences between trauma and the experience of having a child diagnosed with cancer” (705). And the second (citing Bruce 2006) is that the findings from these studies tend to be inconsistent. Without wanting to delve too deeply into analysing the differences between trauma, and being a parent of a childhood cancer patient, I can say that while there were very intense and traumatic moments during Charlotte’s illness, I do agree with the authors who outline that the major difference “pertains to the nature of cancer where the sense of threat is quite different to that associated with trauma more generally (705)”. Arguably, and despite the war metaphors, journeying through cancer with your child is very different than being a soldier at war.

Wanting to make sense of my experiences has led me to look beyond labels rooted in psychopathology. I have wanted to look beyond what medicine has to say about how parents experience childhood cancer and beyond. What did my human suffering, my grief, sadness and my fear, mean to me as I tried to rebuild our lives after cancer? It had felt good to hang on to the hope and optimism proffered by our medical team, and perhaps they had been right, that I needed it to function as a mother should to care for my child. However, there came a time to be honest with myself and others. The suffering hasn’t ended with the end of the chemotherapy and the pronouncement of remission. At best, remission feels like the liminal space that Stoller (2004) describes. A place in between our previous life and towards an uncertain future. I feel as Stoller (2004) and Lorde (1980), that “Like superficial spirituality, looking on the bright side of things is a euphemism used for obscuring certain realities of life, the open consideration of which might

prove threatening or dangerous to the status quo” (74). I have been drawn to a more honest and balanced view of our future.

In chronicling how ordinary people and their families live with illness and personal and medical catastrophes, Kleinman (2006) points out that “neither of my professional backgrounds as anthropologist or psychiatrist prepares me with the technical terms and professional theories to deal with this core human condition” (161). I would similarly argue that being a mother does not prepare you for parenting and journeying with your child through cancer. Likewise, by virtue of their training, medical practitioners are generally not prepared to witness in the suffering of the human psyche and the emotions engendered by disease. By holding out much hope and unbri- dled optimism for the end of treatment, medical practitioners obscure and can make more painful, albeit unwittingly, the reality of life after childhood cancer. Now, as I face our future, I must tame my fears and make peace with uncertainty. I have come to find Lerner’s (1978) words oddly comforting: “If you want to survive horror, you have prepare yourself for the worst. Feel it through, live it through in advance. Then if it does not happen, you’re ahead. If it does, you can bear it” (37).

CONCLUSION

I have learned that the changes that begin during illness do not end when treatment stops. Life after critical illness does not go back to what it was before. A danger of allowing physicians to dominate the drama of illness is that they leave as soon as the disease is resolved to their satisfaction or when they have done all they can. Then the ill person and those around him are left to deal with the consequences of what has not been recognized.

— Frank 1991: 57

Comment donc refermer ce qui s'est ouvert avec le diagnostic? Que faire de la question insistante: «Est-ce terminé; cela va-t-il recommencer?» Il faut souligner l'importance dans ce processus de la parole du médecin (...) Cette parole vient boucler un cycle (mais non pas clore une histoire, ni une relation).

— Oppenheim D. et al. 1995: 268-269

Concluding thoughts

As I conclude this project, I reflect on what started with a goal to understand the disconnect between what I was led to believe would happen after my daughter's cancer treatment and what I was actually experiencing. I realize that during a process that was lonely and at times painful, I have managed to reach beyond this goal, and started to make peace with a disease that has redrawn the map of my life even though I do not yet fully understand its meaning. In this conclusion, I sum up my arguments and findings, discuss a few limitations of this project and I offer thoughts on future directions, both personal and for paediatric oncology.

In the first chapter, I used Kleinman (1988) to first distinguish illness from disease and sickness, and pointed out that illness is the lived experience of coping with symptoms, and distress engendered by disrupted physiological process. I then started to sketch out a theoretical framework through which I could analyse my own experiences of illness. I did this by looking at how anthropologists Stoller (2004), Frank (1991) and Jain (2014) have lived through cancer and beyond. Reading them helped crystallize my understanding of how cancer is viewed and lived in a Canadian hospital for children, and how that framed my experiences of illness and expectations regarding how health is restored. I argued that the prevalence of the war metaphor in cancer mediates the experience of being ill and expectations of becoming well again. I then reviewed the extensive literature on parents' experiences of childhood cancer extensively to be able to situate myself. What I found was that my experiences were not unlike that of other parents. In fact, most parents continue to experience trauma, grief and pain well beyond the end of treatment. This led me to question why, if this was such a common phenomena, why was it so unexpected for me? Why had I not been prepared for what came after? Why did our doctors and healthcare team fo

cus only on getting us to the end of treatment, when in reality that wasn't really the end? I showed how part of the answer lies in how the medical community views disease and how medicine is practiced — with a goal of eradicating the disease rather than healing a person. I also argued that our care practitioners had a vested interest in keeping me optimistically focused on the end of treatment. As I did that, I became, in their eyes, a better mother to Charlotte, and their ally in caring for her.

Finally I again drew on Frank (2013) and explained how his medical narrative typologies could be useful to my analysis. I argued that while the narrative I heard during treatment was a narrative of restitution, my experience was that of chaos. And as I sought to understand our journey, my own narrative would become at once restitutive, chaotic and questful. Like Frank (2013), I argued the importance of narratives; both the narratives I heard and internalized, as well as what my personal narrative could contribute. It is in that spirit that I offered my own autoethnographic story.

Telling stories about the self, within a broader agenda of connecting our experience to the social and cultural is what autoethnography does. As a method of inquiry, I highlighted how it was well suited to analysing my journey through childhood cancer and beyond. In writing about and analyzing the events that marked me during treatment and how I have continued to live with the fear, grief, sadness and even anger they have left behind, I have argued that while our health care team was caring in their manner, and efficient in their delivery of medicine and support to our family, they missed an important opportunity to prepare us for what came once treatment had ended and Charlotte was in remission. I have also argued that what is most useful to me as I try to rebuild our lives is finding meaning in what has happened to us, rather than labelling residual

fears, grief and trauma as PTS. Finally, while there is an abundant literature on parents' experiences after cancer treatment which points to ongoing distress, there is a gap that remains regarding the role that practitioners in oncology might play in supporting families and parents through and especially after childhood cancer. I suggest that in addition to approaching this need for support from a psychosocial perspective, and developing and promoting coping strategies, health practitioners have an important role to play in witnessing the human suffering of families and preparing them for what happens after treatment has ended.

Limitations

Evidently, there are limitations to this project. By using only my own experiences as primary data, the claims of knowledge I can make are restricted to what I have experienced, in the time and place that I've experienced it. My story, though some features of it may be shared with others', is unique in many ways, and thus not generalizable in the traditional sense. Furthermore, despite extensive record-keeping and journaling, memory is not an infallible tool. In recalling events, I may have inadvertently omitted certain facts. And in my analysis, I may have privileged certain interpretations over others. Still, my hope is that I will have offered an honest, if partial representation of what it is like to be the mother of a childhood cancer survivor.

Final thoughts — What medicine can learn

If medicine cannot describe the actual experience of illness, it can benefit from the narratives being shared by patients and their families. This is the main argument made by practicing family physician, Rita Charon (2006). Charon, who is also trained in literary studies, has witnessed the divide that exists between a patient and his family and their physician. She points out that "a scientifically competent medicine alone cannot help a patient grapple with the loss of

health and find meaning in illness and dying” (3). She acknowledges that though health care professionals may be knowledgeable regarding disease and competent in their practice of medicine, they nonetheless do not generally entertain the very human experience of illness, the fear and rage for example, from the patient’s point of view. This speaks to the divide I have described in earlier chapters and attempted to bridge in various ways.

Charon (2006) proposes narrative medicine to help bridge that divide. In doing this, she distinguishes narrative knowledge from scientific knowledge. While scientific knowledge strives to make discoveries about the natural world which are universally true, narrative knowledge enables us to understand particular events in a particular individual’s life and the meaning he attaches to them as they affect him. Thus “Nonnarrative knowledge attempts to illuminate the universal by transcending the particular; narrative knowledge, by looking closely at individual human beings grappling with the conditions of life, attempts to illuminate the universals of the human condition by revealing the particular” (2006:21). An ability for a physician to hear the narrative and comprehend with, and through it, is at the heart of sharing the experience of illness together.

Physician and anthropologist Arthur Kleinman (1995) argues that the divide between physicians and patients (and their families) exists because practitioners of biomedicine are trained to treat diseases and faulty biological processes rather than heal persons, and that as a result, there is very little space in the physician-patient relationship to share in the human suffering that illness presents:

That serious illness involves a quest for ultimate meaning is disavowed. Because of distrust of qualitative interpretations and concomitant emphasis on quantitative data, the biomedical framework accords no legitimacy to values. Hence the practitioner of

biomedicine must struggle to practice competent biomedicine, while at the same time searching for some extra-biomedical means to authorize the professionals's empathic response to the patient's and family's moral needs to have a witness to the story of suffering, to find support for the experience of illness, and to collaborate with others in the struggle to fashion a meaningful interpretation of what is at stake for them in their local world (32-33).

Frank (2004), also acknowledges the divide that exists between ill persons and their medical practitioners, and agrees with Kleinman (1988) who asserts that because of it, medicine and medical treatment are demoralizing (128). While Kleinman makes uses of various illness narratives to demonstrate the suffering of patients, Frank presents a more philosophical argument to support the role of narratives in medicine.

Indeed, Frank (2004) argues that illness presents an occasion of generosity for both patient (and I would add family as well) and practitioner. He defines generosity as the "resonance of touch, endowing the act with a capacity to give beyond its practical significance" (6) and argues that "There is no reason why the skilled touch cannot also be generous. On the contrary, true skill has to include generosity" (ibid). He explains that "medical hospitality" (3) is an early ideal of medicine in which medical practitioners would welcome ill persons not only to be treated medically, but to be cared for and healed in their relationship with the practitioner, and was based medicine's dedication to reducing suffering. It was an act of generosity by both the patient who, in his vulnerability, welcomed treatment and by the practitioner who welcomed the patient, not only with his medical skills, but with moral sensitivity. However, modern medicine and its emphasis on biomedical models, efficiency and practicality of treatment pose an obstacle to hospitality in the relationship between patient and practitioner more often than not. Stories and narratives are key in illustrating how true healing benefits from generosity. In *The Renewal of Gen*

erosity, Frank (2004) gathers stories of generosity “to show how these stories ought to count for more people, more of the time” (4).

Generosity in medicine, as a clear philosophical concept, was not something I was paying any particular attention to during Charlotte’s treatment. Nonetheless, I can easily recall a number of instances where a nurse’s or physician’s touch went beyond physical skill and kindness. It is probably the one which has marked me the most in our journey, and inspired me to keep sharing, likely because it has occurred in the last nine months, while I’ve been focussed on writing this thesis, and reflecting on Frank’s (2004) thoughts.

Since Charlotte has been off-treatment, we visit the Medical Day Unit every three months and Charlotte undergoes regular MRIs, CT scans, x-rays and bloodwork, and again, we may see different oncologists depending on who has follow-up clinic duties that month. For the last two three visits, we have seen Dr. M From what I know of Dr. M she is also mother. She is gregarious, patient, and very skilled at engaging Charlotte to talk. She supervises residents and I suspect she must be very busy, like the rest of the staff in the unit, although she always takes as much time as we need to consult with us. She has patiently answered my questions and even re-answered them when I’d forgotten answers or wanted to be reassured from one visit to the next. Without a doubt she is a skilled oncologist. But what has made her generous in my eyes, is her ability to take the time to ask me how I was doing, and listen. She has thoughtfully considered and accepted what I have said about having mixed feelings after the end of treatment, feeling unprepared and how I worry about the future. She has managed to connect with me not only as an oncologist-patient’s mother, but beyond her kindness and skill in practicing medicine, she has taken the time to share in some of our suffering.

Perhaps Charon (2006) says it best: “Medicine can benefit from learning that which literary scholars and psychologists and anthropologists and storytellers have known for some time—that is what narratives are, how they are built, how they convey their knowledge about the world, what happens when stories are told and listened to, how narratives organize life, and how they let those who live life recognize what it means” (9).

Looking to the Future

The ultimate meaning of our suffering, beyond the clichéd renewed appreciation for my family, still eludes me some days because I have found it hard to accept being powerless as I saw my child suffer through a life-threatening illness. I also still find our uncertain future hard to accept but I have been committed to making peace with whatever lies ahead.

In Chapter 3, I admitted finding it difficult to connect with other parents during the time Charlotte was sick because my pain was too raw to be amplified by someone else pain. And, in these last paragraphs I have made a final point regarding a role that oncology practioners might play in witnessing the suffering that families undergo during childhood cancer. But reading and re-reading Frank (2013, 2004) and Kleinman (2006) has caused me to reflect on the role I might play as well as I continue researching the effects of childhood cancer on families. Both authors draw on philosopher’s Emmanuel Lévinas’ ideas on the ethics of suffering to argue that witnessing should come before studying and analysing, or as Kleinman explains: “the ethical precedes the epistemological, that acknowledgement and affirmation of the other precedes inquiry (...)” (234). One of my goals all along has been to pursue a PhD and further research. For practical reasons, and to support my family, seeking employment has become pressing. But beyond those reasons, an ethical understanding of my own suffering has motivated me to take a detour en

route to a PhD, to complete another master's degree, this time in spiritual counselling. I am excited to be headed to St. Paul's University this Fall where I plan on continuing to learning with medicine and hope to learn to accompany parents and families who journey through childhood cancer and other life-threatening illnesses.

Epilogue

*I took my love and took it down
I climbed a mountain and I turned around
And I saw my reflection in the snow-covered hills
'Till the landslide brought me down*

*Oh, mirror in the sky, what is love?
Can the child within my heart rise above?
Can I sail through the changing ocean tides?
Can I handle the seasons of my life?*

(Nicks, 1975)

April 2015

This project, while focussed on healing as a parent and family after childhood cancer, has been, admittedly, all along part of a larger process.

As I sit at the dining room table, with the furnace humming in the background, the kids are tucked away in bed and our new family retriever, a young redhead named Stella is warming my feet. I flip through the folders of chapters, all neatly organized on my computer's desktop and prepare each of them, one by one, for submission as that Whole that we call a Thesis. I sigh, bone tired, and just then an electronic copy of the court order for my divorce catches my eye.

I realize that while I felt somewhat misled by our oncology team with regards to what happens after childhood cancer, they at least gave me (very literally, if not figuratively) a roadmap on how they would heal my Charlotte's little body, and remained true to their promise. Beyond that, it has been up to me to heal myself and my family from the illness.

I can see now that my expectations of myself in the last two years have likely been unjust and disproportionate to the challenge that lay ahead in November 2012. It's become clear in the last months, that while considering all of the ways in which I could continue journeying with childhood cancer, and equipping myself with courage and resilience, I failed to realize that I also needed to make a roadmap for myself for healing after divorce.

In the same way that the oncology team protected me from the future so that I could deal with the present and (in their eyes) function as a parent should, I had, all along denied myself the opportunity to mourn a marriage that I felt was, if not openly, somewhat secretly toxic. First because I was too busy caring alone for a child with a life-threatening illness and her brothers, and because after I was too busy trying to cope with the aftermath of childhood cancer and gathering

my kids close to me. What I had missed, in that mayhem, was the need I had to mourn the loss of my family as I knew it and as I had expected it to remain, for better or worse, in illness and in health. Another journey begins.

REFERENCES

- Anderson, Leon. 2013. "Learn by Going" in *Handbook of Autoethnography*. Holman Jones, Stacy, Tony Adams and Carolyn Ellis. eds. 2013. Walnut Creek CA: Left Coast Press Inc.
- Anderson, Leon. 2006. "Analytic Autoethnography". *Journal of Contemporary Ethnography*. 35 (4). 373-395. Andrews, Molly, Corinne Squire and Maria Tamboukou. eds. 2013. *Doing Narrative Research*. Thousand Oaks: Sage Publications Inc.
- Atkinson. Paul. 2006. "Rescuing Ethnography" in *Journal of Contemporary Ethnography*. 35 (4): 400-404.
- Behar, Ruth. 1996. *The Vulnerable Observer*. Boston: Beacon Press.
- Chang, Heewon. 2008. *Autoethnography as a Method*. Walnut Creek CA: Left Coast Press Inc.
- Charon, Rita. 2006. *Narrative Medicine, Honoring the Stories of Illness*. New York: Oxford University Press.
- Coffee, Amanda. 1999. *The Ethnographic Self*. London: Sage.
- Dixon-Woods, Mary, Bridget Yound and David Heney. 2005. *Rethinking Experiences of Childhood Cancer: A Multidisciplinary Approach to Chronic Childhood Illness*. New York: Open University Press.
- Ellis, Carolyn. 2007. "Telling Secrets, Revealing Lives: Relational Ethics in Research with Intimate Others". *Qualitative Inquiry*. 13 (1): 3-29.
- Ellis, Carolyn. 2004. *The Ethnographic I*. New York: Altamira Press.
- Ellis, Carolyn. 1995. *Final Negotiations, A Story of Love, Loss, and Chronic Illness*. Philadelphia: Temple University Press.
- Ettore, Elizabeth. 2005. "Gender, older female bodies and autoethnography: finding my feminist voice by telling my illness story". *Women's Studies International Forum*. (28): 535-546.

- Fletcher, Paula C. 2011. "My child has cancer: finding the silver lining in every mother's nightmare". *Issues in Comprehensive Nursing*. 34: 40-55.
- Fletcher, Paula C. 2010. "My child has cancer: the costs of mothers' experiences of having a child with paediatric cancer". *Issues in Comprehensive Nursing*. 33: 164-184.
- Frank, Arthur W. 2013 (1995). *The Wounded Storyteller*, 2nd Edition. Chicago: The University of Chicago Press.
- Frank, Arthur W. 2004. *The Renewal of Generosity: Illness, Medicine and How to Live*. Chicago: The University of Chicago Press.
- Frank, Arthur W. 2000. "The Standpoint of Storyteller". *Qualitative Health Research*. 10 (3): 354-365.
- Frank, Arthur W. 1991. *At the Will of the Body*. Boston: Houghton Mifflin Company.
- Gannon, Susanne. 2013. "Sketching Subjectivities" in *Handbook of Autoethnography*. Holman Jones, Stacy, Tony Adams and Carolyn Ellis. eds. 2013. Walnut Creek CA: Left Coast Press Inc.
- Goldenberg Libov, B. Nevid J., Pelcovitz, D. and Carmony T. 2002. Posttraumatic stress symptomatology in mothers of pediatric cancer survivors. *Psychology and Health* (17): 501-511.
- Green, Judith and Nicki Thorogood. 2009. *Qualitative Methods for Health Research* Second Edition. Washington: Sage.
- Holman Jones, Stacy, Tony Adams and Carolyn Ellis. eds. 2013. *Handbook of Autoethnography*. Walnut Creek CA: Left Coast Press Inc.
- Jain, S. Lochlann. 2013. *Malignant, How Cancer Becomes Us*. Berkeley: University Of California Press.

- Janes-Hodder, Honna and Keene, Nancy. 2002. *Childhood Cancer, A Parent's Guide to Solid Tumor Cancers*. Sebastopol (CA): O'Reilly.
- Kelly, Daniel et al. 2004. "Being in the same boat: ethnographic insights into an adolescent cancer unit." *International Journal of Nursing Studies*. 41: 847-857
- Kids Cancer Care Foundation of Canada web site: <http://www.kidscancercare.ab.ca/childhood-cancer/stats>
- Kleinman, Arthur. 2006. *What Really Matters*. New York: Oxford University Press.
- Kleinman, Arthur. 1995. *Writing at the Margin*. Berkeley: University of California Press.
- Kleinman, Arthur. 1988. *The Illness Narratives*. n.c.: Basic Books.
- Lorde. Audre. 1980. *The Cancer Journals*. San Francisco: aunt lute books.
- Maurice-Stam, Heleen, Frans J. Oort, Bob F. Last and Martha A. 2007. Grootenhuis, "Emotional functioning of parents of children with cancer: the first five years of continuous remission after the end of treatment" *Psycho-Oncology*. 17: 448-459.
- McKenzie, Sian E. and Christine Curle. 2012. "The end of treatment is not the end': parents' experiences of their child's transition from treatment for childhood cancer" *Psycho-Oncology*. 21: 647-654.
- Murphy, Robert F. (1987) 1990. *The Body Silent*. New York: W.W. Norton.
- Nader, Laura. (2012). "Ethnography as Theory". *Journal of Ethnographic Theory*. 1 (11): 211-219.
- Nancarrow Clarke, Juaane (with Lauren Nancarrow Clarke). 1999. *Finding Strength: A Mother and Daughter's Story of Childhood Cancer*. Don Mills: Oxford University Press.
- Norberg, Annika Lindahl, Ulrika Pöder, gustaf Ljungman, Louise von Essen. 2012. "Objective and subjective factors as predictors of post-traumatic stress symptoms in parents of children with cancer - A longitudinal study". *PloSONE*. 7 (5): e36218.

- Oppenheim, D., Y. Bruno, D. Grujard, J. Lemerle. 1995. "Fin(s) de traitement et guérison". *Arch. Pédiatr.* (2): 267-272.
- Papaikonomou, Maria. 2007. "Childhood cancer: a parent's perspective on social support, with a case illustration". *Journal of Child and Adolescent Mental Health.* 19 (1): 65-73.
- Rabinow, Paul. 2007. "Anthropological Observation and Self-Formation" (ch. 4) in *Subjectivity*, Biehl, J. et al. Eds., Berkeley: University of California Press.
- Richards, Rose. 2008. "Writing the othered self: autoethnography and the problem of objectification in writing about illness and disability". *Qualitative Health Research.* 18 (12): 1717-1728.
- Roth, Wolff-Michael. 2009. "Auto/Ethnography and the Question of Ethics". *Forum: Qualitative Social Research.* 10 (1): art. 38
- Sontag, Susan. 1978. *Illness as Metaphor*. New York: Farrar, Straus and Giroux.
- Stoller, Paul. 2004. *Stranger in the Village of the Sick*. Boston: Beacon Press.
- Stuber, Margaret. 1995. Stress Responses to Pediatric Cancer: A Family Phenomenon. *Family Systems Medicine.* Vol. 13: 163-172.
- Stuber, Margaret L., Sandra Gonzales, Kathleen Meeske, Donald Guthrie, Beth Houskamp, Robert Pynoos and Anne Kazak. 1994. "Post-traumatic stress after childhood cancer II: a family model". *Psycho-Oncology.* (3): 313-319.
- Tsimcalis, Argerie, Patricia McKeever, Tricia Kavanagh, Bonnie Stevens. 2006. "The costs children incur during treatment for cancer: a neglected area in theory and research". *Journal of Child Health Care.* 10 (20): 111-125.

Van Dongen-Melman, J.E.M.W., F.J. Van Zuuren and F.C. Verhulst. "Experiences of parents of childhood cancer survivor: a qualitative analysis". *Patient Education and Counselling*. (34): 185-200.

Woodgate, R.L. 2006. "Life is never the same: childhood cancer narratives". *European Journal of Cancer Care*. 15: 8-18.

Zebrack, Brad et al. 2002. "Mothers of Survivors of Childhood Cancer: Their Worries and Concerns". *Journal of Psychosocial Oncology*. 20 (2): 1-25