

RECONSTRUCTING EXPERIENCE OF CHILDHOOD CANCER:  
A NARRATIVE INQUIRY

by

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A Thesis Submitted in Partial Fulfillment  
of the Requirements for the Degree of

Master of Health Sciences

in

The Faculty of Health Sciences

Program

University of Ontario Institute of Technology

December, 2016

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## **AUTHOR'S DECLARATION**

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## ABSTRACT

### RECONSTRUCTING EXPERIENCE OF CHILDHOOD CANCER:

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Many childhood cancer survivors experience long-term effects from their illness long after their treatments are over. In order to more fully understand the impact these effects have on a young person's life, there is a need for more patient illness narratives. Using Connelly and Clandinin's Narrative Inquiry methodology, I explored the experience of a young adult survivor of childhood cancer. My co-participant and I engaged in narrative interviews and creative self-expression activities. To reconstruct and critically examine the story of her childhood cancer experience, I used two theoretical frameworks, Erikson's (1968) Psychosocial Stages of Development and Cellular Memory, based on Porges' Polyvagal Theory (1995). The narrative patterns that emerge are: *relationships*, *identity* and the *embodied experience*. The co-participant's story is re-presented in a letter, accompanied by a poem, addressed to healthcare professionals. Implications for healthcare practice include the need for increased sensitivity to patient's lived experience of the illness. More specifically, there is a need for further education of healthcare professionals on the long-term effects of childhood cancer that include mind-body-spirit.

**Key Words: Narrative Inquiry, Childhood Cancer, Patient Illness Narrative**

## ACKNOWLEDGEMENT

First and foremost, I want to thank my parents, Thambiah and Savuntharadevi Thavakugathasalingam, along with my sisters and brothers-in-law. Your love and support were my light during the darkest and hardest moments during this journey.

To my two wonderful co-supervisors, Dr. Otto Sanchez and Dr. Jasna Schwind: I am greatly indebted to the both of you for your wisdom, encouragement and belief in me. Your teachings have a permanent place in my heart.

I want to thank my committee member, Dr. Hilde Zitzelsberger, for providing insightful feedback, even when time was short.

My sincere thank-you to Dr. Gail Lindsay for introducing me to Narrative Inquiry, which allowed me to honor the experience of childhood cancer in a scholarly context.

I want to thank my external examiner, Dr. Rick Vanderlee, for a stimulating discussion and a refreshing perspective.

To my wonderful co-participant, Noelle: I want to thank you for sharing yourself with me. Your story is the soul of this thesis. As I pursue different avenues in research, I will carry your stories with me, which have enlightened me in many ways.

I also want to thank my wonderful Narrative Inquiry Works-In Progress Group: Louela, Victoria, Nicole, Neelam, Poonam and Elizabeth. Our discussions fostered the initial seed of growth as a researcher for me and I am very grateful!

Finally, thank you to all my friends, whose encouragement and support extend beyond the last two years. I am lucky to have a wonderful cheer squad!

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## **DEDICATION**

This work is dedicated to:

Thambiah S. and Savuntharadevi Thavakugathasalingam

My past, present and future

To Pranavan, Thavappiriya, Thaneshkumar, Baviththira, Prashath and Suganya

Who inspire the best version of myself

and

To Noelle

Whose story will forever be intertwined in my own as I go on ...

Thank you!

## Prologue

*We come into the world intent on finding narrative in everything,  
In the landscape, in the skies, in the faces of others, and, of course  
in the images and words that our species creates.  
-Alberto Manguel –*

I have always been inspired by books. At the age of four, my mother introduced me to the library and I was fascinated! I began to read many different genres. These many pages taught me how to imagine. Soon, it became easier for me to imagine the situations people experience, to imagine how big the world is and the vast possibilities in each of us. I learned, I was inspired by, and I developed from interacting with the varied characters I encountered from these books.

For me, my inquiry into childhood cancer experience, came to resemble a beloved book in a library, where I enjoy spending time, reflecting on and learning from the storied events I encounter there. For this reason, I structured my inquiry using the metaphor of a library, each chapter representing a section of the library, and my co-participant's illness story, as a book in my favorite section, Biographies...

## Chapter One: Circulation Desk

### Introduction

*Every Story I create, creates me.  
I write to create myself.  
- Octavia E. Butler –*

*Paidia Gia Vivliothiki, the children's library is a historic-looking building. I open the doors and walk up the marble stairs. In my brief observations, the library is decorated with Baroque stylings. As I make my way to the top of the stairs, I come face-to-face with the circulation desk. Here, I learn the history and stories that inspired the reasons for creating this library and what is to follow in this expedition.*

The above quote by Octavia E. Butler illustrates the importance of our autobiographical stories, which allow us to understand who we are in the present moment. Pratt (1991) suggests we start with ourselves and our different versions, “the one who has been hurt, the one who has worked hurt on another, the one who has despised, the one who has gloried in another and in her self” (p. 219). In Narrative Inquiry, “identities have histories” (Connelly & Clandinin, 1999, p. 95), implying both origin and opportunity for change. In the “stories we live by”, our multiple identities emerge. The phrase, *stories we live by* is used by Connelly & Clandinin (1999) in Narrative Inquiry to refer to emerging identity. It aligns with the narrative pedagogy of the dualistic relationship between context and knowledge (Connelly & Clandinin, 1999). Multiple identities are used because individuals are “somehow or other different people at work from who they are at home or at a social gathering, with their children, and so on” (Connelly & Clandinin, 1999, p. 95). In re-telling, re-living and thereby, by reflecting on these stories, different facets of a situation are illuminated (Connelly & Clandinin, 1999).

In respect to the above notion, I recall four particular experiences in my life that have inspired me, like classic literature encouraging aspiring authors, to explore the experience of childhood cancer using Connelly and Clandinin's Narrative Inquiry. Each story stands on its own and yet, is connected to the others.

## **My Story**

### **Story 1: Children as individuals**

Since a very early age, I have been fortunate to be respected, heard and seen by healthcare professionals who cared for me.

Dr. David walks the patient he just saw out and looks at the next folder on the table. I am four years old and with my mom to receive my vaccination.

He calls my name and smiles. Dr. David is a very friendly man. When we sit down, I tell him I don't like needles. He gently holds my arm and says, *It'll be good.* He asks me questions about school, my teachers and friends.

In answering his questions, I don't notice the needle. As he says, *All done!*

I smile and say, *I didn't feel it!*

At a young age, my doctor provided me with a comfortable and safe space to express my opinions and fears. My doctor addressed me directly. As I grew older, I internalized the importance of listening to children.

### **Story 2: Making Sense of Death**

When I was school aged, I made sense of health, illness, and death in my own unique way. I believed the little bubble I lived in with my family would last forever.

I am six years old. I have a diary with purple letters that emphasize 'My Diary', and with my added notation in black permanent marker, 'Private

Property.’ One day, before I could stop it from happening, my sister took my white plush diary from where it was resting. I knew she was going to share with mom and dad what I had written: “I wish me and my family were happy, healthy, always living and always together.” It was my prayer. I would repeat it in the morning, at the temple and before bed. I believed that if I said it often, it was more likely to come true.

My parents call me from the living room. I slowly make my way in, not wanting to explain my prayer. I nervously sit on the couch across from them. I am scared of how they will react, but also embarrassed that my secret prayer was out. Surprisingly, my parents do not look upset. They explain life and death in Tamil (our mother tongue): “Death is also a part of life. Even if we are not with you, it does not mean that you should not be happy.”

This conversation stayed with me throughout my experiences in life. I was fearful of confronting death, but have since become interested in how we come to terms when we face potential death at a young age.

### **Story 3: Meeting Sadako Sasaki**

Then one day, I confronted death through Sadako Sasaki, the protagonist in Eleanor Coerr’s (1977) *Sadako and the Thousand Paper Cranes*. Meeting Sadako brought a deeper appreciation of what confronting death at a young age could be like, instilling in me a passion for personal illness stories of young people living with cancer.

The only thing I looked forward to in grade seven English was free reading periods during our library visits. Eleanor Coerr’s book in hand, I

sit across my friend in the tables that seat four. Sadako reminds me of me. She is an excellent runner and an enthusiastic student. As Sadako's doctor diagnoses her with Leukemia, I feel upset and angry. Life has cheated Sadako. To me Sadako feels like a friend or a family member that I cannot help. I feel uncomfortable and fearful of her journey. I adjust my seat and continue reading till the end. "[S]he thought more about death. Would she live on a heavenly mountain? Did it hurt to die? Or was it like falling asleep...Death crept back into her mind" (Coerr, 1977, p. 60-61). My heart skips a beat. Sadako voiced my own thoughts as she faced death. I don't hear the clock ticking or the conversations nearby. Wiping uncontrollable tears streaming down my cheek, I look at my friend. She asks what happened. I nonchalantly say, "*Sad book.*" It wasn't just a sad book. It was the reality of life. The two extremes: the living and the dying. Sadako changed how I understand life and death, "She was part of that warm, loving circle where she would always be. Nothing could ever change that" (Coerr, 1977, p. 63). The first image that appears in my mind as I close the book is the yin and yang symbols used in Chinese philosophy: Death and life are complementary.

As I re-open the book, twelve years after my first interaction, nothing has changed. Sadako's experience is as haunting now as it was to my twelve-year-old self. How does the young individual experience all of this? His or her world is changing at both an unexpected way, and at an uncontrollable rate. My experience has since moved from being an internalized question to one that has shaped this inquiry puzzle.

Above stories reveal how I came to situate myself within my inquiry puzzle on childhood cancer experience. The next story reveals how I chose Connelly and Clandinin's (1990) Narrative Inquiry qualitative approach to explore this phenomenon.

#### **Story 4: The Importance of our Stories**

In my community health class, we were asked to present our proposals, allowing colleagues the opportunity to be familiar with the different research scopes. Prior to going up, I feel anxious. As I present my proposed study, my professor points out the unique difference in my presentation style and that of my classmates, "a natural storyteller." (MT, journal entry, September 28, 2014).

This feedback inspired me to reflect on how I could connect my passion for reading and my research interest. I reflect in my journal:

The scope of pediatric oncology research is missing a critical piece of the puzzle. The picture is blurry because it is often seen from the outside. Someone who sees a lake will describe the picture, but someone who is at the lake will make you feel as if you were there as well. This story is missing in the literature on pediatric oncology. The stories of illness of children having to experience and live with cancer. Stories are a natural way to reflect on our experiences and so make sense of them (MT, journal entry, September 28, 2014).

Connelly and Clandinin's Narrative Inquiry (1990) is informed by Dewey (1938), who claims that experience, which is both continuous and interactive, if intentionally reflected upon, is a source of education. "Deliberately storying and restorying one's life

is, therefore, a fundamental method of personal (and social) growth. Narrative research can only build on this process of growth” (Connelly & Clandinin, 1990, p. 11). The process of reflective restorying, then, is essentially educational.

To understand the experience of childhood cancer, I chose to explore the illness story of my co-participant Noelle, whose life confronted cancer and the accompanying changes it introduced. Noelle was thirteen when she was diagnosed with cancer (Meeting #1 with Noelle, May 3 2016). Dismissing her pain as yet another bladder infection, the reality of her diagnosis did not sink in until the hospital became her second home. Noelle experienced physical changes (hair loss, lack of appetite, fatigue) and the emotional realities (isolation from friends, loneliness, and change in family dynamics) that cancer brought into her life. Even after surviving, she continues to live with cancer (Meeting #2 with Noelle, May 10 2016) because in her words, “it is never really gone.”

### **Statement of Study Purpose**

The purpose of this Narrative Inquiry is to gain a deeper understanding of how adolescents may experience childhood cancer.

### **Inquiry Puzzle**

How do young adults reconstruct their experience with childhood cancer?

This thesis is a Narrative Inquiry into Noelle’s experience with childhood cancer. In learning how Noelle’s illness is shaped by her life story and how the illness in turn shapes her life as a person and later as a professional, give us an opportunity to gain a deeper understanding of what it means to be an adolescent patient from her perspective. My inquiry aims to contribute to the paucity of personal illness experiences of childhood cancer survivors and so emphasizes the importance of this gap. The words in my study

are addressed to healthcare professionals, as well as family members and individuals diagnosed with a serious illness, who can reflect on my research and draw meaningful interpretations relevant to their own life situations. Finally, I hope readers of this work are able to bring their own connections and conclusions reflective of their personal life experiences into a process of entering into narratives of a childhood cancer survivor that is insightful, meaningful and transformational for them.

### **What is to Follow ...**

“The story is not in the plot but in the telling. It is the telling that moves” (Le Guin, 2015, p. 123). As the quotation illustrates and is in agreement with Connelly and Clandinin’s Narrative Inquiry, I use present tense, except in Chapter Four, where I discuss the Inquiry Process and Chapter Eight, where I consider implications of this inquiry to healthcare practice, education and research. Present tense gives the immediacy that Noelle’s story deserves (Langacker, 2001). It also ensures that as the inquirer, I remain close to the experience of childhood cancer, the phenomenon under investigation.

Also, I refer to Noelle as co-participant, rather than participant throughout this inquiry process. Co-participant is terminology used in Narrative Inquiry, as it underlines the co-creation of knowledge that occurs between the participant and the researcher. This relationship that weaves understanding and knowledge together not only prompts the researcher to become a participant in their own research, but acknowledges the participant as a contributor to making meaning of their stories (Clandinin & Connelly, 2000).

Moreover, I capitalize Narrative Inquiry throughout the thesis to distinguish Connelly and Clandinin’s methodology from other forms of narrative inquiry (Lindsay &

Schwind, 2016). All names and places are fictionalized to protect the privacy of my co-participant. Each chapter begins with a description reflective of my metaphoric library expedition to embody the focus of the chapter. I briefly outline the focus of each chapter below using my metaphor of a library expedition. I call this library, Paidia Gia Vivliothiki, Greek for, Children's Library.

In Chapter One, the Circulation Desk, I've come to understand the library's roots and inspirations. Why was this library built and for whom? Here, we have heard my stories, the ones I live by. We briefly meet a beautiful biography of a young woman, Noelle, who experienced childhood cancer that I discover on this expedition.

In Chapter Two, I explore the History Section. Here, I review relevant scholarly literature on childhood cancer and acknowledge the need for more such stories of illness from the perspective of the young patients who experience it.

In Chapter Three, the Archeology Section, I explicate the theoretical and philosophical underpinnings of Narrative Inquiry qualitative research approach. By understanding the methodology and its roots, the reader is better equipped to join me on my scholarly exploration of childhood cancer as experienced by a patient.

In Chapter Four, the Geography Section, I detail the study design. That is to say, I outline how I uphold Connelly and Clandinin's (2006) seven considerations for Narrative Inquiry, including rigour, reflexivity, and ethical considerations.

In Chapter Five, I move from the bookshelves to the reading circles to visit the Biography Section. Here, I present Noelle's story, interspersed with my spontaneous responses to her experience. This is the first level of analysis, Personal Justification.

In Chapter Six, the Education Section, I explicate the two theoretical frameworks, Erikson's Stages of Psychosocial Development and The Polyvagal Theory, which I use to make sense of Noelle's experience.

In Chapter Seven, I visit the Philosophy and Psychology Section. Reflecting on the sections explored earlier, here I use the two theoretical lenses and analyze Noelle's experience in light of scholarly literature. This is the second level of analysis, Practical Justification.

Chapter Eight, the Social Studies Section is, for me, the soul of the library. Here, new materials are considered in light of the social implications and benefits of this inquiry. The heart of this inquiry is the reconstruction of Noelle's story, the narrative. In particular, I consider the implications this research could have for healthcare professionals, education and research. This is the third level of analysis, Social Justification.

I book-end this inquiry with a prologue and an epilogue.

As Connelly and Clandinin (1990) articulate, our narratives are already in progress and through interactions, narratives intertwine and connect with one another in time, place and relationships. I hope, dear reader that, as you experience this thesis, you are prompted to reflect and make meaningful connections with your own personal and professional experiences.

## **Chapter Two: History Section**

### **Literature Review and Synthesis**

*As I leave the Circulation Desk, I recognize that this is a unique library. I feel an instant connection. I have always been inspired by books and the wisdom they hold. Excited to discover other sections of the library, I walk over to the History Section and begin there. In this section, I discover the scholarly literature and specifically research done on childhood cancer: What has been explored? What do we know so far about this phenomenon? I wonder, what, if anything, has been written about the personal illness experiences of these children.*

In Chapter Two, I review and synthesize existing literature on childhood cancer, in healthcare, psychology and beyond. This supports my rationale in undertaking this Narrative Inquiry at the second and third levels of justification, the practical and the social respectively. These levels are defined in detail in Chapters Three and Four.

#### **Background Information: Childhood Cancer Overview**

Childhood cancer is a cancer diagnosis given to individuals aged zero to fourteen years of age diagnosed with cancer (DeSantis et al., 2014; Oeffinger et al., 2006). In the 1950s, less than ten percent of the children diagnosed with cancer were cured (Mertens et al., 2001; Ghaderi et al., 2016; DeSantis et al., 2014). Today, approximately eighty percent of the children survive (Mertens et al., 2001; Ghaderi et al., 2016; DeSantis et al., 2014). Federally-funded clinical trials, focused on treatment, are being conducted on an ongoing basis by the Canadian Cancer Trial Group, a group that conducts trials to improve treatment and prevention of cancer (Oeffinger et al., 2006). However, there are still important gaps (Ward, DeSantis, Robbins, Kohler & Jemal, 2014). One in five

children will not survive their cancer diagnosis. And two-thirds of the childhood cancer survivors will develop at least one chronic or long-term effect of cancer (DeSantis et al., 2014). While some cancer diagnoses, such as brain tumors, are still too aggressive and difficult to treat, other forms of cancer, such as leukemia, are treatable. However, what researchers conclude with treatable cancers is the invasive treatments influence the development of long-term effects that impact the quality of life for these children (Ward et al., 2014). Long term effects can range from infertility, due to the impact of chemotherapy and radiation, and second cancers that may arise later in life (Mertens & Marchak, 2015; Psych, 2015). The confidence levels of many children who experience cancer are also impacted, because individuals assume these children always require assistance (Gibbins, Steinhardt & Beinart, 2012). Wicks and Mitchell (2010) write that often, while the body is debilitated by cancer, many children feel debilitated by lack of psychosocial autonomy.

I arrange the extracted scholarly literature thematically: perceptions of the self, loss of control, coping, positivity, cultural influence, benefits of cancer camps, and future implications of childhood cancer.

### **Perceptions of the Self**

The body undergoes physical changes due to cancer. Many children experience weight loss, hair loss and fatigue (Oeffinger et al., 2006; Hokkanen, Eriksson, Ahonen, & Salanterä, 2004; Gray et al., 2014). In having experienced such drastic changes, several young patients change their perception of the self. They perceive an obvious difference between themselves and their healthy peers. In recognizing these differences, these children often feel more self-conscious (Miller, Young & Novakovic, 1995).

How one thinks of themselves, the formation of identity, is in flux when children experiences the trauma of cancer (Lozowski, 1993). In a retrospective, quantitative study by Lozowski (1993), three hundred childhood cancer survivors, who finished their treatment were surveyed. The researcher established a focus group, which was led by a childhood cancer survivor affiliated with the research. The research findings reveal that survivors embodied a more positive outlook about life in comparison to their peers (Lozowski, 1993). These children, however, had a negative health status, specifically, negative perceptions of their body's physical strength and endurance, and they expressed more worries about the likelihood of cancer-related illness. This study raises an important question regarding the quality of life for these children after treatment. There is a need for more services and institutions where the concerns of these survivor children can be addressed. Lozowski (1993) articulates that some children carry these side-effects in many different aspects of their life. For example, one child in particular stated, "I can't remember that good" (Lozowski, 1993, p. 3356), referring to the child's memory impairment as a result of their cancer and its treatment. Such side-effects cause such children further difficulties in meeting their psychosocial stages of development.

Kameny and Bearison (1999) articulate that the self becomes a complicated canvas when illness is introduced at such a young age. These researchers examine the narratives collected in Bearison's (1991) earlier study for the construction of "self" in adolescent cancer patients. The researchers extract three domains of the self that are embedded in the narratives: biomedical, social and personal. According to Kameny and Bearison (1999), while research explores social and personal context, it is equally important to explore the *biomedical* domain introduced into the child's life due to their

illness, as the hospitals and care clinics become familiar places where the children interact and develop. Moving from playgrounds and schools to hospitals creates tensions for these young patients. For this reason, many children's sense of self and identity are negatively influenced by these places. In a longitudinal, qualitative study, Woodgate (2005) used open-ended interviews, focus groups and participant observations with adolescent survivors of childhood cancer. The researcher used constant comparative method of data analysis to examine how the individuals form identities about their self. Here, the adolescent's perception is categorized into one of six ways: klutz, prisoner, invalid, alien, zombie and kid. The categories were based on the words the adolescents used to describe themselves. Researchers found that cancer not only weakens their body, it causes many adolescents to struggle in defining "the self." However, Woodgate (2005) conclude that these individuals reclaim ownership in defining "the self" by the end of treatment and care. The researcher goes on to state that by the end of the treatment, the individuals felt the same as prior to the initiation of their treatments. This contradicts other literature about identity formation. What these studies lack is the piece describing the young individual's life before cancer and how they make sense of their life after cancer. In this way we could examine if these young patients still feel that they are the "same" long after their treatments and care.

These studies provide evidence that cancer inflicts changes both in the present, while experiencing cancer, and in the future, while surviving cancer, as well as how significant these changes can be to children's lives. However, to what degree cancer affects the quality of these children's lives is not discussed. What else is missing is the voice of these children who were diagnosed with cancer. In engaging in a Narrative

Inquiry, the story of the young individual will weave an understanding that will provide us with the closest relationship to the phenomenon, childhood cancer.

### **Loss of Control**

With the onset of cancer and undergoing treatments, life completely changes (Neglia et al., 2001). For many children, their developmental stages, their relationships and routine become disrupted (Neglia et al., 2001). Therefore, feeling a “loss of control” is understandable as the child’s expected life trajectory changes. In a study conducted by Essen, Enskär, Kreuger, Larsson and Sjöden (2000), which is a subset of a larger research project entitled *Care of Children and Adolescents with Cancer*, the researchers applied a mixed-methods approach. They employed the following self-reported measures, “I Think I Am”, the Children’s Depression Inventory and the Revised Children’s Manifest Anxiety Scale, to examine aspects of care and assistance that are important for children aged eight to twelve years. These researchers found that it was important for children to have *amusement, information, satisfaction of basic needs and honest communication*, while including *family participation* during their treatment. Having these concerns met seems to allow these children to feel safe and comfortable. Furthermore, the study acknowledges the importance of healthcare professionals having *clinical competence, continuity, social competence and time*. When healthcare professional use a holistic approach to care, they tend, not only to the disease, but also to the care of the child on a human level. As a result, several children feel validated and responds to care positively (Essen et al., 2000).

Hokkanen et al. (2004) suggest that many adolescents eventually resent their situation, as it prevents them from doing many of the “normal” activities in which their peers typically participate. In a grounded theory study conducted by Woodgate (2006),

thirty-nine children shared their stories with childhood cancer. From the stories, a core narrative that is a major theme running throughout the stories was that “life is never the same” (Woodgate, 2006, p. 4). However, the analysis demonstrates a lack of in-depth exploration into some critical aspects of the participants’ lives. I am left with questions: *How the life changed for these children? How did these children cope with the onset of their illness?*

The research just described allows us to see how much a child loses beyond their pre-cancer body while experiencing cancer (Essen et al., 2000). The impact of cancer is felt beyond hospitalization (body changes, emotional turmoil, family dynamics, peer relationships and so on). The child brings these experiences into their personal and social lives. As a result, we need to involve young individuals in open ended dialogues to see how these changes affect their relationships and their lives from their perspective, asking questions such as: *How do these changes present themselves in their lives after cancer? How do these children learn from their diagnosis of cancer?* Narrative Inquiry allows these individuals to address these questions and tap into experiences as they arise (Clandinin & Connelly, 2000).

### **Coping**

Young individuals are learning and understanding the world around them. In doing so, illness such as cancer greatly disrupts an individual’s psyche, especially so in developing children, because it takes from these children the social contexts their expected to interact in (Miller et al., 1995). These children are not interacting in schools and playgrounds as often as their healthier peers. For this reason, many children diagnosed with cancer miss out. In many cases, these children are expected to make sense

of the changes that is happening to them. Hence, there is a lack of time to really understand and take in *what is happening* and *why it happens* (Miller et al., 1995). Kyngäs et al. (2001), using a mixed methods approach, analyzed a collection of open-ended interviews with adolescents and young adults aged sixteen to twenty-two years to explore coping mechanisms. The researchers included an equal number of healthy children to children with cancer. This allowed a comparison between how healthy children developed coping skills as compared to those who experienced cancer. The researchers determined that many individuals who experienced cancer develop their coping skills by applying three different mechanisms: using emotion, evaluating the problem and making sense of the problem. Time played a big factor in putting these mechanisms into place. As time elapsed, individuals became more and more confident in addressing their concerns.

Wu et al. (2009) used Giorgi's phenomenological methodology and interviewed ten Taiwanese adolescents in different stages of cancer treatment. These researchers found that there is an initial loss of confidence, followed by a rebuilding of hope. The reason for the initial loss is greatly due to the physical weaknesses the illness brings to the body. While the coping mechanisms were acknowledged, it is not clearly stated if these coping mechanisms arise from young patients' understanding of their illness or if they are innate to their personality.

There is a huge lack of understanding in regards to how the young individual's life and identity were conceived prior to the introduction of cancer. For this reason, it is hard to understand how deep the impact of cancer is felt by the individual. Narrative

Inquiry provides us with this missing piece. We are able to see the stories this individual lives by prior to cancer and how then, these stories change with the onset of cancer.

### **Positivity**

Several children diagnosed with cancer often develop and mature quickly in comparison to their peers who do not experience cancer (Wicks & Mitchell, 2010). From their experiences, they learn to rationalize their behaviours and actions reflective of wisdom beyond their years (Wicks & Mitchell, 2010). Zebrack et al. (2007) used a long-term follow-up questionnaire that assessed the long-term effects of childhood cancer amongst children diagnosed with solid tumors and their siblings. These researchers found that children struggled with high levels of anxiety and depression. Although, these children had positive perceptions of their family, which is reflective of the support the family provided for the child. Wicks and Mitchell's (2010) suggest that many ill adolescents referenced aspects of their life that were not medically related, which provided them with comfort. Thus, hospitalization is not the only context which a young individual's diagnosis unfolds. Exploring, narratively, the threads that emerge in different places allows for a deeper understanding regarding childhood cancer. These threads will also help us understand where anxiety and depression may stem from.

### **Cultural Influence**

There is an abundance of literature focused on the ethnic and religious background of the parents and the impact this has on the adolescent's treatment and therapy (Banerjee et al., 2011; Rollins, Bolig & Mahan, 2005; Leavitt et al., 1999; Banerjee et al., 2011; Gray, Szulczewski, Regan, Williams & Pai, 2014; Yeh, 2001; Yin & Twinn, 2004). Culture, in these scholarly literature, refer to the social, ethnic and

religious roots, which influence an individual's upbringing. Gray et al. (2014) explored the impact of a child's culture on clinical care and family relationships with youth under the age of nineteen years. Using open ended interviews, the children and adolescent survivors were asked to discuss their experiences of cancer, important clinical care aspects, and whether aspects of their culture was prominent in coping with these changes. Data were organized around several clinically driven themes: illness representations, reaction to diagnosis, illness disclosure patterns, complementary and alternative medicine use, management of medical procedures, coping strategies and end of life issues (Gray et al., 2014). Researchers found that there needs to be an improved clinical awareness regarding cultural factors, such as young individuals wanting to consult a healthcare professional of their own gender. In being aware, healthcare professionals need to incorporate specific strategies to support the different cultural concerns. These researchers articulated that, "While Western medicine emphasizes maintaining an open dialog regarding illness" (Gray et al., 2014, p. 258), openly discussing cancer may be difficult for patients and parents from communities that have a difficult time discussing illnesses such as cancer, which is associated with guilt, self-blame, and stigma. Future studies could focus on initiating the process of bridging transcultural gaps by exploring culture as healing.

### **Benefits of Cancer Camps**

Most images of childhood include ideas that children are, and like to, participate in recreational activities, interact with individuals their own age, engage in arts and crafts or explore nature. However, when an illness is introduced into a child's life, there are very few moments where the child can behave as one expects a child would. Cancer

Camps are dedicated to bringing expected childhood experiences back to the child diagnosed with cancer (Beckwitt, 2014). Hence, they are a huge support system and allow the child to reconnect with friends and family, allowing them to feel “normal” once again. Beckwitt (2014) explored the role of camps, such as Trillium and Oochigeas, on the adolescents’ experiences as they completed chemotherapy. Using grounded theory involving open-ended interview questions, twenty-three adolescents attending camp were asked to discuss their experiences of being at camp. For these adolescents, camp symbolizes a physical place where they can assume the expected trajectory of adolescent psychosocial development: interacting with other teenagers, experimenting with various identities and having fun. In having a small break from the hospital scenery, the change of location and being in nature provides these children with a respite from thinking about their illness and treatments. It provides these children with the opportunity to engage in age-appropriate activities.

### **Future Implications of Childhood Cancer**

There is some evidence that many children who experienced cancer may feel the physical symptoms even after their treatment is over (Steliarova-Foucher, Stiller, Lacour & Kaatsch, 2005). Mertens et al. (2001) used a retrospective cohort study to examine the deaths of individuals diagnosed with cancer before the age of twenty-one and five years after treatment. The reasons of death were obtained through death certificates and other sources. These researchers found that recurrence of the original cancer was the leading cause of death amongst five-year survivors. Furthermore, the risk of death was statistically higher in females (Steliarova-Foucher et al., 2005). The treatment-related complications remain present up to twenty-five years after the initial diagnosis

(Steliarova-Foucher et al., 2005). Oeffinger et al. (2006) contribute to these findings by using a retrospective-cohort study to track the health status of adult survivors between the age of twenty and thirty-nine years who received a diagnosis of childhood cancer before the age thirteen. Amongst their findings, survivors admitted to having at least one chronic health condition. Other relevant scholarly literature (Mulrooney et al., 2009; Neglia et al., 2001; Miller et al., 1995) also supports these claims. The reality of a second diagnosis and long-term psychological effects due to cancer is present in these individuals.

Research that supports the likelihood of relapses and complications for young survivors creates a constant fear of, once again, confronting the hospital scene.

Above research literature illustrates that while cancer treatments terminate the relationship between cancerous cells and the patient's body, it does not terminate the relationship between the individual and cancer. These patients experience a looming fear of relapse along with the potential for infertility and negative psychosocial symptoms. To get the full picture of the effects of cancer, we would need to understand more about the child's life before cancer and how it has changed after diagnosis.

### **The Need for Narratives of Childhood Cancer**

The review of the scholarly literature suggests that there is a lot of research that focuses on childhood cancer. There is an understanding that a child diagnosed with cancer experiences a distortion while defining the self, feels a lack of control, requires new coping mechanisms and experiences an accelerated personal growth throughout the illness. However, children's illness stories from their perspectives, describing how cancer may disrupt their lives and how they go on living afterwards, is missing from the research literature. This is an important gap that we need to fill.

By using Narrative Inquiry (Connelly & Clandinin, 1990) to explore childhood cancer experience from the patient's perspective, I give voice to children diagnosed with cancer. This Narrative Inquiry addresses the gap in the pediatric oncology literature by adding to the understanding of how adolescents experience and make meaning of their cancer experience.

In the next chapter, I explicate the research methodology I use in this inquiry. I provide a brief overview of the philosophical and theoretical underpinnings of Connelly and Clandinin's Narrative Inquiry (1990).

## **Chapter Three: Archeology Section**

### **Research Methodology**

*In synthesizing the information from the valuable historic accounts of what we know, I turn the corner to discover the section ahead. I stumble upon the Archeology Section, where I learn about the research approach, Narrative Inquiry (Connelly & Clandinin, 1990) that I came to use to explore childhood cancer experience. Here I learn what Narrative Inquiry is, including its philosophical underpinnings, and how a narrative inquirer looks at and understands the experiential landscapes.*

In this chapter, I explain the philosophical foundation of Connelly and Clandinin's (1990) Narrative Inquiry, which is based in Dewey's (1938) pragmatic philosophy. I briefly outline the roots, along with the development of the methodology of Narrative Inquiry. In doing so, and because the particularity of words and what they mean are important in Narrative Inquiry, I delineate terms and assumptions, such as story and narrative, three-dimensional space (temporality, sociality and place), the four directions (backward, forward, inward and outward) and the three justifications (personal, practical and social) of Narrative Inquiry. I end this chapter by discussing the Narrative Reflective Process (Schwind, 2008, 2016). Inspired by Narrative Inquiry, the Narrative Reflective Process is a creative approach to data collection that allows us to tap into our experiences more deeply and calls forth new meanings of lived and told stories.

### **Narrative Inquiry as a Methodology**

#### **Defining Story and Narrative**

In Narrative Inquiry, reconstructing the storied lives of people and their life experiences provides us a new avenue of understanding (Connelly & Clandinin, 1990).

However, it is important to distinguish between the terms story and narrative. These two terms within the context of this methodology are not interchangeable. Narrative Inquiries begin with the telling of the stories we live by (Connelly & Clandinin, 1990). Stories are extracted in interviews using different methods such as “responding to more or less structured interview questions, engaging in conversation or dialogue, and telling stories triggered by various artifacts such as photographs” (Clandinin, 2013, p. 5). The inquirer then reads, reflects and interprets the story to construct a sequential and cohesive sequence, which is deconstructed through discussions with the co-participant and further interpreted using Narrative Inquiry analysis. Here, the inquirer is immersed in the story and new understandings of living story emerge. This analysis is then reconstructed to represent the *narrative* of the experience.

### **Philosophical Foundations of Narrative Inquiry**

In Narrative Inquiry, a primary assumption is the understanding that human beings naturally gravitate towards the living and telling of stories (Connelly & Clandinin, 2006; Clandinin & Connelly 2000; Clandinin, 2013). Through telling and retelling stories, we create meanings. This understanding was relatively unknown in realm of research within social sciences. However, this process is often practiced in the field of humanities and is referenced by a different name, “narratology” (Clandinin & Connelly, 2000). In the late 1980s and early 1990s, this form of research methodology began to emerge in many areas within social sciences (Connelly & Clandinin, 1999, 2006; Clandinin, 2013; Clandinin & Connelly, 2000). In 1990, Connelly and Clandinin published their first article about Narrative Inquiry in the field of education.

In this groundbreaking article, Connelly and Clandinin emphasize experiential knowledge as the cornerstone of Narrative Inquiry stemming from the Deweyan philosophy on experience. Drawing on two of Dewey's criteria that, "Interaction and continuity [are] enacted in situations" (Clandinin, Caine, Lessard & Huber, 2016, p. 15), Connelly and Clandinin articulate the narrative view of experience. They write: "[People] are always in relation, always in a social context" (Clandinin & Connelly, 2000, p. 2). They continue to explain that: "Experiences lead to further experiences. Wherever one positions oneself in that continuum – the imagined now, some imagined past, or some imagined future – each point has a past experiential base and leads to an experiential future" (Clandinin & Connelly, 2000, p. 2). Here, there is an understanding that time is in transition and fluid. Experiences do not end once they have passed. Rather, experiences are carried by the individual into the past, present and future.

Building on this thought, Connelly and Clandinin took a narrative turn in defining Narrative Inquiry as a methodology. As a methodology, Narrative Inquiry became a "way of understanding experience" (Clandinin & Connelly, 2000, p. 20) that eventually translates into "a way of being in the world" (Schwind, Personal Communication, October 15, 2016). In this approach, collaboration between researcher and co-participants is maintained throughout the process (Clandinin & Connelly, 2000). The researcher enters into the stories of the co-participant and weaves new understandings through their discussions. These new understandings, then, are situated into greater social, cultural and institutional contexts to highlight the broader and multi-level significance of the experience under study.

## **Thinking Narratively**

To think narratively about the inquiry while upholding Dewey's two criteria of continuity of experience and interaction, Connelly and Clandinin (1990) create a metaphoric three-dimensional narrative inquiry space. This three-dimensional space is conceived as personal and social interactions occurring along time in a place or a series of places at particular times. Experiences within the three-dimensional space are looked at through four narrative directions: forward, backward, inward and outward. In thinking narratively, the inquirer must learn and subsequently frame their research inquiry within these understandings to create field texts, interim texts and research texts accordingly. The important components of a Narrative Inquiry are elaborated in the following sections.

### **Three-Dimensional Space**

The three-dimensional space is the conceptual framework that is simultaneously explored as we share our stories. In telling and retelling their story, the individual is able to not only present their story, but also reflect on it in the present moment alongside the inquirer. Using this framework, then, we are able to learn the "complexity of the relational composition of people's lived experiences both inside and outside of an inquiry and, as well, to imagine the future possibilities of these lives" (Clandinin & Rosiek, 2007).

**Temporality.** Connelly and Clandinin articulate that, "events under study are in temporal transition" (2006, p. 479). In Narrative Inquiry (Connelly & Clandinin, 1990, 2006; Clandinin & Rosiek, 2007), temporality is addressed as the inquirer looks at the past and understand how the experience has shaped the co-participant. We see here how

the past translates into the present life and experiences of the individual. As we move towards looking into the future, we see how the individual carries a new understanding of these experiences with them, enabling them to conceive of new possibilities about the future. The final re-presentation of the participant's story, the *narrative*, is re-interpreted by readers across various places or *landscapes* to emphasize, once again, that experience is both continuous and transferable.

**Sociality.** Both personal and social conditions are simultaneously attended to in Narrative Inquiry. Connelly and Clandinin (2006) articulate that the personal conditions attends to the “feelings, hopes, desires, aesthetic reactions and moral dispositions of the inquirer and participants” (p. 480). In doing so, the human and personal aspect rooted in experiences are brought forward. They also note that social conditions attend to “the milieu [or], “environment and surrounding factors and forces, [and] people” (Connelly & Clandinin, 2006, p. 480). These factors can be cultural, social, institutional and linguistic in nature depending on the person's experience and where the events are occurring

An additional dimension of sociality is the relationship between researchers' and co-participants' lives. In Narrative Inquiry, it is assumed that researchers are not removed or detached from the inquiry relationship. The researcher shares their own stories of experience that creates a relational space (Connelly & Clandinin, 1990). In this interaction, which occurs naturally over the course of the inquiry, a co-creation of knowledge occurs where new ways of thinking and living for both researcher and co-participant emerge. (Connelly & Clandinin, 1990). This illustrates the epistemology of Narrative Inquiry that existential experience is educational.

**Place.** Place is the, “specific concrete, physical [...] place or sequences of places where the inquiry and events take place” (Connelly & Clandinin, 2006, p. 480). The key to understanding the role of “place” lies in our own understanding that the place in which our experiences unfold are instrumental in how we understand them and what we take away from them (Connelly & Clandinin, 2006). For this reason, our identities are shaped by these places as we shape the places themselves. Similar to sociality, the narrative inquirer must understand that they too are now a part of the places in which the stories are unfolding. This interaction allows both the inquirer and the participant to personally evolve through the sharing of the stories (Clandinin & Connelly, 2000).

#### **Four Directions of Narrative Inquiry**

Connelly and Clandinin (1990), in addition to the metaphoric three-dimensional space, identify four directions in which the inquiry is considered: backward, forward, inward and outward. *Backward* and *forward* are terms that refer to viewing the experience along a temporal trajectory i.e. in the past, present and future. *Inward* makes reference to the individual’s personal conditions, such as feelings, moral dispositions and hopes. The last direction, *outward*, refers to conditions present in our environment. These can be social or institutional constraints and limitations (Clandinin & Connelly, 2000).

In the telling of their story, participants move backward, forwards and inward and outward as they articulate how the experience unfolds and in turn, how the experience has shaped them. As inquirers move from *field text* to *research text*, they too observe and understand the inquiry in these multiple directions. In using the term *field text* in Narrative Inquiry, we refer to the interview transcripts, metaphor writing and short-story writing (Clandinin & Connelly, 2000). In comparison, *research text* refers to the

reconstruction of the interview transcripts, metaphor writing and so on into one cohesive piece. Research texts are co-created as the co-participant and inquirer move fluidly throughout the four directions (Clandinin & Connelly, 2000).

### **Three Levels of Justification**

In Narrative Inquiry, the three levels of justification (personal, practical and social) are used to both justify the reason for undertaking a Narrative Inquiry (Clandinin, Pushor, & Orr, 2007) and to analyze the lived and told stories. In this section I address how I used the three levels of justification to provide the rationale for my study. In Chapter Four, I explicate how I use the three levels of justification in the analysis process.

**First Level of Justification: The Personal.** The first level of justification, the personal, is the telling of the lived stories of the inquirer and the co-participant. The researcher situates themselves in relation to the phenomenon under study by engaging with the stories they live by in relation to the inquiry. In doing so, the inquirer answers the question: *Why is this important for me, as a person and researcher, to study the phenomenon of study?* As we saw in Chapter One, the story that inspired me to explore the experience of childhood cancer was the book, *Sadako and the Thousand Paper Cranes*. When I read the book at the age of twelve, I realized the young cancer patient, Sadako could be me or a beloved sibling. As a result, I wanted to understand and know more about the experience of childhood cancer: *How does a child go through this experience? How does the experience change them? How do they carry these changes with them?*

**Second Level of Justification: The Practical.** The second level of justification, the practical, moves from the relational context of the inquirer and co-participant to a more professional level of the inquiry. Here, the researcher justifies the research in respect to how it contributes to changing or thinking differently about the ways in which we practice in our professional landscapes. I explored this level of justification in Chapter Two. The preliminary literature review earlier in the research process rationalizes the need for this study through showing the paucity of illness narratives from the young patient’s perspective. This Narrative Inquiry provides another puzzle piece in our understanding of how children experience the trauma of illness.

**Third Level of Justification: The Social.** The third level of justification, the social, answers the questions, “So what?” and “Who cares?” (Clandinin et al., 2006, p. 25). Here, the research moves beyond the professional field and illuminates the meaning this inquiry has within the broader context of healthcare. Through synthesizing the scholarly literature relevant to childhood cancer, there is need for patient illness narratives because survivors of childhood cancer experience long term effects (Oeffinger et al., 2006; Mertens et al., 2001). It is important to study “the patient’s body [because it] is a landscape where experience is drawn up and reconstructed, [...] which [has the] potential to generate knowledge” (Schwind, 2003, p.284). I agree with Erikson and Erikson (1998) that it is important to bring these narratives to healthcare to make changes and improvements to the understanding and care of these children.

### **Reflective Process in Narrative Inquiry**

There are various means of narrative self-expressions, for example drawing, storytelling, creative writing, photography, collages and metaphors. In this inquiry, I

adapt Schwind's (2008, 2016) Narrative Reflective Process, which arises from Narrative Inquiry and resonates with Dewey's understanding of experience. In Schwind's Narrative Reflective Process, the co-participant and inquirer uses storytelling, creative writing and metaphors to tap more deeply into their experiences. Most often, the meanings we associate with experiences are embedded in the subconscious and using creative reflective process brings meanings to the surface (Schwind, personal communication, July 4, 2014). Through discussing, reflecting and asking questions during creative processes, we move beyond established understandings, augmenting these ideas by incorporating this new knowledge. In doing so, "we live the consciousness [that] involves dialogic relations between persons" (Newman, 2006, p. 66–67; Schwind et al., 2011, p.227). Hence, the researcher and the participant, then, co-create new ways of knowing that by extension broaden both the "personal and the collective consciousness" (Schwind et al., 2011, p.227).

In particular, metaphoric reflection and writing, as articulated by Schwind (2003), has the potential to elicit the multidimensional stories of experiences. For individuals who are logical, linear or positivist thinkers, like me, conceptualizing one's illness using metaphorical imagination is difficult. Relationships with our experiences are very much embedded in our everyday, so much so that they become tacit. Metaphors aim to surface this tacit knowing and so to facilitate our understanding of what these experiences mean in our lives. Moreover, it also allows the readers to imagine more fully what this experience must have been like for the storyteller; the reciprocity becomes easier to embody.

## **Re-constructing Childhood Cancer: A Narrative Inquiry**

A Narrative Inquiry enables inquirers to understand how space, time and internal and external factors interplay in every human experience. “Stories are [essentially] the closest we can come to experience, as we and others tell of our experience. A story has a sense of being full, a sense of coming out of a personal and social history” (Connelly & Clandinin, 1990, p. 415). For this reason, I use Narrative Inquiry to answer my inquiry puzzle.

In using Narrative Inquiry, I am able to study the uniqueness and the nuances of experiencing childhood cancer. We can explore more deeply how the dynamics of the child’s life change with cancer and how this child then sees themselves and the world. In thinking narratively, the co-participant and I observe the three-dimensional space (temporality, place and sociality) rooted in the experience in four directions throughout the inquiry. In doing so, I reveal how we act together to co-construct the retelling and thereby, the reliving, of the illness stories of experience.

## Chapter Four: Geography Section

### Inquiry Process

*The Archeology section was interesting. Reading through the history and the description of Narrative Inquiry, helps to position this journey into perspective. I begin to conceptualize why I'm on this journey and its importance to me. I feel excited to continue my expedition. As I go up the flight of stairs, I come across the Geography Section. This section gives a topographical overview of the inquiry; the lay of the land.*

In the previous chapter, I explain the historical roots of Narrative Inquiry. Now, I move forward to describe the inquiry process: the steps I followed in this inquiry. This chapter begins with how rigour is achieved in Narrative Inquiry. Following this, I provide detailed description of how I implemented the seven considerations, in respective order: Self-Investment, Researcher-Participant Relationship, Study Duration, Imagining the Lifespace of the Inquiry Puzzle, Balancing the Three-Dimensional Space, Methods: A Telling Inquiry, and Ethical Considerations (Connelly & Clandinin, 2006) I used while designing this Narrative Inquiry, including collecting field text and composing the research text. These considerations collectively strengthen the rigour of this qualitative study. Next, I explicate the Narrative Inquiry analysis process and conclude with a discussion on how I weave reflexivity throughout my thesis.

### Rigour

In addressing the question, “what makes a good Narrative Inquiry” Clandinin and Connelly (2000, p. 185) articulate five points for thought, which collectively make a rigorous Narrative Inquiry. First, the study must be *explanatory*. Narratives must examine how the past and present interact with one another. Here, the participant explores how

they carry the past into their present lives and how their present lives help make sense of the story. Inquirers must also examine how internal and external factors change as time elapses, how the social contexts of the participant's life change, and how the participant changes. This then allows us to discover how the study contributes to the future experiences of both participant and researcher. Additionally, Narrative Inquiry is *invitational*. The narrative invites the reader to feel and reflect on their own experiences and draw conclusions about these experiences, creating the potential to broaden their own understanding. In doing so, we recognize the continuity and transferability of experience. The co-participant's experiences, examined through Narrative Inquiry, need to be *authentic* and honest accounts of the lived and told stories shared within the inquiry process. In Narrative Inquiry, the reconstructed story presented at the First Level of Justification reflects the participant's experience and uses their words while incorporating the researcher's interpretation. In doing so, a narrative inquirer ensures authenticity. Moreover, narratives need to appropriately represent the human experience under study to address the inquiry puzzle and achieve the purpose of the study, which speaks to the *adequacy* of a Narrative Inquiry. Additionally, while providing an authentic account, we must also ensure of providing a *plausible* one. The reader must be able to imagine the story unfold.

Throughout the entire inquiry process, Clandinin and Connelly (2000) advise that the researcher must establish a sense of *wakefulness* (p. 185) when in the field and while composing the research texts. When the researcher is awake and mindful that the metaphorical three-dimensional space (temporality, sociality and place) are rooted in every human experience, they can achieve rigorous quality of narrative that embody,

simultaneously, the six aforementioned tenets. I explain these elements of rigor in detail as it unfolded in my inquiry in the sections below.

### **Reflexivity**

The self-reflective practice is established from the onset of the research process. I reflected on the stories that I live by, which resulted in a genuine interest in exploring the experiences of childhood cancer and why I chose Narrative Inquiry as the medium to explore this experience. I reflected and looked forward, backward, inward and outward on my own internal and external conditions. I recorded my thoughts and feelings in a journal before and after my meetings with my co-participant, Noelle. The purpose of this journal was to interpret and make sense of my thoughts and to connect these responses with the stories shared by Noelle. These journal entries made up part of the field text, which were used during the data analysis stage of this Narrative Inquiry.

### **Seven Considerations of a Narrative Inquiry**

#### **Investment of the Self**

This study is a telling inquiry, because I begin with Noelle's told stories of her childhood experience of cancer. However, as a narrative inquirer, I am not outside of this inquiry. I am very much a part of it, co-creating knowledge with Noelle (Connelly & Clandinin, 2006). I share with Noelle my past and present experiences, which motivated this Narrative Inquiry. This relationship component inherent in Narrative Inquiry fosters the relational bond between the researcher and the co-participant as co-composing knowledge. Through this process I develop a deeper understanding of experiences and the meanings of what it may be like to be diagnosed and to live with childhood cancer.

## **Researcher-Participant Relationship**

The relationship between the co-participant and the researcher varies in strength and closeness (Clandinin & Connelly, 2000). I develop a significant relationship with my co-participant because this allows me to understand how she is able to make sense of her experiences and how she then makes sense of her world. Through our shared interests for music and seeking a career in helping young individuals, both Noelle and I share a comradeship with mutual respect and empathy for one another.

However, I am aware of the potential for tensions between maintaining an ethical and professional boundary while forming a close relationship. Since the beginning of this inquiry, I have been mindful of the potential for forming intimate relationships with my co-participant, field text and research text. I entered the researcher-co-participant relationship with prior knowledge of the phenomenon under study. In debriefing prior to my interviews and reflecting shortly afterwards, reflexive journaling is a method developed to become aware of the impact of this relational association and to ensure research-related decisions are made in this sense of wakefulness. These continuous self-checks ensure I am aware of how I contribute to the study as a co-participant and a researcher, from the questions I ask during the interview process to the understandings of the field and research texts.

## **Study Duration**

The design and implementation of the study is based on the Master of Health Science (MHSc) program restrictions, along with the inquiry's starting point of telling stories. Designing and engaging in a participatory study as a "living inquiry", where the researcher lives alongside a child experiencing cancer for an extended period of time is

not feasible or realistic due to the MHSc program time parameters. For this reason, I have created a “telling inquiry”, which is also referred to as an interview study (Connelly & Clandinin, 2006, p. 480). Predominately, the telling of lived stories and the interpretation of these texts are at the centre of this inquiry. From the time of co-participant recruitment to thesis completion, this Narrative Inquiry lasted eight months.

### **Imagining the Lifespace of the Inquiry Puzzle**

When embarking on a Narrative Inquiry, the inquirer and the co-participant enter an inquiry lifespace (Clandinin & Connelly, 2000). This lifespace is called the *field*. While the lived stories are told and shared in a place or series of places at particular times, the field represents the conversations between the co-participant and the researcher. My inquiry puzzle began with my own self-examination and reflection of my experiences that instill an interest in studying childhood cancer. I began my inquiry puzzle by considering the stories that I am a part of and carry with me that motivate my journey in understanding childhood cancer. I imagined the inquiry lifespace as a classroom landscape where my co-participant, Noelle, who experienced childhood cancer is the teacher. The individuals involved in Noelle’s experience of cancer: her parents, siblings, friends and healthcare professionals are all part of this classroom. In situating the lifespace in this image, I imagined how experiencing childhood cancer, interacting with multiple levels of care and fostering a long-term relationship with their illness, may influence the stories lived and told by my co-participant. Through conceptualizing an inquiry lifespace, I was able to specify and strengthen the inquiry puzzle and its design (Clandinin & Connelly, 2000).

This inquiry lifespace, known as the *field*, provided a comfortable and safe space where I participated with my co-participant in narrative interviews. To ensure the space was in fact comfortable and safe for Noelle, I asked Noelle to choose where she wanted our sessions to take place in. She chose Hestia, which is a center that supports cancer patients and families. She had interacted in this space when she was a young individual and was very familiar with the staff. Here, I told my own stories and invited Noelle to share her stories of experiencing childhood cancer through conversation, metaphors, and images. I gathered my field notes and reflected in my journal entries throughout my meetings with the co-participant.

### **Balancing the Three-Dimensional Space**

The three-dimensional space involving temporality, sociality and place are embedded in our experiences (Clandinin et al., 2006; Clandinin & Connelly, 2000; Connelly & Clandinin, 2006). In order to think narratively, I must be mindful of how I build and interact with the three-dimensional space in this inquiry. In applying the four directions of Narrative Inquiry identified by Clandinin and Connelly (2000) and the broad questions to begin with, I explored how the three-dimensional space interplays in my co-participant's experiences. In Chapters Five, Seven and Eight, I described how I move along these directions in deconstructing, analyzing and reconstructing Noelle's illness story. Through exploring the narrative threads that emerge in Noelle's story, I see how time, place and the personal-social are influential in how Noelle and I, as the inquirer, come to understand her illness experience.

## **Methods: A Telling Inquiry**

**Participant recruitment.** I used a purposeful sampling approach to seek out one young adult who experienced childhood cancer, speaks and reads English, and currently lives in the province. I first posted an advertisement at the university (Appendix C), but when no volunteers came forward after three weeks, I sent an electronic advertisement (Appendix D) to childhood cancer supports in the province. Through collaboration with Hestia, I recruited my co-participant, a young woman, Noelle who was diagnosed with cancer when she was thirteen.

Narrative Inquiry honours the experiences of its co-participants rather than adopting a reductionist purpose of forming generalizations based on the co-participant's narrative (Clandinin et al., 2006). It is an in-depth and extensive study of human experience with one to five participants (Creswell, 2013; Lindsay, 2006; Schwind, 2003). In this inquiry, I focus on the experience of reconstructing childhood cancer from a young adult's perspective. This allows me to explicate the nuances and richness in Noelle's experience, which makes her visible and heard within the landscape of healthcare.

**Collection of field texts: Telling of Lived Stories.** Through interviews and creative expressions, stories are shared between the co-participant and the inquirer. Field texts co-created by the inquirer and co-participant are reflective of co-participant's experience, representing the starting point of the inquiry (Connelly & Clandinin, 1999). With the telling and retelling, overtime, these field texts may change. Therefore, as the narrative inquirer, I was very diligent and alert to how Noelle and I were situated within the context of the three-dimensional space, temporal, spatial and personal-social during

all stages of the inquiry process, and especially as the field texts were co-constructed (Connelly & Clandinin, 1990). In this section, I describe in more detail our engagement in the inquiry process and the development of the field texts.

Over the five sessions that Noelle and I met at Hestia's library, we engaged in an on-going one-on-one interview, along with creative self-expression activities. Our conversations were audio-recorded and transcribed verbatim. The sessions are described below:

**First Session.** The first meeting lasted for an hour and a half. Our starting point for collecting field texts focused on creating a comfortable space where Noelle could share her lived stories of childhood cancer experience. In our first session, we began by my invitation to Noelle to engage in Lifeline activity (Connelly & Clandinin, 1999; Schwind & Lindsay, 2016) which is a creative self-expression. Including creative self-expression activities allows for a more complete and authentic retelling of Noelle's experience, which adds to the rigour of this inquiry. "[Art] is known to elicit the depths of our being unreachable by words" (Schwind, 2003, p. 25) and in doing so, we enter a deeper understanding: a reflective process, which essentially opens us up to new ways of making sense of life events. I joined Noelle in this creative self-expression activity to nurture the relational connection between the inquirer and the co-participant. After discussing the dates on our respective timelines, I invited Noelle to participate in a narrative interview guided by the following conversation starters:

- Tell me about your experience with childhood cancer.
- In your own words, how would you define cancer?
- In your own words, how would you define surviving cancer?

- How did your family experience your cancer?
- How is the way you make sense of the world different now, after experiencing childhood cancer?

The interview that encompasses these questions, spanned the five meetings, and was conversational and fluid. As the interview progressed, new questions emerged. For example, later in the interview, this question arose: What made you choose to study Social Work? Our first meeting ended with Noelle defining what the words cancer and surviving cancer means to her.

In applying the Narrative Reflective Process (Schwind, 2003, 2008, 2016; Schwind, Cameron, Franks, Graham & Robinson, 2011), in subsequent sessions, I used a variety of creative data collection methods, such as short story writing, letter writing, metaphors, and images to assist Noelle in drawing out the multidimensional aspects of her experience of childhood cancer. Following the completion of each activity, Noelle provided a verbal description in regards to the reasons she chose the metaphor and images. This allowed new feelings, thoughts and experiences to emerge. The tacit knowing of her experience brought a deeper understanding of how impactful cancer is on an adolescent and how the adolescent then goes on to make meaning of their experiences. These new understandings were facilitated through the creative activities that may not have been accessible through a traditional interview and discussion (Schwind, Zanchetta, Aksenchuk, & Gorospe, 2013).

**Second Session.** The meeting lasted for an hour and a half. During this session, I invited Noelle to write two short stories about her experience with cancer and surviving

cancer (Schwind et al., 2014). Noelle read her story aloud and we discussed components of the story that stood out to her and how she made sense of them.

**Third Session.** The meeting lasted for forty-five minutes. During this session, I invited Noelle to think of an image that expresses her understanding of cancer (Schwind et al., 2014). Noelle was then encouraged to write one or two metaphoric sentences describing her experience of having cancer. Then, I invited Noelle to write a letter to herself from the perspective of the metaphor. Following this, Noelle read aloud her letter and we discussed how the letter relates to experiencing cancer (Schwind et al., 2014). At the end of our meeting, I asked Noelle to bring two images for the next meeting, one image that represents having cancer and one image that represents surviving cancer.

**Fourth Session.** The meeting lasted for forty minutes. During this session, I invited Noelle to describe each image separately. First, Noelle described her image that represents having cancer. She explained how it reflects her experience with cancer. Then, Noelle described her image that represents surviving cancer. She explained how the image represented being in remission and why she chose this image. At the end of this session, I gave Noelle *Sadako and the Thousand Paper Cranes*, the book whose story awoken within me an interest in childhood experiences of living with cancer.

**Fifth Session.** The meeting lasted for forty minutes. During this session, Noelle and I discussed *Sadako and the Thousand Paper Cranes* and her experience of it. We chatted about the potential strong impact this book could have on a young individual, such as myself. At the end of this session, I ask Noelle to refine or affirm her initial definition of cancer and surviving cancer from the first session.

After each conversation with Noelle, I reflected on our discussions and wrote field notes to identify characteristics that were not evident in the tape recordings. These supplementary details are non-verbal communications, such as pauses, facial reactions and body positions (Clandinin & Connelly, 2000).

In this process, I worked with the participant in the three-dimensional space to gather and create the field texts. Field texts (transcribed interviews, metaphor, short story writing and images) in combination with my own reflective journaling allowed me, as the narrative inquirer, to move forward, backwards, inward and outward. In being thorough, effective and composing field texts on a day-by-day basis, I continuously addressed my tensions during the inquiry process in maintaining boundaries between professional, ethical and relational aspects of our encounters and interactions. These methods allowed me to maintain a professional and ethical attitude, while forming a close relationship with Noelle.

After each narrative interview session, I listened to the audio-recordings once before transcription. During this time, I went over my own field notes to ensure I had acknowledged audible changes, silences and pauses. To further ensuring that the transcripts were correct, I then listened to the audio-recordings of the interviews two times to guarantee I accurately transcribed the field notes into field texts. I listened to the recordings once more while I read my own notes to make sure that I accounted for every word. The narrative interview transcripts, the Narrative Reflective Process creative activities completed by Noelle and me, along with the field notes, came to be my field text.

When we tell our stories, we do not tell them in a linear, chronological sequence (Connelly & Clandinin, 1990). In our telling and retelling, we often remember forgotten details, add extra information or go off on a tangent (Connelly & Clandinin, 1990). For this reason, I read and reread my field texts of Noelle's story several times. I put these texts in chronological order. In having read the long texts, I realized the importance of each individual story. Hence, I separated each account into its own smaller section, which highlights the experience and its impact on Noelle. This makes up the *interim research text* (Clandinin, 2013). Interim research texts are "partial texts that are open to support the participants and researcher to further co-compose stories interpretations and to negotiate the multiplicity of possible meanings" (p.47). This interim text was then negotiated with Noelle and co-composed to ensure that it was *authentic* and *plausible*. For this reason, Noelle and I discussed over e-mail the anonymity and the accuracy of the text. The next steps were to analyze the narratives through the three levels of justification of Narrative Inquiry (Connelly & Clandinin, 1990).

**Data Analysis and Interpretation.** In immersing myself in the texts, I analyzed Noelle's stories as expressed through the field texts, images and conversations using Narrative Inquiry's three-dimensional space, which reflect the three-dimensional analysis process (Connelly & Clandinin, 2006). Throughout the entire inquiry process, and specifically analysis and interpretation, I was aware of where Noelle and I were placed spatially, temporally and within a personal-social relationship to ensure the narratives meet all the requirements of Narrative Inquiry rigour (Clandinin & Connelly, 2000; Connelly & Clandinin, 2006). Using the four directions identified in Narrative Inquiry, I looked forward and backward to reflect on the temporal and the spatial resonance within

the storied moments. I looked inward and outward to reflect on the personal-social weavings in the storied moments. As Clandinin and Connelly (2000) suggest that the three-dimensional space within the inquiry lifespace are open, vast and explored simultaneously throughout the inquiry process.

During the inquiry process involving the analysis and interpretation of the field texts, I weaved the field text with the research text (Clandinin & Connelly, 2000). Importantly, I needed to consider the significance of this inquiry. What does my study contribute to Noelle and childhood cancer in general? In order to do so, I read and reread the field texts and highlighted repeated patterns, threads or concerns using different color highlighters. In reviewing the colors and the experiences they covered, some of them began to overlap. I then grouped the stories that connected, identifying the narrative threads that emerged with Noelle's story. From this point onward, I began to delve deeper into making meanings of the experience relevant to the inquiry puzzle.

**Personal Justification.** Personal Justification is the first level of analysis. Through the telling of the co-participant's story intertwined with the immediate reactions of the inquirer, as a person, to the told story, the inquirer demonstrates the relational quality of Narrative Inquiry. In my study, in Chapter Five, I situated myself as a narrative inquirer as I co-constructed Noelle's story. As I read and reread the field texts, I remained aware of my own spontaneous reactions to the shared stories. I weaved my own personal interjections with that of Noelle's stories to gain insight into my relationship with this inquiry. This process emphasizes what comes forth on a personal, human level while hearing Noelle's story (Clandinin et al., 2006). As a co-participant in this inquiry, I questioned my own growth. I also considered what I bring into this inquiry. In practicing

self-reflection, I became mindful of how the stories I live and tell are becoming influenced and woven through Noelle's story. At this level, my role as a co-participant is evident.

**Practical Justification.** Practical Justification is the second level of justification. In Chapter six and seven, I analyzed the field text in terms of its relevancy to scholarly literature. I look at Noelle's illness story using the two theoretical frameworks, Erikson's Psychosocial Stages of Development (1968) and Cellular Memory using Porges' Polyvagal Theory (1995). In interweaving Noelle's story with what we already know in broader scholarly literature, I also considered significant concepts and future opportunities for research. This illustrates the new knowledge that emerges from Noelle's illness experience of cancer.

By using these two theoretical frameworks, the meaning of the inquiry in a broader sense is surfaced (Clandinin & Connelly, 2000). I used Erikson's Stages of Psychosocial Development (1968) and Cellular Memory inspired by Porges (1995), as the two theoretical lenses to examine Noelle's story of childhood cancer. I deconstructed, interpreted and critically considered, while synergistically using the three-dimensional space, Noelle's illness story. Essentially, while the first level of justification weaves my personal interjections, this second level weaves the theoretical frameworks and the concerns raised within the broader research literature. While the personal justification provides the contributions this study makes on a personal and human level, the practical justification acknowledges the contribution this study makes towards expanding our knowledge on childhood cancer (Schwind, Personal Communication, October 15, 2016).

**Social Justification.** Social Justification is the third level of justification identified in Narrative Inquiry. This level answers the questions, “So what?” and “Who cares?” (Clandinin et al., 2006, p. 25). I explored this level in Chapter Eight, where I synthesized knowledge from my inquiry to discuss the contributions it makes towards healthcare research, education and practice. I explicated what understanding childhood cancer experience from the patient’s perspective means to healthcare practice and education. What does Noelle’s illness teach healthcare professionals? What does Noelle’s illness teach research in healthcare? Through this examination, the narrative threads and their significance to a larger social context were acknowledged.

I remained aware of the political, social cultural, institutional and economic narratives that mold the identities and lives of the participants (Connelly & Clandinin, 1990). I answered why the personal illness narrative of an adolescent named Noelle matters to the broader sense of healthcare system and society at large. Once again, the weaving process adds a third layer as I move from weaving scholarly literature to explicating the ways that Noelle’s experience has meaning in a broader sense.

In reflecting with my co-supervisor, Dr. Jasna Schwind (Personal Communication, October 4, 2016) articulated that the research text that was created at the first, second and third levels of justification add multidimensional pieces to the inquiry puzzle. These pieces are also meant to involve various audiences to reflect, reimagine, ask questions and create new ways of understanding and doing, on personal and professional levels. Through Noelle’s letter and poem explicated in Chapter Eight, I represent Noelle’s story. This is the *narrative*, which stimulates the audiences to engage, and so meets the criterion of *invitational quality* needed for a rigorous Narrative Inquiry.

## **Ethical Considerations**

Connelly and Clandinin (2006) identify Ethical Considerations as the seventh consideration for a Narrative Inquiry. It is important to understand that Narrative Inquiry is a life study, which involve the researcher and co-participant to assume a relational rapport, where both the researcher and the co-participant live and tell the stories in the context of a relationship (Connelly & Clandinin, 2006; Clandinin et al., 2006). As the inquirer, it is crucial that I am both mindful and attentive to the ethical responsibilities we have towards the co-participant throughout the inquiry since relational encounters must always be ethical and ethical problems may arise at any given time (Clandinin, 2013).

**Research Ethics Board Approval.** Research that involves humans requires ethical reviews (Connelly & Clandinin, 2006). Therefore, this inquiry began once approval from the university's Research Ethics Board Approval was received (Appendix A).

**Autonomy.** To upkeep with the ethical principle of autonomy, I obtained written informed consent (Appendix B) at the beginning of the inquiry process. At the start of the researcher-co-participant relationship, Noelle was informed of her right to pause temporarily or withdraw permanently from the study without any penalty or loss of benefits. There was no coercion or deception of the participant throughout the study.

**Respect for Participants.** Throughout this part of my writing I explicate many measures where I maintain and uphold the respect for my co-participant. The co-participant, Noelle, was treated with respect and dignity throughout the inquiry process. I fulfilled, with the study parameters, her requests in order to honor her privacy, anonymity, respect and comfort. I did this by ensuring that all documents had her

pseudonym, allowing her to choose the location of our meetings, being flexible regarding the dates of our interview sessions and respecting her wishes if she chose not to answer or participate in the day's activity.

***Benefits.*** The co-participant may experience potential benefits, which include personal growth through self-reflection and awareness, personal satisfaction in sharing and contributing their story towards the enhancement of other students, along with the establishment of an outlet for thoughts and feelings. Researchers (Drury, Francis & Chapman 2007; Lindsay & Schwind, 2014; Sharoff, 2008) have concluded that the use of qualitative research and the process of being interviewed is not only beneficial, but also therapeutic to participants as it encourages self-reflection and provides an outlet for everyone to express their thoughts, stories and feelings.

***Risk for Harm.*** I recognize that telling personal stories in the context of an inquiry has the potential for psychological and emotional harm for the co-participant. During our interviews and throughout the course of this inquiry, Noelle did not express any psychological or emotional discomfort. However, to ensure Noelle's comfort, I attended to the potential for psychological and emotional risk by providing her with sufficient information regarding the upcoming meeting to choose to continue or bypass proposed activities and conversation topics. In addition, I was prepared to provide emotional support if in the case a question or activity surfaced emotional discomfort. Moreover, I was prepared to end the interview and provide Noelle with information regarding the resources available to her, such as the psychological counselling supports available through campus services.

***Confidentiality.*** Confidentiality is the researcher's responsibility to prevent the public reporting of information that causes the research participant to be identifiable (Speziale, Streubert & Carpenter, 2011). I have maintained the confidentiality of my participant by ensuring that the research data that consist of participant identifiers are only accessible to me. For this reason, this thesis does not include factual years, locations, events and names which would make Noelle identifiable. The consent forms are the only documents that contain participant identifiers. These documents are stored separately from all the electronic and hard copies of the research data. I have ensured anonymity of the participants by using pseudonyms for all identifiers, including places, throughout the research process, including data storage and future research publications.

Electronic research files of the narrative interviews, metaphor and short story writing are saved as password protected Word documents in a biometric-encrypted USB memory card. The electronic research files do not contain identifiable data. This electronic version is transferred to my thesis supervisor through the University of Ontario Institute of Technology's portal to maintain the participants' privacy and confidentiality. To ensure confidentiality, I have stored the hard copy version of my research files in a double locked filing cabinet in my home from the time of participant recruitment to research dissemination. The consent forms are stored in a different section of the filing cabinet in my home to maintain the anonymity and confidentiality of the participants. The audio recording will be destroyed within six months after transcripts have been written. The electronic and hard copy files of the de-identified research data, including the life-line drawing, journal and images will be stored in a double locked filing cabinet at my home. Within the three years within the completion of the study, I will use Fileshredder, a

free application that shreds and permanently removes files from my computer beyond recovery. Should there be a breach of confidentiality, University of Ontario Institute of Technology's Research Ethics Boards would be notified to obtain instructions on how to contain the problem.

***Privacy.*** Privacy is defined as the ethical principle of privacy as one's right to be free from unreasonable or unauthorized interruption or intrusion. I protected my co-participant's privacy by giving Noelle the choice to select the time and place for our interviews. I used an audio-recording device to document the interviews with the consent from the participant each time. I synergistically applied methods of field text collections (i.e. narrative interview) with Narrative Reflective Process to ensure accurate and holistic representation of my co-participant's lived stories in the field texts.

After I developed the interim research text, which is known as the constructed stories in Narrative Inquiry, I sent an email to Noelle, through the university portal, to negotiate the material that I had written. This process is also referred to as *member checking*. Although, I was ready to negotiate any adjustments to the interim field text, Noelle was satisfied with her constructed story.

Throughout the face-to-face interviews with Noelle, I was alert and attentive to how I asked my questions. I continuously assessed her comfort level with each of my interview questions. Furthermore, I created alternative questions, in order to bypass the creative activities scheduled for that session if Noelle chose to do so. In ensuring these respectful and ethical measures were available to Noelle throughout this Narrative Inquiry process, I safeguard her privacy.

***Communication.*** As a researcher, I am the main point of contact for the co-participant. To protect myself from harm, I have utilized my email address provided by the University of Ontario Institute of Technology. This address is the primary mode of contact between myself and Noelle. Furthermore, the recruitment poster explicated, with the permission of my co-supervisor, Dr. Otto Sanchez, his institution telephone number. This number is provided through the University of Ontario Institute of Technology.

In the next chapter, we meet Noelle, who shares her stories of experiencing childhood cancer.

## **Chapter Five: Biography Section**

### **First Level of Analysis**

#### **Noelle's Illness Story**

*As I move from the Geography Section, I make way to the reading circles to enter the Biography Section. In a cozy room with carpeted floors, there are many biographies to choose from. I pick up Noelle's story and settle into a comfortable reading chair. Here, we learn the story that Noelle is a part of and carries with her. These stories are interspersed with my immediate reactions.*

#### ***Meeting Noelle***

It is Tuesday morning. I wake up in a disarray, thinking that I missed my meeting with Noelle. Springing up from bed to check the time, I relax. It is only seven and I have plenty of time before my meeting with Noelle at eleven. I walk over to the window and open the curtains, illuminating the room with the morning light. The cloudless sky is bright blue. What a wonderful day to meet Noelle!

I arrive at the bus loop in time to catch the nine o'clock bus going south. I sit in my usual spot, the second set of two-seaters on the left, next to the window. I think about meeting Noelle. We have only communicated through emails. I wonder, *How does she look? Will she be comfortable with me? Will I be comfortable with her?* I am anxious, but still very excited. I arrive an hour early and head towards the nearby library. I feel very comfortable and at peace when I am surrounded by books. I often ponder what the pages in the books have witnessed over the course of their many readers.

I enter the quaint library, taking in the lime green walls and the carpeted green floors. To the right of the entrance, lining the walls, are familiar elementary school

textbooks. I place my bag down and peruse the shelves. The clock chimes at the half-hour mark, reminding me it is time to go. I quickly gather my belongings and walk towards Hestia, the center that provides support to individuals and families living with cancer which is nearby the library. I am surprised by an old unassuming house hidden behind the vast bushes, and so easily missed. With a white picketed ramp, Hestia resembles a country house in a tranquil, rural setting. When I open the door, two elderly women at the reception greet me with a smile. Of the two, Margaret, dressed in a pastel blue dress helps me sign in and asks the reason for my visit. She asks me about my research topic. I tell her I am interested in childhood experience of cancer. She smiles and says this line of research is much needed. From the reception we turn right into another hallway. The house is a labyrinth of hallways, which I imagine have their own stories to tell. We come to the library, she gestures me in and wishes me good luck. Before I walk into the library, the gold frame beside the door captures my attention: *What counts in life is not the mere fact that we have lived. It is what difference we have made to the lives of others that will determine the significance of the life we lead. Nelson Mandela.* The quote momentarily takes me back to my own questions about death and life.

Hestia's library is cozy and its walls are hidden by bookshelves filled with diverse literature on cancer. The furniture resembles antique family heirlooms, passed between generations. The two chairs face each other, perfected this way for conversations. As I settle on the couch, Noelle walks in. I stand up to greet her with a warm smile. Noelle is a tall, slender woman with long, blond hair. As she makes her way towards the chair opposite me, she comments, *It is nice to be back.* She relaxes into the chair. I ponder

her comment, and wonder what memories are coming up for her. Maybe Hestia, in many ways, has helped and supported her with her illness.

Before Noelle begins her story, I invite her to engage in a creative self-expression, Lifeline activity (Clandinin & Connelly, 1998; Lindsay & Schwind, 2014; Schwind & Lindsay, 2016). I chose to start this way, as drawing is “known to elicit the depths of our being unreachable by words” (Schwind, 2003, p. 25). I bring out markers, pencil crayons and eleven by sixteen inch sheets of white paper. Noelle comments, *Arts and craft! I think carpet is perfect for this.* I join her on the carpet. It reminds me of elementary school. Often, teachers would seat us on the carpet to participate in songs and stories. In creating our timelines together and sharing thereafter, I want to create a safe and comfortable space. I am also on this journey with her. Essentially, in Narrative Inquiry the researcher’s involvement and interaction with the participant contributes to the co-creation of knowledge (Clandinin & Connelly, 1995). Noelle and I make light conversation about our lack of artistic abilities. I reassure her that the timeline does not need to mirror Picasso’s works. She laughs, Good, I’m all for stick figures and rough sketches! The activity takes us about ten minutes to complete.

We both include family birthdays, graduation dates, and other significant family events. But, our timelines are also very different, for obvious reasons. Noelle highlights going in for surgery, being diagnosed with cancer, losing her hair, being put in remission and losing her dog to cancer. However, it is also very similar. We both grew up with siblings and have fond memories of a lively childhood. As I listen to Noelle briefly share the significance of each date, I can’t help wanting to know more. Noelle rubs her knees. *Is it okay to talk while sitting on the couch?* For a moment, I worry if her leg is

hurting because she is not able to sit too long or is it somehow related to her illness. But, Noelle puts me at ease, commenting, *Carpets start to get prickly after a while*. I relax. I feel the same way. We return to our chairs. I meet with Noelle five times in this peaceful space in Hestia's Library. Each and every week, we sit in the same chairs.

Later, when re-constructing Noelle's story, I ask her what font and name she would like to present her voice in the study. She chooses Helvetica font, italics, size 12 and "Noelle" as her pseudonym. However, she worries that her choices are "*too boring*". Helvetica is a type-face font created by a Swiss designer, Max Miedinger (Warnock, 1993). It became immensely popular in the 20<sup>th</sup> century. Helvetica is also the Latin adjective for Switzerland (Warnock, 1993). For me, Helvetica reminds me of the beautiful landscape of Switzerland and the delicious chocolate. It is also a font where the lower case "i" and the upper case "I" are not physically different. This reminds me of Noelle's relationship with her illness. The younger "i" that had experienced cancer and the adult "I" that is now telling me of her illness are intertwined. To distinguish my voice from Noelle's, for mine I use the Times New Roman, size 12 font and indent my responses to Noelle's story.

Although, Noelle has her own reasons for choosing her pseudonym, it reminds me of my favorite holiday. In French, "Noel" means Christmas. Although, I do not religiously celebrate Christmas, the lights, the tree and the gleeful atmosphere warm my heart. Hearing the name, "Noelle" reminds me of settling into the couch with a warm blanket, hot tea and a holiday classic. Sitting across from Noelle at our first meeting, I feel a similar kind of comforting anticipation ...

***Knowing, but not wanting to know: Don't diagnose me***

*For me, cancer is a disease that took so much from me and the people I love. And, surviving has become to mean not always living past it, but more importantly, just fighting through it. It happened so fast for me, and to be honest, at the time, I didn't know what was happening.*

*In August of 2009, while I was hanging out with my neighbor, I suddenly felt a really weird pain in my abdomen. It was the most excruciating pain that I have ever felt. Pressure and sharp-shooting pains. I thought I just have to go to the bathroom, but the pain got worse. I stormed out of the bathroom. In a rush that barely resembled my urgency, I said I was not feeling well and left. Her house was two houses away from home, but it felt longer at that moment. I was doubled-over in pain and wet with tears. I walked into my house. I couldn't speak. I just remember screaming and crying, shouting 'Hospital!' My parents sat on the couch, shocked, not knowing what the hell was going on.*

She pauses for a moment, as if briefly reliving that moment.

Although nowhere near as painful and urgent as Noelle's event, I recall my own experience with food poisoning when I was .... I was hunched over in bed with strong cramps. Everyone else at home was resting. I couldn't get up from the pain. Eventually, my mom found me. Even though I was frightened by the intensity of the cramping pain, I tried to put on a brave face not to worry her. Noelle's story, for me, resurfaces how frightening it is when our bodies deviate from their usual routines. I cannot imagine how it must have felt for Noelle to experience such excruciating pain at such a young age.

*We thought it was appendicitis. But, at the hospital, the pain had subsided. The doctor asked me to do a urine test and concluded that it was just a bladder infection. By then, I've had 3 bladder infections in the past few months. Yet, this one felt different. I had never experienced so much pain. I followed-up with my family doctor a few weeks after and he confirmed it was only a bladder infection. However, for that extra measure of certainty, he ordered an ultrasound for me.*

*The ultrasound technician was the sweetest lady. She continues to, even today, follow-up with me over e-mail. She was the first to see the mass on my ovary. She looked at the image with an intense scrutiny. Her eyes didn't leave this one, particular spot on the image. At that moment I just knew something was wrong. She didn't tell me, but her face gave it away. She then mumbled, "Oh ...this is strange." I was thirteen, I didn't dwell on her comment. I thought it wouldn't be a big deal. But, then they asked me to come the next day. This time, it was her husband who was doing the ultrasound. He asked me questions, but I wasn't paying attention. I was thirteen and the seriousness in his tone didn't register with me. I kept thinking, it was just a bladder infection, nothing else! Then, they asked me to come the following day. I became annoyed that I continued to come and do the same scan over again. But, once again, I came in. At the end, the technician said I'm giving these results to your doctor and you need to get these results checked out. His voice sounded urgent. But, I remember saying to my dad, "It's nothing and I don't know why everybody is freaking out."*

I connect with Noelle's disbelief. It parallels my early thoughts about life before meeting Sadako, the young protagonist who had cancer, in the *Thousand Paper Cranes* book. At thirteen, before reading the book, I hadn't realized how quickly illness could disrupt our world. Although I feared death and the concept of mortality, I didn't fully register how quickly death could follow the onset of illness. Sadako's story made me realize how death and illness are not limited by our age, making me further question my own mortality. How would I die? When would I die?

I wonder if Noelle shares these sentiments. If, deep down, she knew her body was abruptly changing in ways she did not anticipate.

*When my family doctor saw the mass on my ovary, he explained to my mom that it was a pretty big cyst that needed to come out. I remember sitting there, drifting back and forth, still considering the situation to be no big deal. My mom didn't. She asked what the next steps were and my doctor informed her about booking an appointment with a specialist for the surgery in a few weeks' time. The doctor wasn't moving fast enough for my mom. Mom is an administrative professional at a pediatric office. So, she talked to the pediatrician there and immediately got me a consultation with a doctor. In the span of a month, I saw about a million doctors. This doctor got me admitted for surgery at West Care, a children's hospital. At West Care, my doctors told my family that by taking the cyst out, they might have to take one of my ovaries out as well. And it was just like that. I had gone from never having been to a hospital, to spending a lot of coming days there.*

I wonder what the hospital meant to Noelle before becoming ill. Was it a place for dying? Was it a place for new life? I recall the many relatives I had visited in the hospital at a young age. While many of the kids in my school connected the hospital with disease and death, I remembered thinking about it differently. I found it to be a place where my relatives would rest and re-energize. I didn't want to associate death with the hospital because this would mean I was visiting to say my good-byes. I wonder how the meaning of the hospital changed for Noelle with her illness experience.

*While in the hospital I didn't have to go to school, which was fantastic. The day of my surgery, I had an MRI (Magnetic Resonance Imaging), bloodwork, and a bunch of other tests. Throughout all these tests my doctors quietly chatted with my parents. Although, I didn't know at the time, they had told them that it was probably cancer and the tumor had most likely attached to both of my ovaries and my abdominal wall. The surgery would remove the tumor and I would only have to, worst case scenario, do one round of chemotherapy and never deal with this again.*

*My surgery was supposed to be three hours, but it ended up being six and a half, because my tumor had ruptured. They didn't know that. It was half solid, half, like all these weird cancer cells. It was attached to my ovary, strangling it. They took out my left ovary and the tumor. They informed my parents that I'd have to do a few more rounds of chemo than just one because the cancer had ruptured back in August. This was probably the pain I had felt that day.*

*I was not officially diagnosed until seven days after my surgery. In those seven days, in an effort to protect me, no one said anything. My parents, wrapped up in their conversation, forgetting I was there, in quiet desperation said, "What are we going to do if someone says, you have cancer?" I heard the word and uttered, What? My mom was caught off guard, "I was wondering if people, but you're fine. You don't have cancer." But, I knew something was up. I remember overhearing visitors whispering with my mom. My doubts were confirmed when a neighbor came in and said outright, "My mom said that your dad said that you have cancer." When my mom heard this, she became irate, "That's bullshit!" She was angry that someone else had diagnosed me before I was officially diagnosed by the doctor. I was confused. I would try to laugh it off, but deep down I could not shake off this knowing feeling.*

*The day of my diagnosis I sat in the room with a social worker, two nurses and my doctor. They were all looking at me so pitifully. I know it's with empathy, but, they were just looking at me. I couldn't bring myself to make eye contact with them because I didn't want them to diagnose me. I kept repeating to myself, Don't diagnose me! Don't do it! But, they told me it was "funny cells" and that I would have to do treatment. And I remember looking at my mom and just being angry that nobody told me sooner. But, I knew. I was angry at the whole situation. It wasn't fair!!*

I try to imagine how Noelle must have sat on the edge of the bed, looking at the ground, as she received the news. *She is patient. She is a patient.* I contemplate further on these two ideas. The word patient derives from the Latin word *patiens*,

which means *'I am suffering'*. Patient is used as an adjective to describe one's ability to withstand suffering. I believe that both of these resonate with Noelle at this moment of diagnosis. She is suffering because she knows, but she is also withstanding the suffering by holding it in to stay strong for her parents.

*The only thing I knew about cancer was from movies: you lose hair, you throw up, you look really sick and you do not make it. I did not know anything else. I knew very few people who had cancer. A girl in my school had cancer and she died. I asked my doctor if I was going to die. He did not say yes or no. He said they were going to do their best. Doctors were supposed to say that. There was no certainty that I was going to make it. "Try their best", what does that even mean?*

I am afraid of confronting death and coming to terms with my own mortality.

However, Noelle had to confront the possibility of death and face it head on at the age of thirteen. At such a young age, she had to come to terms with the idea that she might not have "forever" as she may have expected. I can only begin to imagine how it must have felt ...

### ***Something to hold onto***

*My doctor said you need to start chemo as soon as possible. The date was right before Iestyn Ryzan's concert. I said I couldn't. He wasn't too pleased. I chose to rebel here. I was excited about this concert since the summer. I could not let cancer have this one thing too.*

*Actually, I heard about the concert in July. I found out that this up-and-coming musician, Iestyn Ryzan, was coming to perform at a club in the East end.*

*I told my sister I needed to go. I don't know why, but I just needed to go. At first, my sister said she was not able to get the tickets and I started to cry. My reaction didn't make sense to me. I could hardly pronounce the singer's name. But I had this gut feeling, I guess. I just knew I needed to go. My sister said she was just joking, showing me the tickets. I was so happy! In the midst of the diagnosis, I was still looking forward to the concert because it was something I held onto. Cancer is happening, but I had this one thing still left. My doctor still disagreed, but I wasn't budging. He said the next morning you will have to start chemo because it's life or death here. I heard the seriousness in his tone. I saw his eyebrows furrow. Yet, I still wanted to go to the concert. So I went, even though chemo was the next day.*

I reflect on the symbolism of the concert for Noelle. I wonder if, while everything was changing, the concert symbolized a normalcy for her that she could control and enjoy. A normal experience that another thirteen-year-old would be experiencing.

*The day of the concert, I didn't know, but my sister contacted the manager, emailing back and forth regarding my situation. I had a picc line [an intravenous line, used to administer necessary medications] at the time, so I couldn't be in a big crowd because it could be easily ripped out. I wasn't able to stand outside too long because I could get a cold and the risk of infections was high. To prevent having to wait in lines or the exposure of the picc, my sister was able to get us backstage access. When we arrived, the manager awkwardly said, I just*

*need to see that she is actually sick, I'm sorry for asking. My sister and I showed her my picc line and the paperwork.*

*We went in early and saw the rehearsals. Iestyn was singing. I was freaking out. He had asked why we were in earlier. Coming to know of my illness, he wanted to sing to me. Basically, I got star treatment and hung out with his friends. That night, I forgot about my cancer and my chemo. I just enjoyed the moment. He brought me up on stage, gave me his hat and sang to me. It was a perfect night!*

*I held onto this moment throughout my treatment. Iestyn helped me through the cancer. I had his poster in my hospital room and I would wear his hat while I rested. This sounds really funny, but I remember sitting on the bed, being afraid that I was going to get sick after my treatment. And would stop myself from doing it, calming myself by saying that Iestyn was 'watching'. I took my Gravol [an anti-nausea medication] and I was fine. My parents were surrounding me, encouraging me to throw up in the garbage can if I had to. It was never good to vomit after chemo. This time I didn't because I kept telling myself the poster was there. It would be embarrassing if he saw me vomit. It was silly, but to a thirteen-year-old girl, he gave me hope.*

Her tenacity encouraged by music and Iestyn Ryzan reminds me of my own connection with music. For me, music can be reflective of my moods. It also helps me connect with my experiences. It makes me feel calm, happy, peaceful, motivated and any other feeling, depending on the choice of music. I wonder if her connection to Iestyn Ryzan and music symbolizes something more. I wonder

if the words in his music helped her to continue fighting. Or is it a typical teenage response to a young contemporary rising star?

*Iestyn's songs were also being released at the time of my diagnosis. So, my mom and I would stand in the kid's lounge, listening on the computer to the new songs and dance. My mom had even tried to bring him to visit the hospital. She contacted almost all the radio stations, explaining my situation and requesting the singer to visit West Care. He did in fact come, but I missed seeing him because I had chemo the next day. It was apparently Iestyn's first visit to West Care, but at least he was able to meet the girls upstairs. To be honest, I was really upset. But, my mom was more upset than me. This was another situation in which she had to accept that she couldn't control everything. She couldn't control my diagnosis. She couldn't control chemo. She couldn't control whether I got to see Iestyn Ryzan. There were some things that I had to face, and watching it happen to me was hard for her.*

I ponder Noelle's words. I imagine, it must have been difficult for Noelle's mother to see her daughter go through such difficulties. To have to sit back and watch Noelle's body alter in response to the cancerous cells and the treatment. To watch her daughter struggle with her illness. To watch her identify the hospital as a second home. Noelle's mom must have felt powerless because cancer prevented her from having that motherly protective control. In all her attempts, her daughter was still not able to see Iestyn Ryzan.

This reminds me that the effects of cancer are like ever-expanding waves made by a stone thrown into the calm of the water surface. For me, cancer is the stone, and

the physical body is the calm water surface. The rippling effect of the ever-expanding waves eventually reach the individual's emotional, mental and spiritual body, as well as her social body, her family, friends and community.

I think of Noelle's mom. It must be hard to watch Noelle go through such devastating trauma, and have no power to stop it.

*Everyone at the hospital came to know about my enthusiasm for Lestyn Ryzan, his songs and music in general. During my treatment doctors and nurses would make me sing as I became under anesthetic.*

*When I look back, I genuinely believe everything happens for a reason. I was always passionate about music at such a young age because both my dad and brother sing. I even wrote songs about my cancer experience. So, this musical experience came at the perfect moment in my life, because it helped me. It immediately diffused all the internal tensions I was going through. Even now, the mention of the concert reminds me of all the fond memories, though little, that I experienced. I felt really happy. I was still at the hospital. I still had to do chemo. I knew what I was going through, but the concert gave me that feeling of being a "teenager" again. Nothing I was going through was normal enough to ask someone, Did you go through this too? But, the concert was normal!*

As Noelle reflects on the concert, I can't help notice how passionate she is about it. It was not JUST a concert to her. It meant so much more! I can't help wonder if it was, what would be considered a "normal" experience that connected her back to her peers. Everything that she went through with cancer was not relatable to the general thirteen-year-old cohort. But, this concert was. Reflecting on Noelle's

interpretation of fate and chance, everything connects. *Everything happens for a reason*, Noelle says. I wonder if Noelle feels the same now, all these years after her surgery and chemo treatment.

***Reality hits: Facing chemo***

*The happiness and buzz of the concert was replaced by the eerie silence of the next morning. I woke up at six in the morning and went to West Care. My treatment was three days straight and then I was given two weeks break. There were four rounds of chemo. During the two weeks of break, I was not on vacation. I was at the hospital, doing bloodwork and tests to see if the treatments were working. It seems simple as I say it, but you can't really prepare for treatment. Doctors and nurses could tell you the symptoms, but it is an experience that, until your body physically goes through it, you cannot understand. The severity of the pain was incredible. I remember asking my doctor if I was going to get sick and selectively choosing what to hear from him. He said, Sometimes people get sick, feel a lack of appetite and experience dehydration. I thought to myself, My cancer is not as bad, so I'm not going to get sick! As if there is a cancer that is better off than the others! I asked if I was going to lose my hair. My doctor said some people don't. You are only doing 4 rounds, so you might lose a bit of hair. I took this to mean, My cancer is not as bad, so I was not going to lose my hair.*

*When it came down to it, chemo was nothing I'd ever experienced before or since. It was the flu, ache, pain, fever, throwing up, and nausea, all at once,*

*ten times the normal dosage. It was like being hit by a truck [laughs]. There is nothing good about chemo. Nothing!*

Noelle's imagery makes me shift uncomfortably in my chair. I cannot imagine experiencing such severe pain. How did she deal with such an extraordinary pain at such a young age? I can only remember chemo from what I've seen in movies. Nevertheless, it isn't depicted in a fun light. When she talks about it, she sounds defiant, and yet I wonder if, deep down inside she was scared beyond belief.

*Being in the hospital helped because I was monitored. So, if I wasn't feeling good, I could get medication for it. But, that first chemo-round was difficult. I didn't know what to expect. I ended up vomiting because of the treatments. I remember the food. The searing residue at the back of my tongue. It was hard to eat that food again. Chemo really heightened my own emetaphobia, which is an extreme fear and anxiety towards anything to do with vomiting. I remember going home after the first round, but the following five days after chemo is a blur. I can't remember the specific details. Laid in bed, hydrated, bathroom, laid in bed, hydrated. It was too much, all at once!*

*My mom was my support and with me every step of the way. Although helpful, her hypervigilance started to overwhelm me as well. She was told by the doctors that hydration, medication and constant bathroom trips were important. So, she would constantly come into my room and ask, Do you need water? Do you need to go to the bathroom? Do you need water? Did you take your medication? I think you need water right now. I was so frustrated. I was so exhausted. I did not feel good at all. And, the last thing I wanted was water. We*

*ended up having a screaming match. She went downstairs, throwing stuff. I sat on my bed, crying. It was just a really hard time. I got too selfish with the diagnosis and that moment was a hit from reality. I wasn't the only one diagnosed! Mom, dad, my siblings ... they were all there with me. My aunt, who survived breast cancer a year before my diagnosis, called me. She calmed me down and shared her own experience. She told me this wasn't an illness that held only the person hostage. It was an illness that took everyone in this person's world.*

I empathize with Noelle. But, I understand the perspective of her mom also. I recall my sister's encounter with a cyst. It was scary for everyone in our family. We did not know if it was cancerous or fluid until after the surgery. My family and I ensured that one of us would sit with my sister at all times. It comforted our own worries and anxiety about her wellbeing. Cancer doesn't diagnose one person. It affects an entire family. It sounds like Noelle's mom felt the same way.

*This prepared me for the second treatment. I knew when to eat and when to take my meds. I knew when the chemo was going to kick in. I knew when I wouldn't feel good. But, I still had bad anxiety when I saw the IV pole beside my bed. I knew what was coming and instinctively I would start feeling sick before any chemo was injected. So, my mom told the nurses that I don't need to see the IV pole. This helped a bit, but the anxiety was very much there.*

*After finishing my second treatment, I lost my hair. I was sitting in my mom's room, on the phone with my friend. I was scratching the back of my head and my hair came right off. It was a clump of hair. I looked at my mom, with my*

*mouth just wide open. I told my friend I would call her back and hung up the phone. My mom and I were just staring, waiting for the other to react. Suddenly, she just started crying. I had to calm her down. Don't cry, it's just hair. It will come back. Once I left my mom's room, I went to my room and started crying. Oh god, I'm losing my hair. It was my shield, my comfort. By the third and fourth rounds, my hair was falling out quicker. I bought a wig and wore it all the time. I never really embraced my bald head because I was never really happy about it. It reminded me of yet another thing I lost with cancer, first being my carefree life.*

Noelle's bravery and her sensitivity to her mom's response touched my heart. At thirteen, she comforts her mother and cares for her concerns before retreating to her room and freeing her own emotions. I cannot imagine dealing with immense, and life-threatening, insecurities at Noelle's age where we are growing and developing, and appearances are so important. And yet, she seemed to handle it all so maturely. There is something about a serious personal illness that pushes our maturation process forward at lightning speed.

*I was never really happy about a lot of things during my treatment. One thing in particular was my anxiety about my picc line. I was getting blood clots and other complications. One day in particular, my picc line was not flushing. The nurse that came to my house to check this suggested I go to the nearby satellite hospital and get it flushed. Just my luck. I had to get my mom to take the day off work, again! On the way, she wasn't complaining, but just venting about it. I started feeling like a bother, having to be a nuisance to everyone. I noticed that even if I was feeling better during the two weeks I'd be off of treatment, I was not*

*able to do anything. I wanted to go skating with my friends. I asked my mom, almost expecting her answer. It was predictable at that point. She said, No, you could get sick. You'll start bleeding and you won't stop. I just wanted to be normal at least when I was off chemo, something that any thirteen-year-old would be doing.*

*By the third and fourth chemo-round, my hearing tests were not too good because of one of the chemo drugs, Cisplatin. It would affect my hearing and give me ringing in the ears. Also, I had memory loss. So, my doctors decided to change it to a different chemotherapy drug. This meant I had to do an additional round. I thought, This sucks! The only plus point was that, by the third and fourth rounds, I wanted to be out of my room as much as possible. It reminded me that I was almost finishing my last lap in this unwanted marathon.*

### ***Second Home***

*My chemo treatments were during the weekends. I would go in Friday mornings and stay till Sunday night or Monday morning. I'd only get offered to do the programs (arts and crafts) on Friday because there were no programs on Saturday and Sunday. I didn't do the programs because I was grumpy. I was the oldest one there. Everyone else was much younger. Although I wasn't physically alone, I actually felt lonely a lot of the time. My mom must have felt lonely as well. While I was being grumpy in my bed, my mom would have to find things to do. She would be on her computer or reading a book by my side. She couldn't go downstairs to get coffee or walk around in the hallways to make herself feel better because I needed my mom an arm's length away. I didn't feel like talking*

*to her. But, I also did not want her to leave my room because I was terrified of not feeling good and not having my mom there. I was miserable and I felt miserable for making my mom feel that way. I remember this particular moment where my dad came to visit in the evening and said I'm taking mom downstairs to get coffee. I got so mad at my dad and asked why he was taking her away from me. I disassociated him from being my dad and treated him as if he was some kind of a monster. So, family dynamics and relationships played out in a place that wasn't our home, but in fact, for those four months it was home for all intents and purposes.*

*I did, however, have one really amazing volunteer, Jim, who was also my camp counsellor. He walked into my room on my first day of chemo and asked if I wanted to play crafts with the kids in the playroom. We joked around. One day, Jim came to my room and invited me to meet some of the girls on the floor above me. He said that they were excited to meet me because I had met Iestyn Ryzan. I was very close with Jim at this point and in a mean, dismissive tone, I replied, No. I didn't want to meet anyone. I didn't want to leave my room. However, that very summer, I met the girls from the floor above at camp and regretted not meeting them earlier when I was offered the chance.*

*We had some great laughs, stories and fun. He knew when not to cross the line. At a time when I did not want to make any friends, he unknowingly became a friend. He just happened to be there for all my sessions. And by my third or fourth round of chemo, he finally succeeded in convincing me to visit the*

*big arts and craft room. We played Jenga, poker and made crafts. I even got to meet some of the friends I'm still friends with today.*

*By the third and the fourth rounds of chemo, my mom would put me in the wheelchair and we'd take pictures and go downstairs. I wouldn't order the hospital food. She would order the hospital food for herself and pretend I was going to eat it. Then, I'd go downstairs and get pizza [laughs], because nobody likes hospital food when they're in the hospital. So, we'd go downstairs and there'd be one spot we'd always sit in. It was to the left of the cafeteria. The windows faced the streets and we sat in the corner. My mom and I would talk, cry, laugh, play math games and people watch. In the last lap of this marathon, my mom became my best friend. I told her everything about me and she told me everything about her. We'd stroll down the hallways and it was just our place. We'd pass by the shops and look at the stuff to buy. Sometimes, we'd go in and buy stuff. She also gave me a camera and tons of journals to document my experience. When I look back at the pictures, I realize I had no recollection of taking these pictures while I was on chemo.*

Noelle's story reminds me of how her relationship with her mom has grown over the course of her illness and treatment. While at the beginning, Noelle's mother was overbearing, probably out of her own fears and sense of helplessness, by the end of Noelle's treatment, Noelle and her mother became the best of friends.

I reflect on Noelle's earlier words about being too selfish about her illness and unappreciative of her mother. I imagine Noelle's maturation was impacted by her illness experience. She came to understand and make sense of her surroundings in

context of her illness. She also came to empathize and understand the situation her mother was in. She realized while this was scary for her, it was just as scary for her mother.

At an age where we usually discover for ourselves who we are, Noelle was “assigned” an identity, with no instructions. She was a cancer patient. She had to make sense of it and be prepared for whatever came her way. This kind of abrupt and imposed maturation process makes me much fully appreciate the impact of cancer on a young person.

*We spent so much time there. I lived and passed through so much there. I experienced fatigue, anger, depression and anxiety. I made friends, created bonds, and unfortunately, saw friends pass. Everything happened at West Care. So, in every sense, West Care really was a second home for me.*

Noelle’s stories remind me of first impressions when entering a library. We observe and internalize the different sections. There is a space for kids, teenagers, young adults and adult fiction. Then, the library has a section filled with non-fiction texts, followed by a particular shelf or shelves filled with reference materials. It is the initial encounter between the library and an enthusiastic reader. However, the moment we open a book and immerse ourselves, we administer our own labels to sections in the library. It becomes personalized. Similarly, Noelle’s stories make me wonder about the deeper relationship between cancer and herself. Engaging in creative self-expression, like the lifeline, allowed Noelle to enter more deeply into her experience, even those pieces of memory she may have superficially forgotten.

*I feel that, sometimes, it's hard remembering all that I went through; doesn't really even feel like me! My scars and pictures are constant reminders (Noelle's Journal Reflection, May 4<sup>th</sup>, 2016).*

***Cancer: A Dark Cloud with a Silver Lining***

I invite Noelle to engage in describing her illness using a metaphor, followed by two visual representations of her illness. One visual representation is to represent her illness, and the second to represent surviving her illness. Arts-informed expressions help emerge the internalized meanings we formulate during our experiences (Clandinin & Connelly, 1998; Lindsay & Schwind, 2014; Schwind & Lindsay, 2016). Using art to help retell storied experiences, we see more and are provided a different lens to learn about the difficult and precious memories of illness (Schwind et al., 2014). I ask Noelle to write, from the perspective of her cancer metaphor, a letter addressed to herself (Schwind, 2003). She scrunches her face, but does so apprehensively. It takes Noelle fifteen minutes to complete her metaphor and letter. I invite her to read it aloud. She begins by describing her metaphor.

*My metaphor is a dark cloud that follows you around but when you look closely there is a silver lining. In the middle of my treatments, my sister found out she was pregnant with her first kid. I was lying on the couch and my sister told us. We were all at her house. I didn't even take it in. It went right passed me. Then, a few days later I went up to my mom and asked if my sister was pregnant? I completely forgot. From then on, my niece was the silver lining around the dark cloud because she came into our lives as we were recovering from my illness.*

Noelle's describes the recovery from the illness as a collective activity that she and her family were going through. This reminds me again that an illness diagnosis impacts the family as a whole. Each family member experiences, in their own way, the anger, the disappointment, the joys, the challenges and the obstacles. Cancer, and any illness for that matter, interrupts the natural trajectory of the family's life. The parents experienced their daughter's illness, while the siblings experienced their sister's illness.

*Dear Noelle,*

*The journey you are about to embark on will be nothing like you ever experienced. It will be filled with many hardships and downfalls. You will see many tears and acquire scars, cuts and bruises. But what you will face in being diagnosed with cancer is not something that a band aid can fix. When it rains, it will pour. But along the way, you will have support to protect you from the storm. As the cloud called cancer hovers over you, you will be handed umbrellas, offering support, comfort and guidance. You will have rain boots, so that your feet do not get tired and soaked from the puddles. These will act as your doctor, your mom, your dad and your siblings. They will shield you, so that the rain does not soak you entirely. Throughout this journey, you must walk, but you'll know that you are not alone as you are protected by those items. There will be many times where you just want to go and hide from the big dark rain cloud, but you know that you cannot do that or else that would mean the storm wins. By the end of the storm, it will finally start to clear up. The rain will begin to lighten, you will look towards the sky and when you see that big dark cloud named cancer, you'll notice the silver lining around it. As the sun tries its hardest to peak through,*

*you'll recognize that this silver lining is from all the wonderful people you've met, the laughs you've had, though far and few in between, and the lessons you've learned to bring you to the end of the storm.*

There is a moment of silence after Noelle is done reading. It is our third meeting. We are comfortable with each other and the moments of silence do not unnerve us. In truth, they give us time to reflect and make sense of words and phrases that emerge during our conversations. Noelle smiles, *I can understand now the importance of this exercise, of writing a letter through my metaphor.* I share with Noelle the importance of metaphor in Narrative Inquiry. I go on to say,

It is interesting that you chose a dark cloud with a silver lining to symbolically represent cancer. But also, you chose a storm as a metaphoric representation of your entire illness experience. A storm is something that affects more than you alone. It affects your whole family, because it means you cannot do your usual family things, like travel or have barbeques. Although your family did not have cancer directly, they were affected by it through your diagnosis.

Noelle nods and says,

*Exactly! This became so important for me to acknowledge as I was being put in remission and transitioning hospitals. I realized that there is so much about cancer that I had and have to deal with. Losing friends, switching schools, anxiety, depression and the burden of uncertainty and doubt regarding my illness.*

Noelle's words resonate her earlier comment, *It never ends.* I feel nervous anticipation as Noelle begins the aftermath of cancer...

## *Difficult Transitions*

*The days at my second home were, unfortunately, numbered. When I was fifteen-years-old, my nurses at West Care told me when I turned eighteen, I would go to Snowdon Cancer Centre. It is the adult hospital equivalent to West Care. I was nervous to leave West Care. I felt comfortable and I wasn't certain I'd feel the same at Snowdon. My nurses reassured me the transition would be gradual and I would feel confident when I leave. However, it did not happen how they described it. I was definitely not confident when I left.*

*When I was eighteen, I went in for my last appointment at West Care. The nurses told me, Your next appointment is at Snowdon Cancer Centre. Here is your sheet. You have to know all of the information pertaining to your illness. I still don't know all of it. I was thirteen when I was diagnosed. My parents sheltered me from most of the details of my diagnosis and treatment. It was surreal for them to expect me to know all the details.*

As she describes her departure from West Care in short, concise sentences, it feels unsettling. It must have all moved so fast for Noelle. Her illness and treatment were fast paced. It sounds like she felt that she was being kicked out of her “second home”. She had so many memories at West Care.

*At Snowdon, on my first appointment I was given a sheet of paper with the contact information for my main doctor. Not my mom, ME! However, after that first day, I have never seen or spoken to that doctor again. I cannot even remember her name or how she looks, because I saw her only once. I think the first day she had introduced herself as my oncologist. I shared my feelings of*

*discomfort regarding the changes. The atmosphere in this new place was darker. There were fewer lights. It was a gloomy environment. There were older people who were terminally ill. And for someone who was told they were in remission, it didn't feel good to walk through all of that. Nevertheless, my doctor reassured me that she would help me adjust. As I mentioned, I have never heard from her since that first day. When I did call her, she was usually not in. This was very different from West Care. I had nurses and doctors monitor me regularly. They were responsive to my needs. I missed them.*

*My relationship with Snowdon is now long-term. Every year, I have a check-up for half an hour. Prior to the appointment, I fill out a form and they base their questions on this form. At my meeting, the doctor also feels my stomach. However, there are no MRIs, which I was upset about. When I was initially diagnosed, no one knew what was going on. It took three MRIs to confirm that I didn't just have a bladder infection. So, yearly MRIs are important to me. My mom was asked multiple times to leave the room. I had to advocate for myself. This was a drastic change from West Care. I hardly spoke and now, I was the only one expected to speak and discuss my illness. I was diagnosed at thirteen, which means for me, the possibility of being re-diagnosed is real. It isn't just a health scare.*

*I don't have the physical disease in me now. But, every day I have my doubts whether I will relapse. I have seen my friends relapse. Some have even passed away from it the second time around. So, cancer is very much still there. Immediately after I was done treatment, I would feel pain in the side of my body*

*and immediately think, cancer is back. Last summer, in particular, my cervix was bleeding and I was in pain. I started to question whether cancer was back. I'd think, It's back. It's happening all over again. Those were my thoughts and fears. It is a vicious cycle. When I was diagnosed, I didn't believe it. Now, I'm in remission and I don't believe it.*

*I was supposed to see an ob-gyn at Snowdon. They didn't do it. I did it all by myself. I contacted my family doctor, arranged a meeting with an ob-gyn. I had a biopsy of my cervix. My test results came in and I was scared. This was resembling much of my initial experiences with my diagnosis. Fortunately, my results said everything was fine. Days later, my doctor at Snowdon calls informing me of the appointment she had established with an ob-gyn that was not until two months. I informed her I had taken care of it. She asked if I was going to send the results and I curtly responded with a No.*

Noelle's words leave me wondering about the difference in communication between the two healthcare institutions. In her younger days with illness, West Care was responsive, efficient and comforting. However, in her present experience at Snowdon, she is left waiting, not knowing who to contact, and feels, almost, disconnected with the institution. She also has feelings of fear and anxiety about her health. She almost feels abandoned by West Care.

Noelle's story makes me wonder about the need for a transition hospital or care catered towards young adults. I imagine the shift from teenager receiving care to young adult receiving care is not easy. As a young adult there are so many expectations that were not present as a youth. Noelle did not have to know the

details of her illness at thirteen, her parents spoke on her behalf. Now, all of a sudden she is expected to know everything about her illness and to speak for herself. It is a difficult additional stress, while she is coping with the aftermath of her illness.

*At this point, I felt that my needs and concerns were not being taken care of. They were unresponsive, once again, when I was dealing with anxiety and depression. I went to see the psychologist at Snowdon. She was free because it was offered with the hospital. We met every week for two to three months. At first, she was listening, which was helpful. However, at some point, listening can only do so much. I needed help. I'd see her checking the time or she would ask me to repeat what certain situations were about. Essentially, it made our conversations fragmented. She was also judgmental. At one point, she used a word about me that I had never used. Based on my academic experiences regarding social work, I know that during counselling, professionals do not rephrase someone else's words. She called me, "snobby". I had not called myself snobby. So, when she chose to describe me using this word, I was caught off guard. It didn't sit well with me. I had informed her that the commute was difficult for me and so discontinued our sessions.*

*Later in the year, I was going through a really tough time with depression and anxiety resurfacing drastically. I wrote this on my form during my second yearly check-up. The doctor who had seen me informed me that the psychologist was informed. I thought, Shoot, I have to see this lady who I stopped seeing so abruptly. So, she comes into the room and asks how I'm doing. This is a question*

*that at the surface value I understand as a conversation starter. I said, I'm good. She looks at the sheet and then looks at me and says, Apparently not, from your sheet. I felt so uncomfortable. We were in a public space and I didn't know what to do. It was a weird experience.*

Noelle's experience with her doctor and psychologist at Snowdon makes me feel upset and disappointed. Patients confide in their healthcare providers. They share sentimental concerns, making them vulnerable. This is not easy. It is important that patients are seen, validated and valued as human beings. I think about my own experiences with my family doctor, Dr. David. I had an inflammatory response to the heat one summer. I was very upset. My face was swollen and I did not want to go outside. At my doctor's appointment, I teared up and said, *Sorry, I know I'm being silly.* My doctor handed me a tissue and said, *It is not silly at all. Our faces are so important to us. It is important for you to express your feelings. Don't worry, this will clear up!* He acknowledged my feelings. He understood and I felt validated and supported as a young person.

*I don't judge her personally, but I don't know if we were a good fit. Everybody has a different fit. I really fit well with the psychologist I found near my home. She was helping me so much. Each meeting, she would come with her laptop and have sounds associated with my emetaphobia. I would then respond, using a scale she gave me, on how anxious the sounds make me feel. With her, I was able to identify the reasons my anxiety would heighten. However, I had used my student allotted coverage of four hundred dollars. If I wished to continue, the rate would be hundred and forty-five dollars for an hour. I could not afford that.*

*I'm a student. When I had said, I couldn't pay the fees, she felt bad and offered me three free sessions. Obviously, the psychologist realizes my need for therapy. But, the fees and lack of financial support is hard on individuals in my situation. At our last meeting, she gave me a sheet of coping strategies that I can access quickly.*

### ***The Fallout of Cancer***

*The transition between hospitals was not the only difficulty. I realized that the older and healthier I appeared, the less assistance I received. You could physically see the disease when I had cancer. I lost my hair. When I was in pain, you could see that. I looked sick. You can't physically see that I have anxiety. You can't physically see that I have depression. This was the problem for the most part after cancer. When I was put in remission, I talked about my illness and feelings of anxiety and depression. My mom would comfort and be responsive because she was familiar with mental health and illness. However, my dad and siblings denied such a thing. It was harder to accept because it wasn't visible. They would say, Noelle it's gone. It would get me thinking, Why am I still not over it? Through my experiences, I realized I'm not over it because it never left. Cancer will always be there in my life!*

*I will face it once again when I wonder if I am able to have kids. At the time I was receiving chemo, I was told that my eggs may have been damaged. When I was told at thirteen that I may not have the opportunity to become a mother, it was the farthest idea from my mind that day. Today, things have changed. One day, I want to be able have kids. I won't know whether this is possible until I try.*

*So, the transition from cancer was never discussed or even addressed. How will I feel after? Why am I anxious? Why am I depressed? How do I seek help at Snowdon? Who are my point of contacts after my doctor? These are all questions that I find answers to only once I experience them.*

*The transition from hospital to school was just as upsetting. First of all, none of my friends from school came to visit me at the hospital. Not even my best friend, which sucked! It wasn't easy going back. I remember bringing my camera to school and showing my friends the funny pictures I took at the hospital. The picture I took of myself when I was losing hair came up. I had patches of hair, but for the most part my bald head was visible. When my friends came across it, they immediately said, Oh, you look like a monster! Those WERE her words! I mumbled, I know, that was really scary. I wish I had stuck-up for myself and embraced how I looked. I remember specifically wearing my hood in the classroom because my hair was just starting to grow. The teacher was okay with it and nobody else cared. However, this one girl yells, Noelle, no hats in school. No hats in school Noelle. Others would tell me, Stay away from me, I don't want to catch your cancer. One boy in my class said that I looked like my brother and started laughing. I laughed with them. It was my way of coping with it.*

*At this point, everyone expected me to get over my diagnosis. You don't have it anymore, get on with school and life. But, it didn't end for me. I went back to the hospital every month. I got needles. I got MRIs. I still heard the word*

*'cancer' every day. I have depression. I suffer from really bad anxiety and emetophobia. It was a really tough time! And it still is.*

*I simply told myself that they were only thirteen and didn't understand what I went through. Once I was put in remission, I realized I am at a higher maturity level than most of my classmates. I'm not bragging about it because I wish I could just be normal and regular. But, it was time to put elementary school and all the negativity behind. Relationships had been broken and I did not want to mend them. I needed a new start. At the time, my dad was a teacher at another high school and obtained an approval for boundary relocation, which allows me to apply for a high school that isn't the primary high school listed for my neighborhood.*

Noelle pauses for a moment and looks distant, as if she is remembering her lost relationships. I can only imagine how difficult it was for Noelle. At thirteen, my friends and school life were crucial. I remember every small detail: participating in talent shows, volunteering at the school convenience store, and baking for international day. Although my friends from middle school and I have gone on different paths, they were an integral part of my growing up process.

Noelle's path was abruptly interrupted by the trauma of illness. Her friends, most likely out of fear and ignorance, did not stay around to support her. As a result, Noelle felt abandoned and lonely during her illness ordeal. During the high demands of her illness experience (numerous hospital visits, doctor visits, lab work and treatments), I imagine, Noelle would have benefited from having her friends around, just to feel "normal" again.

As teenagers, we are expected to define “who we are” through interactions with our friends and experiment how and where we fit in society. Noelle was not able to define who she was or experiment with her social crowd. She was assigned an identity, a cancer patient, which ultimately left her feeling alienated from her friends and community. While her identity left her outside the circle, it also made her understand and make sense of situations differently, than she would have otherwise. Noelle does not “blames” or “finds faults” in any of her friends. Rather, she sympathizes and understands the situation they were in: thirteen, young and did not know any better.

*So, everyone in my middle school went to this one high school and I didn't. At my new school, I formed relationships with my teachers, new friends and met my boyfriend who have supported me and continue to encourage me today!*

*From here, I honed in on my passion for social work and helping individuals who experienced similar illnesses. In fact, my social worker at West Care had the greatest impact on my career choice. By the end of the day when I was just diagnosed, my social worker had me laughing. I was going through this life-changing illness, but despite the realities of it, she had managed to make me smile and feel happy. It struck a chord with me and I realized I wanted to be that person for someone else. My social work program encouraged me to discuss my illness, share my experience and confront my concerns. I was able to grow further. I came to realize that everyone in my program experienced something.*

*I was also able to do my placement here at Hestia, which was both a learning and healing experience. I sat in meetings with individuals who had terminal cancer. They only had a couple of months left. They were going to die. During discussions, I would feel extremely guilty and uncomfortable. I would think, I survived and they wouldn't. It wasn't fair. Why do I get to survive? One of the staff members sat with me and said, Nobody is mad at you because you survived. This is survivor's guilt and it isn't a bad thing because it allows you to understand and really empathize with these individuals. Yet, you should always remember that you fought your own battles and you have every reason to be proud of yourself for facing them. Every person who comes to Hestia should be proud because facing the battles that cancer brings about is synonymous to beating your battles, not surviving. This really helped me because I internalized a new vision of what beating cancer really meant to me. It wasn't the mere fact that I was here and I survived. It was getting through every battle, every obstacle, and every emotional tug.*

I reflect on my own definition of the phrase, "beating cancer." Noelle's advisor at Hestia was right. Too often we make the phrase synonymous to surviving. In retrospect, beating, overcoming, understanding is all a part of confronting and accepting the challenges and the difficulty of cancer as a disease. Would the families feel better knowing this? I cannot be sure of the answer to this question, but Noelle's words give me solace.

*Once, I internalized this, I was able to continue helping without feeling guilty. I was able to connect and share my experiences. By being there, I was able to support my friends who have relapsed and those who have passed.*

### ***Meeting Sadako***

*I was surprised as I finished reading "Sadako and the Thousand Paper Cranes" and having met Sadako. I thought I would read her story, sympathize with it and forget about it. But, the book stayed with me. I connected with it. Her diagnosis, a side effect from Hiroshima bombings made me interested in researching Hiroshima. Her story and my story really intertwined in that, as I read her story, I was reminded of my own. I would question whether this is Sadako's story or my own. While Sadako's family reacted, Sadako was quiet during her diagnosis. This reminded me of my own situation. Everyone in Sadako's family, just like mine, were in denial. I remember my sister's reaction as my mom told her I had cancer. She said to my mom, Mom, you are stupid. Noelle does not have cancer! My sister did not believe it. So, when you are diagnosed with an illness at a young age, specifically cancer in mine and Sadako's situation, your family is in denial. How can this happen? She doesn't have cancer. How can our child have it? You wish you can be in denial too. But, deep down you know that it's happening. I think it's that way for a lot of people. At least, I've seen this from the friends I've met at camp. Before the reality of a medically administered diagnosis, you knew it was happening when it was happening. So, when everybody else around you is reacting, you have to say it's not a big deal. Everybody kind of takes it in this way and tries to be strong for their family. In a*

*way, you have no choice but to come to terms with it because it is happening. You feel it happen in your body. There is nothing that can change that.*

Noelle's words reminded me of the truth in a simple, cliché statement we use, *Nobody knows your body like you do*. Healthcare providers understand the mechanisms behind how our body works. However, only you know how painful or uncomfortable an illness is to your body. You can explain it to someone and they will understand how it may feel. However, they will not experience the pain with you.

I can't help smile at Noelle while she recounts her interactions with the book. She affirms everything she experienced because she saw it through Sadako's viewpoint. Affirming and making sense of the trauma of illness is important. The battle with cancer, or, as Siddhartha Mukherjee calls it, "The War on Cancer" (2010), is unfair because it uses your body to work against you. In the midst of doctors, treatments and tests, the tenacity of the individuals with cancer might be overlooked, especially when this individual is a child. It is inspiring to hear Noelle confidently internalize her own strength when she confronted cancer at thirteen.

*It was also interesting to see a family from a different culture respond to the illness in similar ways. Sadako started building a thousand paper cranes because in Japanese traditions, a thousand paper cranes have the ability to grant you a wish. It was a symbolism of hope and essentially, her desire to live. When I was sick, I was praying to god. I would visit the hospital chapel and sit silently with my dad. Praying and holding onto my belief and faith. It gave me an*

*opportunity to rely on something else, someone else, because every time my family worried about me, I worried about them. I didn't want to be a burden to them. Even though, I still felt like a burden during my diagnosis. It was no different for Sadako. Throughout her journey, she realized how sad her illness was making people around her. She didn't have the strength to make others happy or show them that she was okay, because she wasn't okay. It is hard. You don't want to be a burden, but the impact of the illness leaves you no choice.*

*I live with the illness and its aftermath. Live and not "lived", because it is never gone. It will always be there. And, while I didn't take in what was happening to me, meeting Sadako and her family gave me the opportunity to see it all unfold. I was reminded of my diagnosis, the changes in my life and that of my family's. I was able to read her story and watch her experience from the outside, even though, I knew exactly what it meant to be on the inside.*

*Cancer is a murderer because it really takes. I don't want to create this image that from experiencing cancer, I was enlightened and developed. No! I accepted my diagnosis. I carry my illness with me, even today. From my experience, I became the person I am today. But, I don't want to reduce the disease from what it really is. Cancer is still, a faceless murderer.*

Noelle's words stay with me. She knows how it feels to be on the inside, even though she is reading Sadako's story from the outside. Noelle will always have this dual citizenship. I recall the two images representing her illness. The first image is of Noelle's illness. She is losing hair, looks ill and is in the hospital room. The second image is the teal candle that was made for her on a family trip

during her remission. Similar to the process of candle making and molding, the experience of cancer molded her. From the frail teenager, assigned the identity of cancer patient, to a mature survivor striving to make a difference and give back.

As Noelle suggests, cancer is a part of her. Always!



Figure 1. Noelle's Visual Re-presentation of Surviving. Noelle's Visual Re-presentation of Having Cancer is of her, sitting in the hospital bed, during the time she began to lose hair due to chemotherapy. This picture is the one her friends described as a monster. It is not included in the thesis because it compromises her anonymity.

## **Chapter Six: The Education Section**

### **Theoretical Frameworks**

*In hearing the telling and retelling of the stories that Noelle lives by, I leave the comfortable space of the reading circles and turn corners to visit the next section. It is the Education section. Here, there are books on a variety of works exploring how we understand and make sense of experiences. I reach for the two texts that catch my attention and elicit my reading experience further.*

After engaging with, and reflecting on Noelle's illness story, the second level of justification, the practical, feels challenging. The practical level of justification invites me as the researcher to further explore the narrative and to make sense of the emerging threads in Noelle's story. In this chapter, I discuss and provide rationale for the two theoretical lenses, through which I interpret Noelle's story in Chapter 7.

### **Chosen Frameworks**

In the following sections, I explain the two theoretical frameworks, Erik Erikson's (1968) Stages of Psychosocial Development and Cellular Memory, primarily inspired by Porges' Polyvagal Theory (Porges, 1995; van der Kolk, 1994, 1996; van der Kolk & Greenberg, 1987; Pert, 1997; Ford & Courtois, 2009; Cozolino, 2002; Cozolino & Sprokay 2006; Levine & Frederick, 1997; Rothschild, 2000, 2003). I apply these two theoretical frameworks are complementary to Noelle's story for two reasons.

The impact of how cancer interrupts the expected trajectory of Noelle's adolescent life, and how she responds to such an interruption, mirrors Erikson's Stages of Psychosocial Development. Therefore, I examine Noelle's story through this

developmental lens to more deeply understand her struggle with her assigned identity of a cancer patient, along with her accelerated emotional maturation process.

Noelle's story also reveals the ability of her body to "know" prior to her diagnosis, and to remember the experience thereafter. Research has revealed the posttraumatic stress symptoms in childhood cancer survivors (Kazak et al., 2001; Kazak et al., 2004; Brown, Madan-Swain & Lambert, 2003). In understanding how the long-term symptoms impact childhood cancer survivors even after remission, we gain a new insight into the body, and specifically the cell's ability to "remember" cancer. For these reasons, I use a collection of theories pertaining to Cellular Memory to deepen my understanding of the lasting impact of cancer on the individual. In the following sections, each theoretical framework is further explicated. Specific application of each of these theories is presented in Chapter 7.

### **Erikson's Stages of Psychosocial Development**

Erikson's Stages of Psychosocial Development was developed from modifying and extending Freud's controversial theory of psychosexual development (Erikson & Erikson, 1998). Erikson (1959) accentuates the positive contributions the ego provides through successfully grasping and learning concepts and the talents and attitudes during each stage of human development. His stages are reflective of the responsibilities life offers each of us as we age and mature. In this way, Erikson's theory is considered a stage theory (Cole, Cole & Lightfoot, 2005). Erikson's stages of development, like Piaget's and Kohlberg's theories, depend on the situations presented to individuals at different stages of their life (Cole, Cole & Lightfoot, 2005). These stages explore general issues and similar sequences, which allow them to be universally applicable.

To understand the stages of psychosocial development, it is important to define Erikson's understanding of the "ego." For Erikson, the ego is more than a mediator between the id and the superego as it is for Freud; it represents the total personality (Fleming, 2004). How an individual's ego masters the challenges of life, or more aptly named, "crises," determines the successful development of the ego and in extension, the personality (Erikson, 1959). He defines the successful mastering of crises as "basic strength" and failure to master crises or withdrawal as "core pathology" (Erikson & Erikson, 1998).

The development is said to proceed in an "epigenetic principle." This term originally arises from embryology, which defines the "physiological development of the embryo into a fetus, then a child as a natural unfolding" (Fleming, 2004, p. 9-4). If the development is disturbed, the organ will never develop properly. Similarly, as we grow, we are confronted by a conflict of "opposing forces" (Erikson & Erikson, 1998). For example, as a child we must equally experience trust versus mistrust to obtain a proper solution. If a child experiences an extreme form of either, the child will be respectively too passive and dependent or cynical. It is also possible for the individual to be set back and regress to previous stages (Erikson, 1968). Table 1 provides a brief overview of each stage and its respective crises. However, in the context of Noelle's experience, Erikson's stage reflective of adolescent years, Identity versus Role Confusion, is specifically explored in further detail. This provides rich understanding of Noelle's own sense of meaning-making of her experiences living with cancer during her adolescent years.

## Adolescent Years: Identity verses Role Confusion

During adolescent years, individuals experience many changes. Primarily, their bodies undergo puberty. For this reason, individuals must cope with, and adjust to, many physical changes. Furthermore, social and academic adjustments are introduced. For many teenagers, middle school transition introduces pressures regarding conformity to peer groups. Teenagers also are expected to be more responsible and are given greater academic responsibilities. Erikson suggest that this stage introduces a need for the individual to separate themselves from his or her parents (especially the same-sex parent) and assume an identity of their own (Fleming, 2004). Teenagers usually displace their sexual feelings for opposite sex parents onto others, socially referred to as “dating” (Fleming, 2004).

Stage	Basic Conflict	Important Events	Outcome
Infancy (birth to 18 months)	<a href="#">Trust vs. Mistrust</a>	Feeding	Children develop a sense of trust when caregivers provide reliability, care, and affection. A lack of this will lead to mistrust.
Early Childhood (2 to 3 years)	<a href="#">Autonomy vs. Shame and Doubt</a>	Toilet Training	Children need to develop a sense of personal control over physical skills and a sense of independence. Success leads to feelings of autonomy, failure results in feelings of shame and doubt.
Preschool (3 to 5 years)	<a href="#">Initiative vs. Guilt</a>	Exploration	Children need to begin asserting control and power over the environment. Success in this stage leads to a sense of purpose. Children who try to exert too much power experience disapproval, resulting in a sense of guilt.
School Age (6 to 11 years)	<a href="#">Industry vs. Inferiority</a>	School	Children need to cope with new social and academic demands. Success leads to a sense of competence, while failure results in feelings of inferiority.
Adolescence (12 to 18 years)	<a href="#">Identity vs. Role Confusion</a>	Social Relationships	Teens need to develop a sense of self and personal identity. Success leads to an ability to stay true to yourself, while failure leads to role confusion and a weak sense of self.
Young Adulthood (19 to 40 years)	<a href="#">Intimacy vs. Isolation</a>	Relationships	Young adults need to form intimate, loving relationships with other people. Success leads to strong relationships, while failure results in loneliness and isolation.
Middle Adulthood (40 to 65 years)	<a href="#">Generativity vs. Stagnation</a>	Work and Parenthood	Adults need to create or nurture things that will outlast them, often by having children or creating a positive change that benefits other people. Success leads to feelings of usefulness and accomplishment, while failure results in shallow involvement in the world.
Maturity (65 to death)	<a href="#">Ego Integrity vs. Despair</a>	Reflection on Life	Older adults need to look back on life and feel a sense of fulfillment. Success at this stage leads to feelings of wisdom, while failure results in regret, bitterness, and despair.

Figure 2. Erikson's Stages of Psychosocial Development (Erikson, 1958).

To determine their identities and understand themselves, teenagers must experiment and invent their respective personalities. As mentioned above, dating is one way. However, being motivated and inspired by individuals in their life is another. Erikson highlights the importance of parents to understand when it is appropriate to impose an authoritarian stance during this development; similar to children, teenagers too need rules and limitations (Erikson & Erikson, 1998). For these reasons, Erikson terms this stage, “A turning point of increased vulnerability and heightened potential” (1968, p. 96). To successfully master the basic task of identity formation, adolescents must be truthful or embody, “fidelity.”

### **Coping Mechanisms during Identity Formation**

Adolescents determining their identities use coping mechanisms, which Erikson (1968) identifies as: Foreclosure, Moratorium, Identity Achievement and Negative Role Identity. I discuss Erikson’s coping mechanisms below:

**Foreclosure.** Foreclosure describes a situation where the individual wishes to avoid the stress and anxiety involved in producing an identity (Kroger, 2000). For this reason, the adolescent prematurely conforms to an identity of closeness, such as a parent or a friend. For example, in situations where the child wishes to become a doctor because his or her parent is a doctor depicts foreclosure.

**Moratorium.** Moratorium refers to the opportunity to explore different options, giving themselves a time of relief from fixating or producing one identity (Kroger, 2000). Most importantly, Marcia (1980) identifies that in some cases individuals may experience a crisis, which impedes their self-discovery. Erikson employed moratorium as a teenager

(Erikson & Erikson, 1998) in his own life when he explored Europe prior to committing to a single career choice.

**Diffusion.** Diffusion illustrates a situation where the adolescent does not feel any kind of dedication or passion towards any one particular thing (Kroger, 2000). It is a strategic method to avoid exploring and making commitments. In an amorphous state, there is no pressure, but individuals are still progressing. For this reason, it is the least complex and mature of the coping mechanisms (Marcia, 1980; Cote, 2002). For example, students who aim to merely get by school but not excel. These individuals do not wish to be extremely successful in a particular area because there is no strong interest for any particular course.

**Identity Achievement.** According to Erikson's stages, Identity Achievement depicts the stage at which the adolescent understands the different components that they are made up of, their multiple "selves" and where they are headed in life (Kroger, 2000). Marcia (1980) articulates that for adolescents to obtain this stage, a likely development can be from experiencing a crisis, exploring different identities and finally making a commitment reflective of the internal definition of self.

**Negative Role Identity.** Negative Role Identity illustrates the rebellious identity of the adolescent (Kroger, 2000). The individual chooses an identity that deviates from societal and familial expectations. For this adolescent, there is a disjointed or fragmented association they feel due to a significant and influential interaction. For this reason, a teenager who is the son or daughter of a police officer may steal.

During hospitalization, the adolescent's ability to determine his or her identity is compromised (Vogel-Scibilia et al., 2009). The hospitalized adolescent now becomes

dependent on adults, as they also harbor feelings of anxiety and distress at the idea of being separated from their family and friends (Rollins, Bolig and Mahan, 2005). There are also concerns about bodily injury, pain, image and sexuality (Rollins, Bolig and Mahan, 2005). Most importantly, amongst many adolescents a central fear is losing their identity and peer group status while hospitalized (Rollins, Bolig and Mahan, 2005). They no longer have the freedom to entertain a variety of possible identities, as they are assigned the primary identity of a patient. Furthermore, the landscapes in which they formulate their identity are narrowed to primarily the hospital and home. In exploring Noelle's experience of "a hospitalized cancer patient" through this lens, I seek to understand further how she articulates her given identity and how this life crisis translates into her multiple I's (Connelly & Clandinin, 1990, Clandinin & Connelly, 1995, 2000).

### **Cellular Memory**

Cartesian philosophy was greatly influenced by René Descartes and his understanding of the mind, "I think, therefore I am." The understanding within this phrase is that the mind through its interaction with the pineal gland [a pea-sized mass of tissue behind the brain] make us aware of our existence (Barratt, 2010 p.118). However, research in the field of neuroscience has demonstrated that consciousness and memory are not limited to the mind. Research on mirror neurons illustrate that neural networks automatically activate during "highly specific relationships between the subject and an 'other'" (Barratt, 2010, p. 120; Koch, 2004). For this reason, the limitation of consciousness within the cerebral cortex seriously overlooks the ability of the body, specifically the cell's ability, to remember. The cellular wisdom proposes a complicated and controversial understanding. "Only 2% of our body's intelligence occurs across

synaptic connections, while the rest occurs at the interface of cellular membranes (Barratt, 2010, p. 121; Pert, 1997).

There are many examples in the body that showcase that consciousness surpasses the walls of the cerebral cortex. The enteric nervous system, also known as the “second brain,” is located inside the lining of the gastrointestinal organs (Furness, 2006; Standring, 2008). It continues to function even when the communication between itself and the central nervous system is damaged. Furthermore, the somatic nervous system, an outbranch of the peripheral nervous system, which is responsible for involuntary muscular movement and processing external stimuli, may have, as Barratt (2010) defines, a “mind of its own” (p.120). The bodies of individuals who have experienced trauma naturally record and remember the social engagement (Naritoku et al., 2000; Rothschild, 2000; Levine et al., 2008). These theoretical explanations regarding cellular memory stems from the first theoretical framework proposed by Stephen Porges (1995), the Polyvagal Theory.

### **The Polyvagal Theory**

Stephen Porges’ (1995) Polyvagal Theory is a sophisticated understanding that provides an insight into why a certain face raises our heartbeats and why some voices are relaxing without consciousness awareness. Through using neural surveillance mechanisms, such as neuroception, our bodies determine safe or problematic features (Porges, 2010). This adaptive nature allows us to distinguish when our environments pose a risk. Reflecting Darwin’s original body-brain connection, the vagus nerve (also known as pneumogastric nerve, the tenth cranial nerve) is critical to both memory, and expression and management of emotions (van der Kolk, 2014).

## **Anatomy of the Vagus Nerve**

Van der Kolk (2014) defines the vagus nerve as, “primarily adjoining the nerves and activating the muscles of the face, throat, middle ear, and larynx” (p.81). When individuals see a familiar face and smile, nod their heads or frown when hearing the despair of their friends, our ventral vagal complex is working (Porges, 1997, 1998, 2001, 2003). This system communicates to our heart and lungs via signals and slows our heart rate, while increasing the depth of breathing, for example. This causes us to be calm and relaxed. When we do not feel safe, our ventral vagal complex shows disappointment in our facial expression and we attempt to go through the aforementioned levels of safety. However, when we are at the final stage and there is no means of help, we use our “ultimate emergency system,” the dorsal vagal complex (van der Kolk, 2014, p.82). This system communicates to the stomach, kidneys and intestines and causes our metabolism to be drastically reduced. This system also causes our heart rate to drop and impede the flow of our breathing. Furthermore, our gut stops working and empties out, causing the system to finally collapse, disengage or freeze (Porges, 2010).

## **Reciprocity**

“To be benevolent rather than malevolent is probably a true feature of our species” (Kagan in van der Kolk, 2014, p. 79). In retrospect, for one act of spite, there are many smaller acts of kindness. Thus, human nature is innately caring. However, in order for a caring relationship to be established, van der Kolk (2014) emphasizes the importance of there being “reciprocity.” The individual must truly feel that they are being heard and seen by their environment. For this reason, an individual who has experienced trauma may feel panic around strangers. However, these individuals feel safer around

people with similar experiences of trauma. For example, teenagers who have experienced abuse tend to relate and have a stronger connection to other teens who have had similar experiences. In situations where reciprocity is not felt, the vagus nerve causes an immobilization of the body, which I explain in the following section.

### **Three Levels of Safety**

In situations where the individuals have a damaged neuroception (their ability to evaluate danger is distorted), Porges' articulates that they have a distorted sense of danger (van der Kolk, 2014). Individuals who experience extreme anxiety or depression as a result of traumatic experiences, collapse mentally, panic and are frantic. Porges' discusses the explanation behind this distorted sense of danger. The autonomic nervous system is a branch stemming from the peripheral nervous system and controls three physiological states (van der Kolk, 2014). Porges (1995) identifies three levels of safety that we experience when we feel threatened. When we first feel at risk, we participate in the first level, "social engagement." We seek help and comfort from individuals around us. If individuals do not successfully help us overcome the threat, we return to our primitive nature, fight-or-flight. This mobilization causes us to attempt to fight that which we perceive to be our attacker. When this fails, we are unable to overcome the risk and our bodies, under the control of the primitive, unmyelinated vagus nerve, freezes or collapses. Our body's immobilization is a result of vagal withdrawal and an attempt to preserve the remaining energy (Porges, 1995, 1997, 1998, 2001, 2003).

Experiencing cancer is traumatizing. The illness and the battles are present in the everyday and continue after treatment because the potential for relapse is very real. This experience is not only registered in the brain, but also the cells enervated by the vagus

nerve (Porges, 1995). For this reason, the body continues to feel unsafe; the past is very much embedded into the cellular membranes.

In the next chapter I apply the two theoretical lenses, Erikson's Psychosocial Stages of Development and Cellular Memory developed through Porge's Polyvagal Theory to Noelle's story of experience of childhood cancer.

## **Chapter Seven: Philosophy and Psychology Section**

### **Second Level of Analysis**

*As I carry with me the two texts I have read in the Education Section, I visit the section next to it, the Philosophy and Psychology Section. While I've read on the ways we can understand our experience, this section allows me to reflect and ponder about the experiences further. How can we create new meaning from Noelle's illness story?*

In this chapter, I explore Noelle's story at the second level of justification, the practical. Here, the researcher digs deeper in understanding the inquiry through the chosen theoretical frameworks and relevant scholarly literature (Connelly & Clandinin, 1990). This entails a conversation between Noelle's story, the existing literature, including my theoretical frameworks Erikson's Psychosocial Stages of Development and Cellular Memory and my own interpretation. During this level, there is a shift from the familiar and relational three-dimensional space between Noelle and myself as the researcher to include other scholarly research. This allows a broader understanding of the experiences of childhood cancer diagnosis, inspiring new questions and inquiries.

#### **Emerging Threads from Noelle's Illness Story**

The first level of justification analysis process, as we saw in Chapter Five, entails my reflective personal responses and ponderings to Noelle's illness story. At the second level, I engage in intentional analysis, having read and re-read Noelle's story, and identified emerging threads, which I critically reflect upon using scholarly literature in this chapter.

These narrative threads in my analysis are different from themes identified in other qualitative methodologies. Denzin and Lincoln (2011) articulate that themes are

patterns found across the data, which is specific to the research question. For this reason, themes are reflective of the phenomenon's description (Denzin & Lincoln, 2011). In contrast, threads in the tradition of Narrative Inquiry allow the researcher to identify relationships between the illness story, existing gaps, differences and silences (Clandinin, Steeves, Li, Michelson, Buck, Pearce et al., 2010).

**Re-presentation of Narrative Threads.** Narrative Inquiry is not limited to re-constructing experience through words. The use of other literary forms of communication also allow a deeper understanding of experiences (Connelly & Clandinin, 1990). Using different forms of self-expression, such as poetry and drawings, provide readers with an alternative lens to view and understand the meanings (Lindsay & Schwind, 2014). In re-constructing Noelle's narrative threads using drawings, a self-reflective process can be triggered in readers allowing them to empathize and more fully understand Noelle's experience. In addition, it allows readers to reflect and draw their own conclusions regarding their own experiences. In this inquiry, I re-present Noelle's narrative threads using three different drawings (Figures 3, 4, & 5).

### **Applying the Two Theoretical Frameworks**

#### **Erikson's Stages of Psychosocial Development**

Erikson's Stages of Psychosocial Development framework allows a deeper understanding of the influence that cancer has on Noelle's psychosocial development during adolescence. Erikson explains that teenagers must discover their identities in order to successfully proceed to subsequent stages of development. However, for Noelle, experiencing an illness introduced an interruption and a different trajectory of her lifeline than the one articulated by Erikson, and the one she seemed to be following to that point.

In understanding how such stages are impacted by illness gives me a deeper understanding of the lived experience of childhood cancer. In this way, I can also come to understand why and how Noelle's ability to understand has come to exceed that of her friends and classmates, as Noelle's illness story reveals.

### **Cellular Memory**

In using Cellular Memory to interpret Noelle's story, I am able to understand how Noelle's body is able to remember her illness so vividly, all these years later. And importantly, I gain an insight into why Noelle still experiences anxiety and depression. In describing her illness, Noelle associates cancer as a permanent fixture in her life and in her body. The embedded memories in cellular membranes, according to Porges' Polyvagal Theory, on which Cellular Memory is based, can account for the natural tendencies of our bodies to remember trauma.

### **Employing Theoretical Frameworks with Three-Dimensional Space**

Connelly and Clandinin (2006) articulate that temporality, sociality and place are implicitly rooted in all human experiences. During the second level of justification then, I use the theoretical frameworks and the three-dimensional space together. The three-dimensional space is analogous to the roots of a plant, while the theoretical frameworks represent the water and sunlight necessary for the plant to grow. Similarly, the theoretical frameworks allow for broader understandings, which creates a, "continual reformulation of the inquiry" (Clandinin & Connelly, 2000, p.124).

By engaging with Noelle's illness story using the theoretical frameworks and moving forward, backward, inside and out while visiting different places, relationships and time periods, I attempt to make meaning and further understand the nuances of her

experience. My initial questions and remarks as the researcher then extended to further conversations with the literature on childhood cancer experiences. In doing so, the literature is strengthened and the voices of Noelle and other young patients like hers can be heard.

### **Understanding Childhood Cancer**

In synergistically applying both Erikson's Stages of Psychosocial Development and Cellular Memory, I critically analyze the three narrative threads that emerge from Noelle's story: Relationships, Identities and the Embodied Experience. I realize that I essentially "suspend" Noelle's life in motion to re-present them. However, I recognize that Noelle's life is in motion as we co-constructed her illness story and that her life and way of making sense of her cancer experience continue once the inquiry is completed.

#### **Relationships**

The significance of relationships is visible throughout Noelle's story. Her relationships with family, specifically with her mother, friends, healthcare professionals, cancer and herself, illustrate the significance that connections and associations have for an adolescent experiencing childhood cancer.

#### **Relationships with Family**

Family is an important thread that Noelle identifies at the get-go of our life-line activity. She associated important dates of her illness with the important dates of her family members. This association reveals how the two are intertwined. During Noelle's initial diagnosis, she shares her sister's reaction to her illness: *She said to my mom, Mom, you are stupid. Noelle does not have cancer!* This is one of the earlier moments where we hear how an illness sounds to family members. It is not believable.

How can our sister have this diagnosis, while we don't? For Noelle, this specific situation was one of many where she quietly accepted what was happening to her body, in order to spare her family's suffering. Kroger (2000) articulates that while adolescents contemplate identities and responsibilities, there is a need for them to validate their capabilities to their family members and peers. In accepting the condition that she has no control over, Noelle illustrates the resilience of adolescents when feeling as if they have to prove themselves.

Furthermore, Noelle later shares that while being told by the doctors she had cancer: *I remember looking at my mom and just being angry that nobody told me sooner.* Noelle's response illustrates Erikson and Erikson (1998) claim that adolescents want their parents to treat them as equals. Noelle was the last to know about her illness. In retrospect, she understands her family was trying to protect her. However, at the same time, in protecting her, Noelle became a "dependent child," which is an identity she grappled with over the course of her illness.

For the above reason, there is a different psychosocial developmental stage for hospitalized children than the one articulated by Erikson (Vogel-Scibilia et al., 2009). These adolescents almost experience a *backwards and then fast-forward* shift that is congruent with the findings of other researchers (Vogel-Scibilia et al., 2009; Gavazzi & Sabatelli, 1990). Here, we can see how Noelle shifts backwards:

*My dad came to visit in the evening and said I'm taking mom downstairs to get coffee. I got so mad at my dad and asked why he was taking her away from me. I disassociated him from being my dad and treated him as if he was some kind of a monster.*

Although, at the adolescent stage, healthy individuals want to separate themselves from their family and be independent (Erikson, 1968). Noelle exemplifies the opposite. At the moment of crisis, Noelle wants her mother there for moral support, while blaming her father for taking her mother out for coffee, just to give her a break. She is inseparable from her mother. Kroger (2000) and Crane (2005) both articulate that dependency on one parent is associated with the stages of psychosocial development prior to twelve years of age. Hence, it is clear that Noelle, along with adolescents experiencing a serious illness, reverts to an earlier stage of psychosocial development.

This dependency is part of an adolescent's struggle with making sense of this new assigned identity of cancer patient. During Noelle's at-home visits, her picc line was not flushing. In order to do so, the nurse suggested to go to the nearby satellite hospital. Here, Noelle shares: *I had to get my mom to take the day off work, again! On the way, she wasn't complaining, but just venting about it. I started feeling like a bother, having to be a nuisance to everyone.* Noelle cannot do this alone, but in asking her mom constantly, she feels that her illness is taking a toll on her mom's life as well.

In having an argument with her mother about the expected routine out of the hospital, Noelle realizes that: *I got too selfish with the diagnosis and that moment was a hit from reality. I wasn't the only one diagnosed! Mom, dad, my siblings ... they were all there with me.* This awareness and wisdom that appear within months of Noelle's illness speaks to the fast-forward maturation I noted earlier. Erikson and Erikson (1998) articulate that individuals aged nineteen to forty years, experience the stage, *Intimacy vs. Isolation*. Here, these individuals develop a sense of self and strong relationships. Noelle does this within the span of months. She re-evaluates her attitude

and makes a conscious effort to understand the perspective of her family members. In some cases, Noelle demonstrated behaviours expected of forty to sixty-five-year-olds in that she creates a positive change that benefits people around her (Fleming, 2004). Erikson articulates that individuals between the ages forty to sixty-five experience *Generativity versus Stagnation* (Fleming, 2004). Here, the individuals create positive changes that benefit other individuals. These individuals embody a deep and emotional involvement in the world they interact in. In every sense, this illustrates that Noelle experiences a *backward-fast-forward* trajectory.

Noelle's maturity extends to being understanding towards her family members even when they don't understand her. In expressing the aftermath of cancer, Noelle shares that the transition was difficult. She survived the cancerous cells, but experiences psychological symptoms that are harder to accept by her family. She shares that her dad would say: *Noelle it's gone*. Noelle does not find fault or reprimand her family members for their lack of understanding. Instead, she sympathizes and rationalizes their judgements: *When I was in pain, you could see that. I looked sick. You can't physically see that I have anxiety. You can't physically see that I have depression*.

The moment Noelle was diagnosed with cancer, there was an urgency. She was immediately seeing doctors, setting up appointments and received diagnostic imaging. However, there is a disbelief and ignorance when mental health and illness concerns arose: "Our daughter does not have depression. She is normal." This particular situation emphasizes the stigma that is inherent in conversations on mental health and illness (Corrigan, 2004; Wahl, 1999; Rüsçh, Angermeyer & Corrigan, 2005). Although society

has progressed in breaking these stigmas, they are still very much present (Rüsch, Angermeyer & Corrigan, 2005). Often, families' worry that society will begin to isolate their child (Wahl, 1999). The family, perhaps, also find it hard to accept their daughter who experienced/is experiencing cancer, has another condition.

Casillas et al. (2010) claim that childhood cancer survivors require family involvement even in the adult health care setting. Noelle shares: *I hardly spoke and now, I was the only one expected to speak and discuss my illness.* Due to the integral role family played during the course of her illness in Noelle's younger years, familial presence helps to reduce her anxiety with the new adult care centre (Casillas et al., 2010). Vogel-Scibilia et al. (2009) acknowledge this in their work, stating that there is always a "psychic reworking of the fundamental steps" (p. 405) when a child experiences hospitalization. This is true for Noelle, as her own psychosocial development is different from the one that is articulated by Erikson.

**Relationship with Mother.** Noelle's relationship with her mother is interesting. In Erikson's stages of psychosocial development, teenagers distance themselves from their parents, especially the same-sex parent in order to establish their unique sense of self (Fleming, 2004). However, in later years of adolescence, the teenager learns and applies core values reflective of their parents (Cole, Cole & Lightfoot, 2005). For Noelle, this transition of dependence, distance and returning is not as clear-cut as Erikson articulates. During the early days of Noelle's diagnosis and treatment, she distances herself to some extent, but still remains very much attached to her mother. Therefore, Noelle seems to occupy this in-between grey space. Noelle explains that:

*She [her mother] couldn't go downstairs to get coffee or walk around in the hallways to make herself feel better because I needed my mom an arm's length away. I didn't feel like talking to her. But, I also did not want her to leave my room because I was terrified of not feeling good and not having my mom there.*

Again, this demonstrates a backward slide, a psychosocial regression, in Noelle because she is experiencing the trauma of her illness.

Noelle's mother also grapples with the changes. While mothers' of adolescents must give them privacy and space to experiment, the illness prevents Noelle's mom from doing so (Erikson & Erikson, 1998). This is expected. It is very hard for the parent to let go when their child is experiencing something that is out of their control. Noelle shares that it was hard for her mother to accept that she couldn't control everything: *She couldn't control chemo. She couldn't control whether I got to see Iestyn Ryzan. There were some things that I had to face, and watching it happen to me was hard for her.* The impact of childhood diagnosis creates ripples that illustrate it is not only the child who is affected, the family members are affected as well. The reactions of Noelle's mother provided Noelle with a window to see past herself in this diagnosis. She became aware of how her mother struggled with accepting her daughter had cancer. She saw that though her body was host, cancer takes each and every family member psychologically.

In retrospect, Noelle and her mother's relationship returns to a healthy understanding quickly after a critical point of tension. Noelle shares an incident where

her mother, who she identifies as her support throughout her journey, overwhelmed her during the first break from chemotherapy:

*I was so frustrated. I was so exhausted. I did not feel good at all. And, the last thing I wanted was water. We ended up having a screaming match. She went downstairs, throwing stuff. I sat on my bed, crying. It was just a really hard time.*

Noelle and her mother struggle to make sense of the traumatic situation they find themselves in. Noelle is further decentered by her assigned cancer patient identity.

As mentioned earlier, Noelle embodies an understanding of her mother that is expected to be seen in the stage Erikson articulates as Young Adulthood (Fleming, 2004). When she begins to lose hair, Noelle was in her mother's room. She shares: *Suddenly, she just started crying. I had to calm her down. Don't cry, it's just hair. It will come back. Once I left my mom's room, I went to my room and started crying.* Noelle's ability to soothe and calm her mother before addressing her emotions, shows how quickly she recovers from being *too selfish with her illness.*

Noelle went on to share: *In the last lap of this marathon, my mom became my best friend. I told her everything about me and she told me everything about her.* Once again, the relationship with her mother changed over several months of the acute illness course to further validate the notion of *backward-fast-forward* trajectory.

### **Relationships with Friends**

We conceptualize who we are within a particular place, where most often, our social interactions take place. During adolescence, this place involves friends and classmates who are at the center when defining one's self-worth (Erikson & Erikson,

1998, Kroger, 2000). For Noelle, this is not the case. For a span of four to five months, the place for peer group social interactions shifted from school to hospital. For Noelle, being isolated from her friends and experiencing events that are very different from common adolescent experiences is difficult. She is not able to interact on the same landscapes as them. Noelle shares: *None of my friends from school came to visit me at the hospital. Not even my best friend, which sucked! It wasn't easy going back.* For this reason, Noelle's stories to live by (Connelly & Clandinin, 1999) are unfolding by the gaps between herself and those who, at one point, were her friends.

Noelle explains that when she did go back, she brought her camera to share the funny pictures she took at the hospital. She shares:

*The picture I took of myself when I was losing hair came up. I had patches of hair, but for the most part my bald head was visible.*

*When my friends came across it, they immediately said, Oh, you look like a monster! Those WERE her words!*

Her friends, rather than supporting her, were triggering her to question her self-worth. Comparing her to a monster creates more distance, causing Noelle to feel as if she is an outsider in a group that was once, her center.

When Noelle wore a hat because her hair was still growing, she remembers three different instances where classmates were being very insensitive. The first involved a classmate yelling repeatedly: *[N]o hats in school. No hats in school Noelle.* While others would tell her to: *Stay away from me, I don't want to catch your cancer.* The third interaction is of a boy who said: *I looked like my brother and started laughing.* Noelle admits that, although she laughed with them as a way of coping with what was

happening, it hurt. These were people she went to school with from such a young age who didn't understand everything that she was, and still is going through.

Although lots relationships placed a toll on Noelle, she reasoned with herself that *they were only thirteen and didn't understand what I went through*. Noelle does not find faults in her peers or friends. She accepts that, while she is at a *higher maturity level than most of [her] classmates*, her classmates are not. They do not understand that cancer is an illness, experience, teacher, friend, foe and part of her throughout her life. As Porges (1995) articulates, Noelle's body will forever remember this trauma. For Noelle, *it was time to put elementary school and all the negativity behind*. She chose a different high school and start with new people; a mature and wise choice.

We can see that Noelle and her friends are at different psychosocial stages. While Noelle exhibits a blend of the stages Erikson articulates as Young Adulthood (nineteen to forty years) and Middle Adulthood (forty to sixty-five years), her friends are still grasping with the Adolescence stage. In being at two different stages, it is hard for her friends to really understand with empathy what Noelle experiences with cancer and there are tensions with fostering a newfound, healthy relationship. Noelle's response to move on shows how she, as Erikson articulates in the Young Adulthood stage, successfully stays true to her self (Fleming, 2004). She also actively creates a nurturing and health environment by choosing a new high school embodying the Middle Adulthood stage (Erikson & Erikson, 1998).

## **Relationships with Healthcare Professionals**

Noelle's relationship with healthcare professionals is important because they played an integral part of her illness from the beginning and continue to do so. However, the relationship between herself and her professional caregivers change as she ages.

At West Care pediatric hospital, Noelle feels connected and cared for. She shares: *During my treatment, doctors and nurses would make me sing as I became under anesthetic.* Recalling her interests and incorporating music into Noelle's care illustrates how these healthcare professionals embody a holistic approach when providing care. It is not just another patient or child. The healthcare professionals see and hear Noelle and recognize her unique interests. Noelle goes on to share: *I had nurses and doctors monitor me regularly. They were responsive to my needs.* It is important for Noelle to be heard and cared for.

Her transition from West Care to Snowdon, adult cancer centre, shows how the individual's relationship with healthcare professionals shifts with age. Noelle shares her experience during her last appointment at West Care at the age of eighteen:

*The nurses told me, Your next appointment is at Snowdon Cancer Centre. Here is your sheet. You have to know all of the information pertaining to your illness...I was thirteen when I was diagnosed. My parents sheltered me from most of the details of my diagnosis and treatment.*

Not only does she feel abandoned, but there is a shift in her responsibilities. Noelle is being addressed, rather than her parents, and asked to take on the adult responsibility of caring for herself.

Her appointments at Snowdon are based on forms with a number of questions she must fill out. From the start, she feels no connection with the institution or any of the healthcare providers. (I changed the word caregivers to healthcare providers here – recognizing that many people beyond professional are caregivers, such as family members, and not just healthcare providers. When Noelle felt scared due to pelvic pain, healthcare professionals at Snowdon were supposed to set an appointment with the gynecology specialist. She was worried whether the cancer had returned because the situation resembled much of her initial pain back in August. She shares:

*They didn't do it. I did it all by myself...Days later, my doctor at Snowdon calls informing me of the appointment she had established with an ob-gyn that was not until two months. I informed her I had taken care of it. She asked if I was going to send the results and I curtly responded with a No.*

For Noelle the reality of cancer and relapse is very real. She has experienced a sudden diagnosis and now lives in remission knowing that cancer could come back any day. The lack of urgency from her doctor at Snowdon made her feel unheard, uncared for and disconnected. There often is a significant gap in healthcare services when providing care for young adults (Casillas et al., 2010; Michaud, Suris, & Viner, 2004). A lack of understanding regarding the transitional period these patients go through continues to create distance between the young adult and access to health services. In not being able to access services confidently, these individuals are left to feel helpless and struggle every day with the feelings. Noelle, for example, does struggle with depression. In carrying her

depression with her, it affects her life in many ways, professionally, relationships and so on.

Specifically, Noelle mentions an interaction at Snowdon Cancer Centre that worsened this disjointed feeling. She made an appointment with the psychologist at Snowdon because it was free of charge to discuss and work through her problems with anxiety and depression. She recalls this one psychologist was listening at first, but then began checking the time and not paying attention. Noelle shares:

*She was also judgmental. At one point, she used a word about me that I had never used. Based on my academic experiences regarding social work, I know that during counselling, professionals do not rephrase someone else's words. She called me, "snobby". I had not called myself snobby. So, when she chose to describe me using this word, I was caught off guard. It didn't sit well with me.*

Sometime after, the same psychologist made Noelle feel uncomfortable once again. At a subsequent hospital visit, Noelle was having great difficulty coping with depression and wrote this on her form. Her doctors then called the same psychologist to come to visit with her. Noelle shares:

*So, she [psychologist] comes into the room and asks how I'm doing. This is a question that at the surface value I understand it as a conversation starter. I said, I'm good. She looks at the sheet and then looks at me and says, apparently not, from your sheet.*

The unprofessional manner in which this doctor addressed Noelle causes her to not only feel uncomfortable, but lack confidence in the services available to her. Van der Kolk

(2014) notes that Porges believes that there needs to be a sense of reciprocity in order for the individual to feel safe. One must feel that they are being heard and seen in their respective surroundings. Here, Noelle does not feel reciprocity. She does not feel heard. And, she feels disrespected. In not feeling the reciprocity, Noelle's body, the cells enervated by the vagus nerve experiences the second level of threat, flight (Porges, 1995). She removes herself from interacting with this doctor in the near future. During the second interaction where Noelle meets the doctor once more, she feels very uncomfortable and her body almost freezes.

### **Relationship with Cancer**

Noelle's relationship with cancer is strikingly important in creating the stories she lives by in relation to how she makes sense of her illness and how her illness shapes how she makes sense of the world (Connelly & Clandinin, 1999). Through our art-informed activities during the Narrative Reflective Process, Noelle's illness metaphor helps her reflect on and make sense of her relationship with cancer.

Within her metaphor, Noelle describes her cancer as *a dark cloud that follows you around but when you look closely there is a silver lining*. Her initial relationship with her illness is dark and foreboding. In drawing parallels with a dark cloud, Noelle describes cancer as being a part of nature, but also intrusive into her life. A dark cloud makes one unable to enjoy the day and have to stay inside, which, is very similar to the effect of cancer. Cancer prevented Noelle from having adolescent experiences similar to her peers. Her acknowledgement of the silver lining shows how her understanding of her illness has evolved. The silver lining of the cloud emphasizes the positive gifts that cancer has brought into her life: her niece who was born months after Noelle went into

remission and the relationships that have strengthened over time, such as her relationship with her mother. Below is an excerpt from Noelle's illness letter describing her journey:

*The journey you are about to embark on will be nothing like you ever experienced. It will be filled with many hardships and downfalls. You will see many tears and acquire scars, cuts and bruises...When it rains, it will pour...As the cloud called cancer hovers over you, you will be handed umbrellas, offering support, comfort and guidance...There will be many times where you just want to go and hide from the big dark rain cloud, but you know that you cannot do that or else that would mean the storm wins. By the end of the storm, it will finally start to clear up. The rain will begin to lighten, you will look towards the sky and when you see that big dark cloud named cancer, you'll notice the silver lining around it.*

Her letter shows the uphill battle that she faced with cancer. She experienced feelings of anger, isolation, acceptance and growth. The letter powerfully describes the support and guidance she has received in overcoming the challenges with her illness. Finally, it also speaks to the long-term connection she will have with her illness. This last acknowledgement regarding the permanent fixture of cancer in the patient's life is often overlooked by healthcare professionals (Casillas et al., 2010; Michaud, Suris, & Viner, 2004). Cancer does not end with removing the cells. It continues to impact the patient's life, as we have seen in Noelle's story. Noelle's body remembers experiencing cancer and through depression, anxiety, emetaphobia and constant fear for relapse, it lives on in Noelle's body, forever (Porges, 1995; van der Kolk, 2014). This is reminiscent of

Elizabeth's metaphor of a "wolf-keeper" for her autoimmune illness, as a life-long companion who can reactivate unexpectedly (Schwind, 2003, p. 29).

### **Relationship with Herself**

Noelle's relationship with herself has evolved and influences the ongoing identities she assumes: student, social worker, girlfriend, daughter, aunt and sister. At the onset of her diagnosis, she was forced to accept her illness, as she had no control of it. However, she struggled with her assigned identity of patient and what it essentially meant to her to be a cancer patient.

In the first couple of days with her diagnosis, she regresses to what Erikson coins as Infancy and Early Childhood stage (Fleming, 2004). She is attached to her mother and does not wish to be separated. She regresses or what I coin in my thesis, she shifts *backwards*. Later on, her mother's constant reminders about medication and hydration, creates tensions between the two. During these moments, Noelle embodies the typical teenager that Erikson articulates in his work. She does not want to have someone constantly checking up on her or being treated like a kid. Through the tensions with her mother, she realizes, understands and accepts that she was being selfish with her illness. Here, we see the development of the *fast-forward* shift I mention earlier in this chapter. What Erikson (1959) articulates during the Young Adulthood and Middle Adulthood stages, Noelle articulates while being thirteen. This illustrates that many children that experience hospitalization at a young age display a very different trajectory than Erikson's'.

Despite her diagnosis, similar to other adolescents, she rebels and attends a concert in order to establish some sort of control over her life. However, as her illness

plays out, she isolates herself in her hospital room with her mother at her side. At one point, Noelle shares that her camp counsellor Jim, who was also a volunteer at the hospital at the time, tried to get her to meet the girls upstairs. She shares: *[I]n a mean, dismissive tone, I replied, No. I didn't want to meet anyone. I didn't want to leave my room.* For a time, she does not know who she is or what she has to offer, because her cancer diagnosis was unexpected and abrupt. Her identity is in flux and she is struggling with the given label of “patient.”

In some sense, Noelle’s relationship with herself developed alongside her relationship with cancer. The moment she internalized that she was not the only person impacted by her illness, she opened herself to becoming more accepting. She began to understand the reactions of her mom, family, peers and doctors. She also pro-actively sought assistance for her healthcare needs. Furthermore, she gained a holistic sense of herself when she no longer passively articulated the thoughts her friends and peers shared. This is seen when Noelle switches schools and forms rich and meaningful friendships reflective of her core values and beliefs. Noelle shares these same thoughts, *I accepted my diagnosis. I carry my illness with me, even today. From my experience, I became the person I am today.*

Noelle’s development is different from her peers and friends who have not experienced illness. The realization and maturation that occur so quickly, further justifies why the psychosocial development for young patients with illness should be seen as a *backwards-fast-forward* trajectory.

### **Re-presentation of narrative thread: Relationships**

I re-present Noelle’s stories related to her relationships with her family, mom, friends, healthcare professionals, her cancer and herself through a drawing in Figure 3.

The multicolored umbrella symbolizes the importance of these relationships, while experiencing the dark cloud, cancer. The different colors on the umbrella symbolize the different relationships. The rips resemble the broken relationships, while the bandages represent the relationships that have mended and continue to support Noelle. Overall, the umbrella protects her from the dark cloud of cancer!



Figure 3. Re-Presentation of Narrative Thread: Relationships

### **Identities**

Identity is another thread that emerges in Noelle's illness story. Adolescents are expected to compose their identities within elementary, middle school and high school landscapes, along with complex home and community landscapes (Clandinin et al., 2010). These stories to live by surround the question of who they were and who they are becoming. Noelle and many children experiencing illness differ from children not

experiencing cancer or another significant illness. These children develop their identities within complex home and hospital landscapes. During this time, they are frequently told what they are and who they are rather than given the time to make sense of themselves.

### **Adolescent-Patient Identity Rift**

Noelle is assigned the identity of “cancer patient.” In understanding what was happening to her, she shares: *I was confused. I would try to laugh it off, but deep down I could not shake off this knowing feeling.* Noelle feels confused and uncertain because she is only given the span of seven days to come to terms with the given identity of patient that she must assume. It is the reality of her situation. She later goes on to reveal that while she was being diagnosed, she did not want her doctors to do it. She doesn’t want an identity that she didn’t choose, an identity that prevents her from experimenting like her friends and doing “normal” teenage things.

*I wanted to go skating with my friends. I asked my mom, almost expecting her answer. It was predictable at that point. She said, No, you could get sick. You’ll start bleeding and you won’t stop. I just wanted to be normal at least when I was off chemo, something that any thirteen-year-old would be doing.*

Noelle’s interactions illustrate two key points. The first is that she struggles with what is expected of her with this new identity of which she wants no part. Secondly, she associates this given identity as not being “normal.” Not being normal means you are different from your friends. This disconnection shows how identity further impacts social interactions. In echoing Noelle’s words, *It is a vicious cycle.*

In alignment with Erikson's four stages of identity formation during a crisis, Noelle is experiencing "Foreclosure." Noelle is committing to an identity due to pressure or uncontrollable factors (Erikson, 1959).

At this point, her illness molds her identity. However, when Noelle begins to understand that her illness is something her family deals with as well, she is able to mold her identity on this understanding. Her intrinsic values and inner-self are projected. Noelle is understanding, strong, passionate and giving. In coping with the difficulties of transition, she experiences "Identity Achievement". As mentioned in Chapter Six, this stage occurs when the adolescent understands, what Erikson (1959) calls as their "true self" and where they are headed in life (Kroger, 2000). Through her experiences and the ways in which she chose to make sense, Noelle sees the profession and practice of social work and giving back to others as one of the "I's" she embodies.

### **Survivorship Status**

Noelle's identity is tested when she struggles with accepting and coming to terms with the status of survivor. She adapts to "patient," and now, must adapt to "survivor." The complications of this identity are revealed during Noelle's placement at Hestia where she sat in meetings with individuals diagnosed with terminal cancers. Noelle shares that: *During discussions, I would feel extremely guilty and uncomfortable. I would think, I survived and they wouldn't. It wasn't fair. Why do I get to survive?* Noelle feels guilty. Why did she survive and not her friends or the individuals at Hestia?

Essentially, Hestia helped shape her understanding of this new addition to her multiple I's. The staff at Hestia briefed with Noelle and discussed the implications of

surviving and the unique qualities she brings into discussions because she survived.

Noelle explains:

*This is survivor's guilt and it isn't a bad thing because it allows you to understand and really empathize with these individuals. Yet, you should always remember that you fought your own battles and you have every reason to be proud of yourself for facing them. Every person who comes to Hestia should be proud because facing the battles that cancer brings about is synonymous to beating your battles, not surviving.*

Noelle begins to make sense of what surviving means. It isn't a gloating victory. It is acknowledging that she fought her battles. In doing so, she begins to accept that part of her as well and therapeutically supports individuals during the session.

### **Re-presentation of narrative thread: Identities**

I re-present the narrative thread: Identities through the visual drawing of the candle-making process. When I asked Noelle to bring an image of surviving cancer, she brought in the image of her Teal candle. The beautiful candle produced from physically shaping the block of wax with hands reminds me of the molding process of Noelle's identity throughout her illness.



Figure 4. Re-Presentation of Narrative Thread: Identities

### **Embodied Experience**

The third narrative thread that emerged from Noelle’s illness is the “Embodied Experience.” Noelle’s body is significant in how Noelle experienced her cancer and continues to experience her cancer now.

### **Philosophical Understanding of “Embodied”**

Embodied cognition is the belief that the mind is not only connected to the body in a unilateral relationship (McNerney, 2011). Our ability to understand our existence stems from the “nature of our brains, bodies and bodily experiences” (McNerney, 2011). Hence, it is not only our cortices, but also visual and motor perceptions that give rise to memory. Thus, “embodied experience” is a thread that emerges from Noelle’s illness story and defines the body’s vivid memory of her traumatic experience with cancer.

## Loss of Body, Loss of Self

In reading and re-reading Noelle's illness story, there is a clear indication that Noelle was aware of her illness prior to a medical diagnosis. Noelle feels an urgency with her first pain in August. Noelle shares: *By then, I've had 3 bladder infections in the past few months. Yet, this one felt different. I had never experienced so much pain.* The urgency she felt internally reflects the cellular memory of our bodies that many researchers (Porges, 1995; van der Kolk, 2014, Cozolino, 2002; Levine & Frederick, 1997) articulate.

She had a gut feeling that she could not shake off and this gut feeling was confirmed during her interaction with the ultrasound technician. *She was the first to see the mass on my ovary. She looked at the image with an intense scrutiny. Her eyes didn't leave this one, particular spot on the image. At that moment I just knew something was wrong.* In particular, Noelle shares that: *Before the reality of a medically administered diagnosis, you knew it was happening when it was happening... You feel it happen in your body.* Again, we see how the body is capable of understanding what is going on. Our bodies are self-aware similarly to how our minds are aware of our surroundings, illustrating a very strong connection between the body and the mind. This illustrates the neural surveillance articulated by Porges (1995) that our bodies use to distinguish the environments that pose risk.

In *The Body Keeps the Score*, van der Kolk (2014) articulates how many rape victims respond immediately after they've been assaulted. Before authoritative figures or caregivers confirm what has happened, they themselves feel the changes in their body. They feel the invasive disruption to the core of their cells. They know. Van der Kolk

(2014) goes on to articulate that when the body is lost this way, the self is lost. This is seen in Noelle. She begins to physically lose the body she knew during her illness with the loss of her hair. Hair loss is a result of chemotherapy and radiation. These treatments target cells that reproduce fast, which includes hair follicles (Botchkarev et al., 2000). Noelle shares: *I'm losing my hair. It was my shield, my comfort...I never really embraced my bald head because I was never really happy about it.* Her body was not the same. Her feelings of discomfort in her own body is confirmed with her discomfort with how she began to look physically. Today, Noelle's anxiety, depression and emetaphobia are feelings from her sensory system. They are means in which her body seeks agency over what has happened to her body (van der Kolk, 2014).

### **Remembering**

Van der Kolk (2014) articulates

Traumatized people chronically feel unsafe inside their bodies: The past is alive in the form of gnawing interior discomfort. Their bodies are constantly bombarded by visceral warning signs, and, in an attempt to control these processes, they often become expert at ignoring their gut feelings and in numbing awareness of what is played out inside. They learn to hide from their selves. (p.97)

This illustrates Noelle's feeling the first couple of days she entered into remission. Noelle describes being constantly alert and visiting the hospital, because she feared any feeling or pain meant her cancer was back. *Last summer, in particular, my cervix was bleeding and I was in pain. I started to question whether cancer was back. I'd think, It's back. It's happening all over again.*

However, the thoughts about cancer do not end here. Through the enervated vagus nerve, Noelle's body continues to remember these sensations, as evident through her anxiety, depression and emetaphobia. These are signs of her body responding to trauma months after the cancerous cells were removed from her body: her body still remembers. Carlsson, Kihlgren, and Sørli (2008) articulate that there will always be this threat of cancer to the personal self. "Fear of an altered appearance, fear of pain, fear related to the sensations of taste and smell, fear related to the bodily intrusions of medical instruments, fear related to bodily complications and fear of exposure" (Carlsson, Kihlgren, & Sørli, 2008, p. 134). These are all fears associated with an embodied experience of traumatic illness, such as cancer.

For Noelle, it doesn't stop here. She will face the long-term effects of living with cancer when she considers the future as well. At the age of thirteen, she was told during chemotherapy, her ovaries may have been damaged. For this reason, she may not have the opportunity for motherhood. However, this did not affect her at that time.

Motherhood was the farthest thing from her mind at that age. Noelle shares: *Today, things have changed. One day, I want to be able have kids.*

If one is lucky, cancer is in every way, body and mind, a life-long companion. Noelle's illness story shows how the effects of cancer are continuously lived and re-lived.

### **Re-presentation of narrative thread: Embodied Experience**

I re-present the narrative thread: Embodied Experience through the visual drawing of the body evolving throughout the process. The image includes a body laying down, followed by a body figure rising up. This symbolizes the initial disconnection Noelle feels with her body and later, the process of "befriending the body" (van der Kolk, 2014).

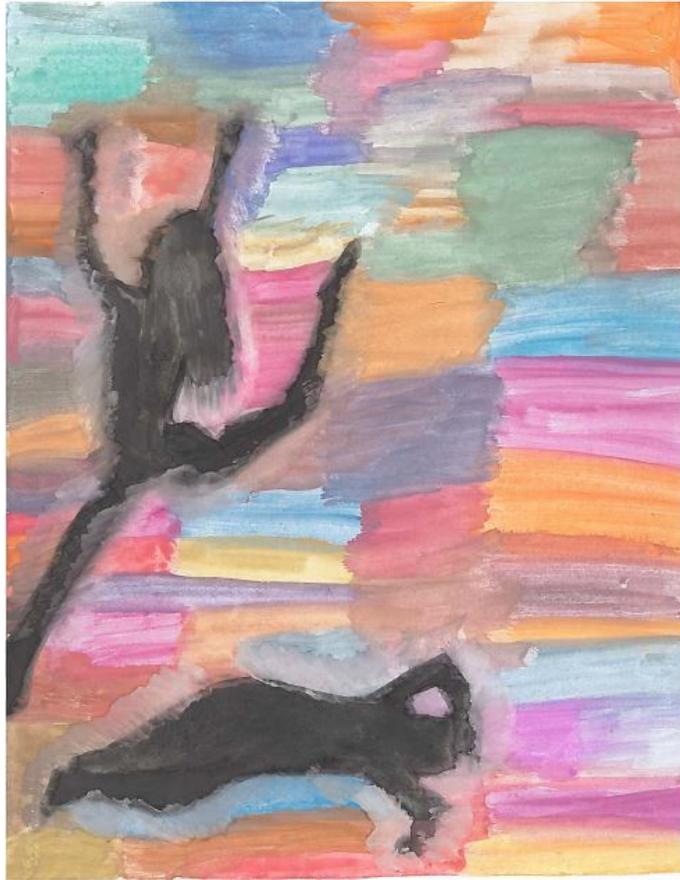


Figure 5. Re-Presentation of Narrative Thread: Embodied Experience

## **Chapter Eight: Social Studies Section**

### **Third Level of Analysis**

*I delve longer in the Philosophy and Psychology Section as I reflect on my reading experiences to create new avenues of understanding. I feel enlightened. In immersing myself in the books of this precious library, I embody an internal growth. As I walk down the section, I turn to the final rooms of the library, the Social Studies Section. Here, we enter the soul of this library, learning the implications of this library.*

In this chapter, I explore the third level of analysis that is social justification. I Here, we discuss the significance of this inquiry in the context of healthcare practice, education and research. In other words, I address why this inquiry is important and who it may impact. I conclude this chapter by addressing healthcare professionals in a letter with a poem. This poem is constructed by me using Noelle's words to re-present her illness experience.

### **Considerations for Healthcare Practice, Education and Research**

#### **Healthcare Practice**

Through this inquiry, I recognize how psychosocial development according to Erickson (1959) follows a different trajectory for adolescents, like Noelle, who experience illness. The backward-fast-forward trajectory of an adolescent's life, I explicate in this inquiry, highlights why it is important for healthcare providers to develop therapeutic relationships with patients that attend to their unique needs and situations. For example, healthcare providers could provide their young patients with privacy. As we see with Noelle, although she desires her mother's presence, she still requires some level of privacy. Thus, it was important for her when caregivers were

mindful of this. Healthcare providers also could encourage peer group activities, respect their choices, motivate their self-expression, and provide teaching about their illness in terms understood by each individual. And, most importantly, healthcare providers could support their patients by addressing their issues and concerns about body image, sexual image and future concerns (Rollins, Bolig & Mahan, 2005; Steenkamp et al., 2012). As we see with Noelle, although she desires her mother's presence, she still requires some level of privacy. Thus, it was important for her when caregivers were mindful of this. In being mindful of the adolescent patient's needs, a trusting and supportive environment is being fostered.

There are many points of contact with healthcare providers in regards to care for adolescent patients. Therefore, healthcare providers need to ensure that all therapeutic encounters demonstrate holistic approaches. For example, there needs to be a clear and strong bridge created to support adolescent patients as they cross from one level of care (pediatric hospital) to another (adult hospital) to help them cope more effectively with their illness in a changing context. Therefore, the challenge faced in the transitions from childhood care facilities to adult cancer care centers need to be addressed to ensure adolescents becoming young adults are supported as they adjust to the new setting and changing expectations regarding their role in their healthcare.

For cancer, in particular, the potential of relapse is ever present. Healthcare providers entrusted in future care of these young adults need to be aware of, and sensitive to anxiety and fears these patients may still feel about their illness. When it comes to cancer, for example, there is no sense of "cure". Thus, caregivers need to keep in mind

that the threat of illness or relapse is very real for the young patient, and may continue into adulthood.

In my inquiry, I also emphasize the importance of being heard by healthcare professionals. Often times, caregivers have presumptive attitudes while supporting young patients. Taking a step back and trying to understand that individuals like Noelle have their own respective concerns, which need to be respectfully heard, is vital. Addressing these concerns and not overbearing the individual with medical authority would create healthy, long-term trusting relationship.

Future inquiries may study effective methods in addressing the tensions in transitions. For example, future research may explore how institutions prepare young patients for the switch of care agencies or how adult care centers welcome and address the young adults who are coming from pediatric settings.

### **Healthcare Education**

Although a lot of research (Kenney et al., 2016; Klassen et al., 2015; Konsler & Jones, 1992; Laar, Glaser, Phillips, Feltbower & Stark, 2013; Oeffinger, Eshelman, Tomlinson & Buchanan, 1998; Rosenberg-Yunger et al., 2013; Sadak, DiNofia & Reaman, 2013; Schwartz, Daniel, Brumley, Barakat, Wesley & Tuchman, 2014) has been done in terms of “transitional education,” further research is required to better support adolescents when they are being integrated into the adult care. Age is a subjective measure for transfer when considering other important characteristics, such as the adolescent’s knowledge of their illness, ability to communicate their needs and their comfort in the new atmosphere. Through a program of comprehensive and thorough transitional education at the age of fifteen or sixteen, the adolescent would have several

years to prepare for the upcoming adjustments. In this program, caregivers could educate the individual on their illness, the process of transition from pediatric to adult care and the major differences in care approaches. This would allow the individual to know what to expect. It would become a stepping-stone program, which could prevent feelings of abandonment and anxiety once adolescent transitions into adult care facilities.

Furthermore, it would maintain the trusting relationship between healthcare professionals, healthcare institutions, the individual patient and their family.

Based on my inquiry, how the individual responds to healthcare services is dependent on their relationship with healthcare professionals and healthcare institutions and how their family's concerns are addressed. I depict the importance of the aforementioned relationships in Figure 6.

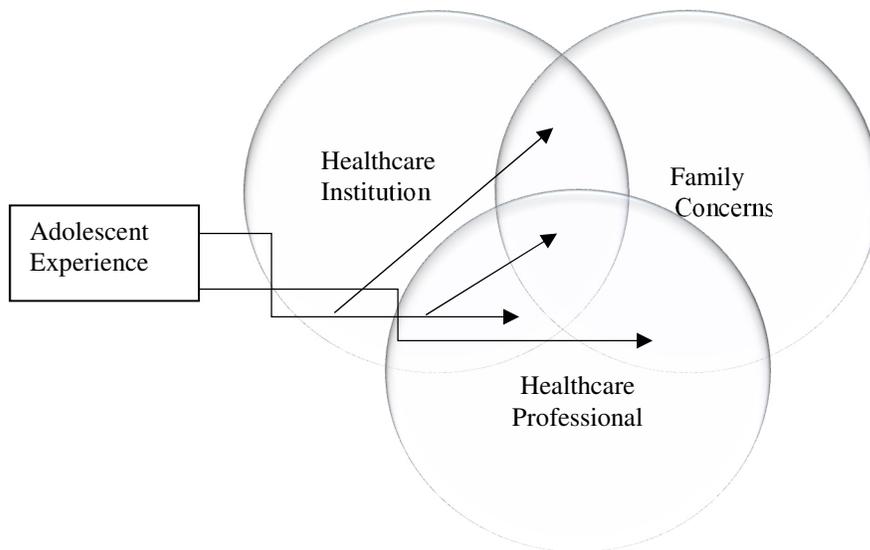


Figure 6. The Relational Components of Adolescent Hospitalization Experience

The sections in which relationships overlap highlights how adolescents experience their hospitalization and by extension, their illness. When family concerns are not acknowledged and included by healthcare professionals, the adolescent has a negative

experience with the healthcare services. Many individuals will feel neglected, as Noelle did with her psychologist at Snowdon. When healthcare professionals acknowledge the concerns of the individual and their family, the adolescent experiences healthcare services in a positive way. Noelle's social worker is a great example of how far the impact can go.

Based on the narrative pattern of relationships, I recognize that health care professionals supporting young adults need to incorporate both emotional intelligence and awareness in their care, which then supports the mental health and wellbeing of patients living with cancer. For adolescents who transition to an adult care center, the lack of support and services to address their mental health and illness is alarming (Vogel-Scibilia et al., 2009; Gavazzi & Sabatelli, 1990; Corrigan, 2004; Wahl, 1999; Rüschi, Angermeyer & Corrigan, 2005). It is important for healthcare professionals to be aware of patients' concerns and the stigma of mental health illnesses or conditions, along with providing avenues for access to mental health services. Cancer is a traumatic experience and caregivers must be equipped with holistic approaches to care in order to provide effective support to these young patients. I believe that this component of care, along with knowledge and skills, should be incorporated into formal education of all healthcare professionals.

### **Healthcare Research**

After my conversations with Noelle, I have a deeper understanding how the trajectory of the psychosocial development of an adolescent can change due to the trauma of cancer, and how the permanence of cancer can impact the mental wellbeing of the patient. I recommend future studies examine the backward-fast-forward trajectory of the

psychosocial development of a child or an adolescent experiencing the trauma of a serious illness like cancer. More research in this particular area would provide knowledge on how a serious illness shapes the individual and how that individual then, shapes their relationships.

Noelle's reconstruction of her childhood cancer is influenced and altered by social, physical and political landscapes such as West Care, Snowdon, Hestia and her relationship with family and friends. This influence is never forgotten by the body. In this way, the impact of cancer is permanent. Although the physical cells may be removed following treatments, bodies down to the cellular level remember every aspect of the treatments and the impact of cancer experiences. I recommend researchers explore the possibility of post-traumatic stress disorder in adolescents who survived cancer. In exploring this, healthcare providers could pay special attention to emotional and mental health symptoms that may arise, and thus, provide necessary treatment. As a result, their young patients would then be more optimally and effectively supported. Furthermore, family members also need to be included in the supportive care of the young patients through education about the psychosocial impact of cancer on the mind and body. By understanding that these symptoms are very much a part of the illness would allow them to seek the support they, themselves, may also be needing.

### **Final Thoughts**

As I embarked on this inquiry, I had never imagined how difficult visiting a library could be. How difficult it would be to reveal an archived story. During this process, I have realized this particular inquiry adds to the body of literature on natural science. Natural science, as I define and use it here, is the science pertaining to the nature

of our experiences. The science of knowledge is emergent and embodied, as we reflect on and tune into our experiences. The experiences that, amidst the noise of life, are seldom heard, and often forgotten. On this journey, I feel as if I fell down a rabbit hole and learned there is a vast unexplored knowledge to be discovered. The deeper I fell, the deeper the knowledge emerged. I conclude this chapter with a letter addressed to healthcare professionals. This is the narrative that re-presents the essence of the co-construction of Noelle's illness story and my inquiry into it.

### **Letter to Healthcare Professionals**

Dear Healthcare Professionals,

Today may be a beautiful sunny day or it may be raining. On your route to work, there may have been traffic or it may have been a smooth ride. This week could have been an exhausting week or a happy one. To be honest, I am not sure. I do not know what you bring into your profession. I have only seen what you leave, the child, whose care is in your hands. I have only experienced the impact you had on me and my family when I was diagnosed with cancer. I know that regardless of time unfolding, the child remembers how you made them feel. Because, I remember how you've made me feel. I remember when my caregivers made a difference. I remember when my concerns were heard. But, I also remember closing myself down because things were changing and no one was providing the care I needed.

In this sense, the child's body is more than one that is a host to the illness of your interest. It is a landscape of knowledge. One, in which, if you listen closely and pay attention, will provide you with a more holistic and human approach in

administering care. This humanness will allow the inherent spiritual understanding in us to rise above the scientific abstractions dominant in today's healthcare

I was thirteen when I was diagnosed with cancer. I experienced changes in relationship dynamics, growth, development and a coming-to-terms with myself and an identity that is permanently fixed within who I am today. I am twenty-one and I still remember each interaction at West Care and Snowdon. This illustrates the important role that caregivers have on hospitalized children. For me, my social worker made me laugh on the day I was told I had cancer. In short moments, the hospital would become my home, but my social worker made me forget this unfortunate fate. She inspired me to pursue the same career choice. However, I also remember the lack of support from Snowdon and feelings of abandonment while leaving West Care.

At Snowdon, I remember sharing my anxiety and depression with a complete stranger. I had to come to terms with what was happening to me and it wasn't easy. When the psychologist called me a "snob," I thought to myself, maybe the problem is with me. What you don't see is that your words and interactions stay with the person.

What I have tried to show is that the individual internalizes the relationships between themselves and healthcare professionals. When the healthcare professional is able to connect with the patient, that young patient will internalize trust and empathy while the opposite is true if no connection is made.

Part of what I've learned is that cancer is a traumatic experience and there is no cure. Yes, I am in remission, but every day I wonder if today I am going to relapse. When it comes time to having kids, I will know if cancer has rid me of yet another experience. I live with cancer. I believe that as a caregiver, you can create a holistic

healing relationship when you draw in the humanness of care and connect with your patients.

Dear healthcare professionals, I hope as you read, re-read and reflect on my story and this inquiry, you revisit your professional encounters across time with different young patients, and that you pause for a moment before you care for another patient and make a conscious choice to consider the whole person. I leave you with the following poem:

*You think I don't KNOW?  
You think I don't FEEL IT?  
It's a part of me  
Yet, I NEVER asked for it  
I was given an identity  
Yet, I NEVER wanted it*

**Blood  
Body  
Pain  
Surrounded ALONE**

**ANGER**

**Drowsy  
Tired  
Quiet  
Bald  
Sick  
Growth**

**G O N E!**

But, where?

---

*OFF my charts and OUT of sight?*

---

**BUT, CANCER IS IN ME**

**CANCER IS WITHIN ME**

**CANCER IS WITH ME**

**ALWAYS!**

## Epilogue

*If your research doesn't change you,  
You did it wrong  
- Elder Albert -*

Elder Albert is a highly loved and respected Elder of the Mi'kmaw Nation. He came into one of the last classes in my qualitative methods course and ended his discussion by saying that the only way you know your research is done correctly is if it changed you. As I stare at the wall, slightly dazed that this inquiry culminates here, for now, change is an understatement in how meeting Noelle, living her stories and storying her life, has affected me.

At first, I was fervently trying to put together this inquiry: the way the world usually works, by doing and making things happen. However, meeting Noelle and being on this journey with her has taught me that our stories emerge from our experiences. For this reason, we need to let our experiences unfold, so that our stories can manifest and offer us opportunities for learning.

Connelly and Clandinin (2006) explain that in Narrative Inquiry, the participant and the researcher co-participate in the co-construction of the told stories, thereby influencing how we live our lives. When I engaged with the book, *Sadako and the Thousand Paper Cranes*, I developed a genuine interest in the experiences of children diagnosed with cancer. I wanted to know: *How does it feel to confront the possibility of death at such a young age? How does this child's life unfold while experiencing a crisis? How do they change because of the cancer? How do they face death at such a young age?*

Based on my inquiry, I learned that Noelle and other children and adolescents in her situation experience psychosocial development differently. There is a backward-fast-forward development. She regresses to being dependent on her parents, and then seemingly quickly, embodies a sort of wisdom well beyond her years.

At the start of my research, my understanding of childhood cancer was narrow. I understood that cancer's impact was present only while the cancerous cells were still in the body. Since encountering Noelle, I learned that the impact of cancer is present even after the malignant cells have been removed. The impact of cancer on the mind-body-spirit is long-lasting. It is a life-long companion, whether the individual accepts this fact or not. Cancer is a chronic, traumatic disease, if one is lucky.

Understanding childhood cancer in this light, I am aware how important it is to provide Noelle, and individuals who experience illness at a young age, with adequate and appropriate support, that is holistic: mind-body-spirit. As Noelle says, *I live with the illness and its aftermath. Live and not "lived", because it is never gone. It will always be there.*

As I sit in the Biography section of the library, I reflect on how I enjoyed discovering, telling and retelling Noelle's illness story with her; learning that "Cancer begins and ends with people" (Goodfield, 1975, p. 219).

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## APPENDIX A: REB APPROVAL

*Date:* March 24, 2016  
*To:* Megalai Thavakugathasalingam  
*From:* Shirley Van Nuland, REB Chair  
*REB # & Title:* (15-099) Reconstructing Childhood Cancer: A Young Adult's Experience  
*Decision:* APPROVED  
*Current Expiry:* March 01, 2017

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Notwithstanding this approval, you are required to obtain/submit, to UOIT's Research Ethics Board, any relevant approvals/permissions required, prior to commencement of this project.

The University of Ontario, Institute of Technology Research Ethics Board (REB) has reviewed and approved the research proposal cited above. This application has been reviewed to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 (2014)) and the UOIT Research Ethics Policy and Procedures. You are required to adhere to the protocol as last reviewed and approved by the REB.

**Continuing Review Requirements** (forms can be found on the [UOIT website](#)):

- **Renewal Request Form:** All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed within 30 days of the expiry date will be automatically suspended by the REB; projects not renewed within 60 days of the expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.
- **Change Request Form:** Any changes or modifications (e.g. adding a Co-PI or a change in methodology) must be approved by the REB through the completion of a change request form before implemented.
- **Adverse or Unexpected Events Form:** Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).
- **Research Project Completion Form:** This form must be completed when the research study is concluded.

Always quote your REB file number (15-099) on future correspondence. We wish you success with your study.

REB Chair  
Dr. Shirley Van Nuland  
shirley.vannuland@uoit.ca

Ethics and Compliance Officer  
researchethics@uoit.ca

NOTE: If you are a student researcher, your supervisor has been copied on this message.

## APPENDIX B: CONSENT FORM



RESEARCH ETHICS BOARD  
OFFICE OF RESEARCH SERVICES

**Title of Research Study: Reconstructing childhood cancer: A Young Adult's Experience**

You are invited to participate in a research study entitled **Reconstructing childhood cancer: A Young Adult's Experience**. This study (# REB 15-099) has been reviewed by University of Ontario Institute of Technology's Research Ethics Board and was originally approved on Date March 24, 2016. Please read this form carefully and feel free to ask any questions you may have of the Researcher, Supervisor or the Ethics and Compliance Officer. If you have any questions about your rights as a participant in this study, please contact the Ethics and Compliance Officer at 905 721 8668 x 3693 or [compliance@uoit.ca](mailto:compliance@uoit.ca).

### **Research Team:**

The research team consists of the principal investigator or researcher who is responsible for conducting the study and the supervisor, who is an academic resource for the researcher in all stages of the study, stimulating and guiding the researcher through the study.

**Principal Investigator (Researcher) is Megalai Thavakugathasalingam (MHS candidate)**

**Contact Information: 416-886-7045  
megalai.thavakugathasalingam@uoit.ca**

**Faculty Supervisor is Dr. Otto Sanchez (MD, PhD)**

**Contact Information: 905-721-8668 x 2518  
otto.sanchez@uoit.ca**

**Departmental and Institutional Affiliation University of Ontario Institute of Technology**

### ***Purpose and Procedure:***

*The purpose of this study is to explore the experience of adult survivors of childhood cancer and how they make meaning from it, both in their present life and past life. In this study, you will be invited to participate in a series of 4-5 arts-informed narrative inquiry sessions. In these sessions, you will be asked for consent to participate in journaling about the sessions, time-line drawing, writing 2 short stories, think of a metaphoric image of having*

*and surviving cancer and discussions. Each research session is expected to be 1.5-2 hours in length and will take place in a quiet location of your choice. Again, with consent these sessions will be audio recorded, the art pieces will be photographed, written pieces will be photocopied and the journal will be kept by the researcher. The audio recording of the interview will then be written down and kept in a secure, password encrypted location. These transcribed interviews will be reconstructed as a story that captures the experience of childhood cancer.*

***Potential Benefits:***

*The potential benefits of this research includes an opportunity for you to talk, write and hear your story which through self-reflection and awareness may provide a personal growth, knowing that your story can potentially contribute to the enhancement of others. Finally, the study also acts as a therapeutic outlet for your thoughts and feelings regarding your experience. However, not all people experience these benefits or experience them in the same ways and there is a chance that you will not benefit directly from participating in this study.*

***Potential Risk or Discomforts:***

*During the course of this research, the researcher does not anticipate any harm to you. However, the retelling of personal experience has the potential to raise emotions. If such situation arises, inform the researcher you do not feel comfortable answering a question or discussing a particular topic. You can choose to change the topic if needed. You may also choose not to participate in any or all of the arts activities. In this case, you may opt to participate only in the interview portion of the session or alternative interview protocol.*

***Risk or Discomfort Management:***

*If you feel any discomfort, the researcher will provide you with information for local counselling services. You will also be given a copy of this consent form to keep for your records and if you wish to contact UOIT's Research Ethics Board to report emotional discomfort that may be experienced after the interview session has ended.*

***Storage of Data:***

*The art activities will be collected at the end of the respective sessions, while the journal will be collected at the end of the study. The audio recording and transcripts will be saved as a file on a password protected computer. Hard copies of the art activities, journal, notes, transcripts and consent forms will be stored in separate folders and will be kept in a locked cabinet in an area that has key holder restricted access (i.e. Dr. Otto Sanchez's office). Collected information will only be shared between the researcher and research supervisor. The audio recording will be destroyed within 6 months after transcripts have been written and both field notes and transcripts will be destroyed within 3 years within the completion of the study.*

***Confidentiality:***

*All of the information collected in this study will be kept confidential. Your name will never be associated with any of the materials (i.e. audio recordings, transcripts, notes, consent forms) in this study, and your data will instead be assigned an alphanumeric participant number or code. Your real name will not be used if your data is referred to in the study's*

*findings, a pseudonym will be used instead (this also applies to any people, groups, or organizations you may mention during the interview). Your privacy shall be respected. No information about your identity will be shared or published without your permission, unless required by law.*

*The researcher will respect your privacy and information concerning your identity will never be published or shared without your voluntary consent. However, sometimes the law requires that we share participant information if the participant reveals that she/he is being abused, is abusing a child, or is planning to commit suicide. Confidentiality will be provided to the fullest extent possible by law, professional practice, and ethical codes of conduct. Please note that confidentiality cannot be guaranteed while data are in-transit over the internet.*

***Right to Withdraw:***

*Your participation is voluntary and you can choose to answer/participate in the questions and activities that you are comfortable with. The information that is shared will be held in strict confidence and discussed only between the researcher and supervisor. You can choose to withdraw from the study at any time without consequences. If you withdraw from the study, the researcher will destroy the information that was collected from you and this information will not be used in the study.*

*Please note, that withdrawal of your data once it has been anonymized and summarized with the data of the study's other participants may not be feasible. It is difficult, if not impossible to withdraw results once they have been published or otherwise disseminated. You will be given information that is relevant to your decision to continue or withdraw from participation.*

***Conflict of Interest:***

*Neither the researcher nor the supervisor have any vested personal, clinical, or financial interest in the study.*

***Compensation:***

*You will receive a \$10 gift card for your participation in this study after each session.*

***Debriefing and Dissemination of Results:***

*The summary of the results of this study will be used as part of the researcher's school project in completing the requirements of UOIT's master studies. The findings of this study may also be used to share the experiences amongst individuals going through similar situations via community health organizations and other institutions. Also, the findings of this study will be used to create presentations and write articles for journals that will be viewed by health care professionals, researchers and so on. While the results of this study may be published, your identity will never be revealed in any journal article, presentation or paper. If other researchers request to use the summary of this study's data for future studies, the researcher must request your permission before sharing this data.*

***Participant Concerns and Reporting:***

This research project has been approved by University of Ontario Institute of Technology's Research Ethics Board on March 24, 2016. If you have any questions concerning the research study, or experience any discomfort related to the study please contact the researcher or supervisor at any time. Any questions regarding your rights as a participant, complaints or adverse events may be addressed to Research Ethics Board through the Ethics and Compliance Office – [researchethics@uoit.ca](mailto:researchethics@uoit.ca) or 905 721 8668 x 3693.

By consenting, you do not waive any rights to legal recourse in the event of research-related harm.

**Consent to Participate:**

- I have read the consent form and understand the study being described;
- I have had an opportunity to ask questions and my questions have been answered, acknowledging that I am free to ask questions about the study in the future;
- I freely consent to participate in the research study, authorizing permission to record all sessions, photograph all art pieces, and the collection of the journal;
- I understand I may discontinue participation at any time without penalty and a copy of this consent form will be made available to me.

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(Name of Participant)

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(Date)

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(Signature of Participant)

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(Signature of Researcher)

**Appendix F: Withdrawal Form**

*As mentioned in the consent form, your choice to withdraw from the study will be honored at any time without consequences. Upon your withdrawal from this study, the researcher will **destroy** the information that was collected from you (i.e., consent form, audio recording of interviews, transcripts of interviews, photographs of artwork, field notes, journal). This information will **not** be used in the study.*

*Please check off box below to confirm your withdrawal from this study and your permission to destroy the data:*

**YES, I am withdrawing from this study and would like the researcher to destroy the data.**

**OPTIONAL:**

*If you **voluntarily** consent, you may choose the degree to which your data (i.e., consent form, audio recordings of each interview, transcripts, condensed stories, hardcopies of artwork, photographs of artwork, pieces of creative writing, field notes, and journal) are removed from the study. You may choose to allow the researcher to keep and use your data, up until the point of withdrawal for research purposes. Alternatively, you may choose to not allow the researcher to use your data, and instead keep this data for your*

own use. In all of these cases, these alternative options for data destruction are completely at your discretion.

If you consent, and would like to keep your data in the study to some degree, please check off the appropriate box below:

**YES, I choose to withdraw from this study, but I voluntarily choose to allow the researcher to keep and use my data up until the point of my withdrawal from the study.**

**OR**

**YES, I choose to withdraw from this study, and I voluntarily choose to not allow the researcher to use my data. Instead, I would like the researcher to give me all of my data to keep for my own use.**

*Please note, that withdrawal of your data once it has been anonymized and summarized with the data of this study's other participants may not be feasible. It is difficult, if not impossible, to withdraw results once they have been published or otherwise disseminated. You will be given information that is relevant to your decision to continue or withdraw from participation.*

\_\_\_\_\_  
**(Name of Participant)**

\_\_\_\_\_  
**(Date)**

\_\_\_\_\_  
**(Signature of Participant)**

\_\_\_\_\_  
**(Signature of Researcher)**

## APPENDIX C: RECRUITMENT POSTER

### Participants Needed!

A research study titled **Reconstructing childhood cancer: A Young Adult's Experience** at University of Ontario Institute of Technology is conducting a one-on-one, 4-5 series of arts-informed narrative inquiry sessions. These sessions will ask the participant to participate in a series of creative writing, art making and interviews about experiencing childhood cancer. Stories of experiencing childhood cancer are important because they are autobiographically meaningful!

You are **eligible** in the study if you:

**Are 18 years of age or older and**

**Has had a childhood (0 to 12 years of age) diagnosis of cancer and thereafter survived and/or is in remission.**

If you are interested in this study please contact us for more information:

Researcher: Megalai Thavakugathasalingam  
Masters of Health Science candidate, UOIT  
[Megalai.thavakugathasalingam@uoit.ca](mailto:Megalai.thavakugathasalingam@uoit.ca)

Supervisor: Dr. Otto Sanchez (MSc, MD, PhD)  
Faculty of Health Science, UOIT  
(905) 721-8669, extension 2518  
[Otto.sanchez@uoit.ca](mailto:Otto.sanchez@uoit.ca)

This study has been approved by the UOIT Research Ethics Board  
(15-099), as of 03/24/16

**APPENDIX D: ONLINE CORRESPONDENCE TO ACCESS POTENTIAL  
CHILDHOOD CANCER SUPPORT GROUPS**

Dear [name of organization OR contact person from the organization],

My name is Megalai Thavakugathasalingam and I am a graduate student from University of Ontario Institute of Technology, working with Dr. Otto Sanchez. Each year, there are an estimated 1,500 new cases of childhood cancer in Canada. Seventy-percent of these children diagnosed with cancer become long-term survivors, however, the effects of treatments are long-term. My research explores how adult survivors experienced childhood cancer and make meaning from it, both in their present life and past life. How is this experience autobiographically meaningful and, at the same time, significant while interacting with the world thereafter? There is a gap in this area in the literature and my thesis aims to bring together information from the uniqueness of childhood survivors' lives, specifically that of the individual I speak with.

To explore this issue, I will be conducting a series of creative writing, art making, and interview sessions with the individual: *Reconstructing childhood cancer: A Young Adult's Experience*.

I am looking for one person to participate in my study who:

**Are 18 years of age or older**

**has a childhood (0 to 12 years of age) diagnosis of cancer and thereafter survived  
and/or in remission.**

There will be a series of 4-5 arts-informed narrative inquiry research sessions. Each session will be 1.5- 2 hours in length and will take place in a quiet location of the participant's choice. The participant will be asked for consent to participate in journaling

about the sessions, time-line drawing, writing 2 short stories, think of a metaphoric image of cancer and discussions. Again, with the consent of the participant, these sessions will be audio recorded and both the journal and art pieces will be kept by the researcher. I am kindly requesting that you share this email in order to assist me in recruiting a participant.

This study has been approved by the UOIT Research Ethics Board  
(#15-099) on 03/24/16

Sincerely,

Megalai Thavakugathasalingam (Master of Health Sciences, candidate),

Otto Sanchez MD, PhD  
Faculty of Health Sciences  
University of Ontario Institute of Technology  
2000 Simcoe Street North  
Oshawa, ON L1H 7K4  
905.721.8668 x 2518 Email: [otto.sanchez@uoit.ca](mailto:otto.sanchez@uoit.ca)

## APPENDIX E: LETTER OF INVITATION

Dear (Insert Name of Participant),

It is a pleasure to invite you on board this study. In brief, my research explores how adult survivors experienced childhood cancer and make meaning from it, both in their present life and past life. How is this experience autobiographically meaningful and, at the same time, significant while interacting with the world thereafter? There is a gap in this area in the literature and my thesis aims to bring together information from the uniqueness of childhood survivors' lives, specifically that of the individual I speak with.

I have attached a document entitled "Consent Form," please carefully read this document. This document will be reviewed by you and I, together and signed during our first session.

Sincerely,

Megalai Thavakugathasalingam (Master of Health Sciences, candidate),

Otto Sanchez MD, PhD  
Faculty of Health Sciences  
University of Ontario Institute of Technology  
2000 Simcoe Street North  
Oshawa, ON L1H 7K4  
905.721.8668, EXT. 3811 Email: [otto.sanchez@uoit.ca](mailto:otto.sanchez@uoit.ca)

## **APPENDIX F: THANK-YOU LETTER**

Dear (Insert Participant's Name),

With the most heartfelt gratitude, I thank you for your generous contribution to my study, but most importantly to the existing knowledge there is regarding the experience of childhood cancer survivors. Over the 4-5 sessions, I appreciate all your hard work and effort in creating to the best of your abilities meaningful projects to enhance the understandings and bring together that visual component. It has been a humbled experiencing in creating this knowledge.

Best,

Megalai Thavakugathasalingam