

**THE EXTRAORDINARY GIFTS RECEIVED FROM LIVING
WITH A CHRONIC ILLNESS**

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Doctor of Philosophy
Nipissing University

2016

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WITH A CHRONIC ILLNESS

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SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE
DEGREE OF DOCTOR OF PHILOSOPHY

NIPISSING UNIVERSITY
SCHOOL OF GRADUATE STUDIES
NORTH BAY, ONTARIO

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Author's Declaration

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Abstract

As a mother, wife, daughter, and sister with a chronic illness, I endeavor to provide an alternate understanding of chronic illness. This study investigated my experiences living with a chronic illness. The study sought to answer a central research question: What are the extraordinary gifts I have received from living with a chronic illness? The study also examined factors that contributed to my positive outlook while living with a chronic illness, and how chronic illness can be reframed. By composing my narrative in chronological sequence, I have captured my experiences of living with a chronic illness. The findings of this study include 3 main themes: issues of identity, extraordinary gifts received, and tensions in understanding chronic illness. The theme of identity addresses how I progressed from desperately wanting to be fixed to reconciling my identity; extraordinary gifts include how I learned to love, continued to have hope, be mindful of my time, and live filled with gratitude; while tensions in understanding chronic illness represent both my fears and the inspiration for a renewed understanding of chronic illness and disability. The implications of this study encompass additional research of those with chronic illness and their families from a strength-based perspective, and the need for continued research that reframes chronic illness by providing an authentic account of what living with a chronic illness entails.

Dedication

For Rob, Cecelia, and Gemma: you are my foundation and my life's most extraordinary gifts.

Acknowledgments

Dr. Carlo Ricci, my doctoral supervisor, thank you for your continued encouragement for me to strive for excellence during my doctoral research. Your guidance and wisdom has been foundational to me as I completed my dissertation. Thank you for always making time to chat, read, and answer my questions.

I am extremely grateful for the thoughts, questions, and feedback from my committee throughout my doctoral journey. Dr. Mike McCabe, your unwavering support and thoughtful responses during this journey have been both unique and instrumental. Thank you for continuing to be a cherished mentor in my life. Dr. Christine Cho, thank you for your honesty, for asking me hard questions, and inspiring me to reflect in ways that I had not considered. Dr. Ellie Berger, thank you for your insight and knowledge as I continued to enhance my dissertation. Dr. Karyn Cooper thank you for your insightful feedback and questions.

To the participants in this research study, thank you for providing me with an opportunity to openly share my story as someone living with a chronic illness.

Dr. Taylor, thank you for seeing what no one else could and for the exquisite care that has followed.

To my critical friend, we have shared our doctoral experiences together which has included celebrating, crying, venting in frustration, cheering each other on, and celebrating some more! Thank you for literally being there every step of the way as we pursue our academic dreams. We got this!

To my family, my doctoral journey began years ago when pursuing this dream seemed anything but possible. Thank you for always believing in me and for seeing in me

what is possible at times when I could not. Mom and Dad, thank you for your unconditional love and support. Sister, you are my best friend and I love that I can always, always be real with you.

To Rob, Cecelia, and Gemma, thank you for the beautiful life we have together, and for the absolute honour of journeying through life with you. Thank you for being willing to expose our lives and share our vulnerabilities for my doctoral research.

This research study was generously funded by Nipissing University's Dean's List Scholarship.

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Chapter 1: Introduction

Living with a chronic illness has undoubtedly changed my life. My chronic illness continues to require adaptations to how I live and the paths I take. My personal experiences as an individual with a chronic illness have informed all the facets of my life, including my professional aspirations and research interests. Acknowledging and exploring the impact of my chronic illness on my life is central to this dissertation. Previously, my research program had focused on investigating learning to live with a chronic illness, challenges that are encountered by individuals with chronic illness while attempting to attend school, parental perceptions of challenges encountered by children with chronic illness, resilience education in the lives of those with chronic illness, as well as holistic strategies for managing chronic illnesses in school settings (Wideman-Johnston, 2010, 2011a, 2011b, 2014a, 2014b). Kant (2010) states the importance of experience to inform knowledge: “That all our knowledge begins with experience there can be no doubt” (p. 26). Toward this end, my interest in the lives of those with chronic illness began as a result of my own personal experiences. I questioned my experiences as a mother, wife, daughter, and sister with a chronic illness, and wondered how others were living with a chronic illness. I wondered how chronic illness influenced other family systems. Further, I was curious to know how they were creating meaning in their lives despite their health implications. What follows is an overview that places me within this study.

Placing Myself Within This Dissertation

When I began my postsecondary education as a young adult, I was a completely different person from the person I am today. Truthfully, I never questioned the path I was on or why I was pursuing certain aspirations. I was a planner. I saw life in a very linear

progression. I knew what I wanted and how I would achieve my goals. In many ways I was quite naïve. I believed that through hard work and obeying the rules of society (or by conforming) that I would be rewarded in life. Working hard and pursuing an education would be worth it and in turn would create the path to the life I wanted to live (Goffman, 1959). I envisioned the world as safe and that my safety was static, especially because I was contributing to society in a positive way.

I clearly remember the day my life drastically changed. I was in my second year of university and it was the second day of classes. As I was going from class to class I noticed that every time I sat up or sat down, I would feel a sharp pain in my lower back. I did not know it at the time but this day was the start of my life with a chronic illness.

It took 3 years for me to receive a medical diagnosis for the symptoms I was experiencing. During those 3 years, I had numerous misdiagnoses that included everything from mental health to inaccurate physical ailments. I was desperate to be “fixed.” I would do anything to return to the life I had. I underwent many tests, surgeries, and treatments all in search of trying to get better.

December 23, 2005 was the day I met the doctor who saved my life. I had been in the hospital since the beginning of December and had now been admitted to a hospital closer to my home for the holidays. It was almost midnight and I was informed there was a bed for me on the eighth floor. As I was being wheeled into my room, a doctor in scrubs was waiting for me. Much to my surprise with the late hour, this doctor would be formative in my care. He was the first doctor to say, “I think I know what is going on with you.” Although my diagnosis was not official at the time, my diagnosis of the motility disorder named Diffuse Irritable Gastrointestinal Tract Syndrome (DIGITS) came in the coming months after I had

been discharged from the hospital. The news of my diagnosis occurred at my doctor's clinic and came with feelings of relief for knowing what was happening, but was also a time of grievance for knowing that this chronic illness would be with me for life (Asbring, 2001; Charmaz, 1983, 1991; Donoghue & Siegel, 2000; Golub, Gamarel, & Rendina, 2014). The day my diagnosis was confirmed was terrifying, and even more so was the rarity of this chronic illness. At the time of my diagnosis, this illness was grouped into the broad category of motility disorders and did not have a set name. Although I knew what type of chronic illness I had, the cause, cure, and treatment were all grey areas, and consequently would require much effort and experimentation by myself and in coordination with my doctors. The journey to a diagnosis had ended. Had this not been what I had searched years for, for someone to tell me what was wrong with my body? The countless doctors, procedures, treatments, therapies, and counselling were all in the hopes of someone telling me what is wrong with me and how they were going to fix it. And then, I found it. I found what I had been searching for but I did not want it anymore. I wanted to go back to the time I was healthy. When I could go to school, work, and participate in my life. While with my doctor, I did not even know what to say or ask for that matter. All I could think of was the unknown and that this chronic illness was a part of my life now.

The hopes of getting better and finding a cure were diminished with the diagnosis of an incurable illness (Edwards, 2013). The overwhelming aspect of this chronic illness was the realization that it was not going away (Edwards, 2013). I felt numb when I left my doctor's clinic that day. The numbness continued with me that whole day. Late that night I decided to have a bath to help soothe myself from the news of the day. When I got into the bath and looked down on my body, the body I thought I had known for 23 years, I suddenly

felt I had been deeply betrayed by my body. I thought I knew my body since I had cared for my body and acted in my best interests by maintaining a healthy lifestyle. I now felt as though I did not know myself anymore and that I had been foolish for thinking otherwise. I did not understand. It meant more tests, more procedures, continued lifestyle changes, and most frighteningly, it meant my body would get worse. In my mind I was at my worst physically, mentally, and spiritually. I could not imagine a life with symptoms that would continue to progress. This day marked the confirmation that the life I had been striving so hard to return to prior to my illness was forever lost, and I needed to find an alternate way to live because I was exhausted. I cried to further exhaustion with the fear of the unknown looming before me.

From that day forward my life has been a cyclical pattern of trying to overcome and even outsmart my body. Needless to say, this approach has not been very successful. Despite my motility disorder, now recently named DIGITS, I wanted to live as everyone else does without health issues. I wanted to prove I could do it, and to me this meant taking control of my chronic illness and of my body. I would not succumb to my chronic illness; I would not be the “sick person” (Charmaz, 1983, 1991). I would fix my body to work properly (Illich, 2013). At this time, I believed a “sick person” meant weakness, dependence, and incapacitation. I thought I did not have any power and would be forever dependent on trying to be fixed (Charmaz, 1983). My chronic illness had taken so many of the elements of my life that I loved that I felt I needed to be stronger and could not surrender to my chronic illness. I viewed my physical body separate from my mental and spiritual bodies (Walker, 2001). How did this approach work out for me? Not well at all, and I cannot believe how

much time passed before I realized the negative implications of my actions and consequently how imminent it was that I would live a short life.

My Chronic Disease

A motility disorder is defined as abnormal intestinal contractions that can include the esophagus, stomach, small intestine, and colon (International Foundation for Functional Gastrointestinal Disorders, 2015). More specifically, I have been diagnosed with the chronic disease named DIGITS which is described as, “the intestinal muscle does not work properly. The contents of the intestine (food or stool) cannot be moved along the intestinal channel, so the bowel is effectively blocked even though there is no physical kink or twist” (London Health Sciences Foundation, 2012, p. 2). Consequently as a result of living with DIGITS, I have had a colectomy which is the removal of my large intestine, and I now have a permanent ileostomy. An ileostomy is a surgically created opening into the small bowel through the abdomen. The intent of an ileostomy is to allow stool to bypass the colon (Hollister, 2004). In the past I have also had numerous central lines that included a peripherally inserted central catheter (PICC), Hickman, and most recently a port-a-cath. The presence of having an ileostomy and requiring regular intravenous therapy continues to drastically change my life and that of my family. As a result of DIGITS, I have been diagnosed with secondary conditions: interstitial cystitis and advanced osteoporosis. Interstitial cystitis is defined as a chronic condition that results in bladder pressure and bladder pain and can include pelvic pain, extending from minor to severe pain (Mayo Foundation for Medical Education and Research, 2016). Osteoporosis “is a disease characterized by low bone mass and deterioration of bone tissue. This leads to increased bone

fragility and risk of fracture (broken bones), particularly of the hip, spine, wrist and shoulder” (Osteoporosis Canada, 2015, para. 1).

From the severity of my chronic illnesses, I have been required to take much time off from work and school. Pursuing my schooling and having a profession have been extremely challenging and in the past have always come with a cost. That cost is usually my health deteriorating. The ups and downs of living with DIGITS often include many hospital stays, surgeries, procedures, tests, and medications. None of the above includes the day-to-day nursing visits, appointments, and other needs of my life with a chronic illness. When I start to recover from a health calamity, I rush back to whatever commitments I had prior without a breath in between, waiting for my system to crash again. I lived this way for years. About three and a half years ago, I was involved in a series of grave conversations with my doctors and many other consulted professionals about the shortness of my life being imminent. I immediately halted all of my schooling and professional responsibilities. We needed to figure out a better plan. That period of time off has continued to foster an abundance of reflection and changes to my life (Asbring, 2000; Boyd, 2005; Carel, 2008; Edwards, 2008).

My intention is to engage and pursue my passions because I want to, and each is of personal importance to me. I have never felt I want to stop living because of my chronic illness. It is important however to realize that in considering to pursue certain goals and aspirations, much thought and time have been given to how I will embark on the journey. It has taken me many years to appreciate the idea of taking alternate paths to living my life. It is my hope that sharing my story will provide awareness about my life with a chronic gastrointestinal illness and give people the opportunity to hear my experiences of learning to live with a chronic gastrointestinal illness. I have now been living with a chronic illness for

12 years (more than a third of my life) and in the last few years I have realized that I have received many extraordinary gifts from living with a chronic illness which include hope to persevere, learning to love, being mindful of my time, and gratitude for the life I have.

Defining Chronic Illness

Finding an exact definition of chronic in biomedical literature is rare. Often when the word “chronic” is added to describe biomedical terminology, chronic is a synonym for a continuing, unexplained illness with potential of a relapse. The variation in defining characteristics of the term chronic suggests a lack of universal understanding of what chronic precisely means within the biomedical model (Walker, 2010). For the purposes of this dissertation, chronic illness will be defined as “the personal experience of living with the affliction that often accompanies chronic disease” (Martin, 2007, para. 2). Further, the emphasis of this definition of chronic illness focuses on how living with the illness impacts the individual. This definition of chronic illness is different from the term chronic disease which is “defined on the basis of the biomedical disease classification” (Martin, 2007, para. 2). For instance, I have a chronic disease but I will be focusing on how I live with a chronic illness. This dissertation will use the terminology chronic illness when referring to my life with a chronic illness and chronic disease when discussing the biomedical components of my illness. Additionally, there are differences between an acute illness and a chronic illness. An acute illness is a sudden onset where symptoms appear and can change quickly. A chronic illness develops and lasts for a long period of time (Murrow & Oglesby, 1996). Edwards (2013) discusses differences between acute and chronic illnesses:

We are familiar with both ends of the spectrum: the short, acute infections and injuries of everyday life and the terminal cases of cancer, heart disease, or stroke that

have a finite end. Chronic illness is somewhere in the middle, confounding and unfamiliar. (p. 10)

Edwards (2013) is emphasizing the muddled space chronic illness occupies. The varying definitions, diseases, and understandings all contribute to an undiscovered terrain.

Research has consistently identified the barriers that individuals with chronic illness confront and how their daily needs differ (Kimpson, 2005; Shaw & McCabe, 2008; Shiu, 2004; Thies & McAllister, 2008; Wideman-Johnston, 2010; 2014b, 2015). Often, learning to live with a chronic illness includes major lifestyle changes, changes in relationships with others, a need for social support, and managing health care obstacles. There are also many emotional effects of living with a chronic illness such as regret or loss, anger, matter-of-fact reactions to health constraints, and shame. The effects listed do not include the complex management of physical components that accompany living with a chronic illness (Lee & Poole, 2005). Additionally, categorizing the experiences of people with chronic illness provides diverse results as many interpret and adjust differently; there is not a single template for the effects of living with a chronic illness (Davison, Pennebaker, & Dickerson, 2000). Chapter 2 of this dissertation provides a more in-depth exploration of chronic illness.

Background of the Problem

Life with a chronic illness often means a reinvention of life and redefining one's identity because the presence of a chronic illness changes the ways in which one lives. Seeking help not only is difficult but also can be misleading and inadequate (Carel, 2008). Different chronic diseases have varying levels of support available to patients. Davison et al. (2000) investigate the social psychology of illness support groups. Their findings indicate patterns between the type on the chronic disease and the support system most utilized. For

example, members of Alcoholics Anonymous (AA) preferred face-to-face interactions whereas individuals with Chronic Fatigue Syndrome preferred online support. Low levels of support and low rates of individuals sharing their stories could result from “embarrassment, stigma, and disfigurement” (Davison et al., 2000, p. 214). It is critical for individuals with chronic illness to share their stories and potentially provide others with chronic illness the opportunity to gather pertinent information that relates to their lives.

Improvements in medical interventions and technology, outpatient care, and survival rates of individuals with chronic illness are providing people with opportunities to participate in schooling, vocational pursuits, and community activities that were previously difficult to access (Asprey & Nash, 2006; Illich, 2013; Rehm, 2002; Rehm & Bradley, 2005a, 2005b; Ryan, 2006; Sexson & Madan-Swain, 2001; Shaw & McCabe, 2008). The medical advancements, improvements in care, and increasing survival rates establish the premise for those living with chronic illness to share their stories and to expose the misconceptions of living with chronic illness (Carel, 2008).

Those with chronic illness need to share their stories as the nature and the severity of each illness influences lives differently (Clay, Cortina, Harper, Cocco, & Drotar, 2004; Thies & McAllister, 2008). Selak and Overman (2013) advocate for those living with chronic illness to be honest about their experiences and explain how freeing honesty can be. Schuster, Chung, and Vestal’s (2011) findings show a need for more support and resources for families affected by chronic illness in order to foster the sharing of stories in a meaningful and positive way. Furthermore, Shiu (2004) identifies the need for positive interventions for families affected with chronic illness, as well as further support and resource development. Schrag, Morley, Quinn, and Jahanshahi (2004) indicate how chronic illness impacts the

quality of life of the individual and how it is critical to realize the impact on the whole family. Additionally, no instrument assessing the impact of parental illness on children exists rather “generic instruments of psychological wellbeing” are utilized (Schrag et al., 2004, p. 403). Schrag et al. (2004) discussed the Parental Illness Impact Scale (Parkinson’s Disease) and included six domains that correlated with the Quality of Life in Epilepsy for Adolescents, the Beck Depression Inventory, and the Rosenberg Self-Esteem Scale. Schrag et al. (2004) urge that this scale be utilized with other chronic diseases to further test the validity.

Statement of the Problem

As a mother, wife, daughter, and sister I have experienced how a chronic illness not only affects the individual but often extends to the family members of those diagnosed. Smith and Friedemann (1999) investigated family perceptions of chronic pain. Although chronic pain and chronic illness are not the same thing, chronic pain is applicable to many living with a chronic illness since chronic illnesses may cause chronic pain. It is necessary to address the issue of chronic pain because addressing individuals’ chronic pain is integral to the personal experiences of living with a chronic illness. Smith and Friedemann’s findings indicated emotional distress, distancing from the family, inability to share feelings, family isolation, intense mutual involvement (between the parent with the illness and immediate family), and healing as being associated with chronic pain. Despite the negative implications from Smith and Friedemann’s findings, the theme of healing reveals the possibility of growth and overcoming the barriers associated with chronic pain. Smith and Friedemann conclude that further research is needed especially with regards to the spouses and children of people with illnesses.

Chronic illness and the family. More recently, Rosland, Heisler, and Piette (2012) conducted a systematic review of the impact of parental chronic illness on the family as a whole. Findings indicated the need for further understanding of both the family and the individual family member with the chronic illness, familial support, as well as additional longitudinal studies to further understand the implications of chronic illness on families. Further, research identifying the influence of parental illness on children is lacking (Mukherjee, Sloper, & Lewin, 2002; Schrag et al. 2004).

Rosenfeld et al. (1983) identify that “little work has been reported on the children of parents who are treated for cancer and who might be expected to be suffering from very high levels of psychological stress” (p. 245). Rosenfeld et al. interviewed eight young females ages 12 to 20 and seven mothers who had breast cancer and a resulting mastectomy. Rosenfeld et al.’s findings included perception of illness, adjustment, and social support. Three of the young females were described to have a realistic understanding of their mother’s illness, as well as knowledge about their health. Six of the young females believed the cancer to be a threat to them. They worried about their mother passing and if they themselves would be diagnosed with cancer. Seven of the young females described the negative implications of their mother having cancer impacting their schooling. Four of the young females felt psychological or psychosomatic symptoms during the time of their mother’s disease, two had physical ailments, and four described mood disturbances. Six of the young females felt they were not provided with an accurate explanation of their mother’s disease. Seven of the young females participated additional household activities. The young females described talking to their mother, family, and friends about their mother’s disease. One young female described wishing she knew someone else her own

age who also had a mother with cancer to talk to. Rosenfeld et al.'s findings continue to be relevant since salient themes in lives of families were identified and continue to resonate through the literature (Blackford, 1999; Mukherjee et al., 2002).

Being a child of a parent with a chronic illness. Schrag et al. (2004) identify how in the presence of a parent with a chronic illness, children tend to feel overwhelmed by the repercussions of the illness. As well, children of parents with chronic illness can internalize feelings of isolation, restriction, and potentially develop their own health problems (Earley & Cushway, 2002). Emotional well-being can also be at risk among children when a parent is living with a chronic illness (Wong, Cavanaugh, MacLeamy, Sojourner-Nelson, & Koopman, 2009). Blackford (1999) synthesizes that children of parents with chronic illness have an increased risk of pathological symptoms, and have parents who may not participate in as much of their life events compared, and are often pitied. It is necessary to address the potential risk factors for children in addition to the effects of being a parent with chronic illness to reveal the implications of the family as a whole.

With the premise that children understand illness by how people behave (Carey, 1999), White, Bellamy, Powell, and Wittenauer (2011) explored conversations mothers had with their toddlers in explaining the differences between an acute illness and a chronic illness through a joint-reading of a storybook featuring a character with a common cold virus. The study examined how mothers portray illness to their children. Findings suggest that mothers with chronic illness used more “sick-type” (White et al., 2011, p. 1411) words than healthy mothers. Examples of phrases used by mothers with chronic illness include: “He feels sick. Awww,” “Aw, everybody’s gotten sick now,” and “He looks so sick” (White et al., 2011, p. 1413). Even though mothers both with and without chronic illness use the word “sick,”

mothers with chronic illness used the word less often. The significance of mothers with chronic illness using “sick” less often reveals their embrace of the complexities involved in living with a chronic illness (White et al., 2011).

Mukherjee et al. (2002) investigated the experiences of young people with a parent with inflammatory bowel disease (IBD). The study included 23 young people ranging in ages from 6 to 20 years. The research questions included, What happens when the parent is unwell? What does the young person know about the illness and how does the young person help? Is there any advice for other young people who have a parent who is not well? In response to understanding the illness, the findings were mixed. Some young people knew a great deal about their parent’s illness while others did not. It is important to note that understanding of the parent’s illness did not relate to age. Participants described feeling sad, concerned, mad, and remorse. If the parent was hospitalized participants were particularly anxious and revealed anger and frustration in response to the limitations on their daily activities. The most shared feeling “was being ‘sad’ or ‘upset,’ with 10 young people using such words to describe how they felt” (Mukherjee et al., 2002, p. 482). Importantly, young people did share their affection for their parent despite the negative reactions to their illness, revealing the bond the child and parent shared.

In relation to talking about the parents’ illnesses, some parents in Mukherjee et al.’s (2002) study disclosed their health to their children and others did not. Six young people felt their parent’s illness had no impact on their life while only three could think of the positives which included a parent reading to them, making their own meals, and being a closer family. Young people were understanding of their parent’s illness but implications were described and included limited participation in social activities, parents unable to complete housework,

children needing to be wellbehaved, and the parent being “withdrawn or irritable” (Mukherjee et al., 2002, p. 479). Young people were asked what helped them and responses included trying to forget by doing something else, talking to others, being given information about their parent’s health, having a friend in a similar situation, having others help calm them, and “hugging cuddly toys” (Mukherjee et al., 2002, p. 483).

In another study, Blackford (1999) reflects on her experience as a mother with a chronic illness and how her initial feelings affected her son: “my own initial fatigue, fear, hospitalisation and medication-induced confusion contributed to my son’s early evident feelings of anxiety, confusion and abandonment” (p. 678). In addition to the adversities experienced by Blackford and her son, she also revealed the altruistic characteristics of her son. Furthermore, Blackford discussed how children with parents who are ill are in need of new understandings of disability, growing up, and family. Children with parents who are ill also have the capacity to re-make their experiences by being actively involved in their family life, being mindful of family needs, possessing strong communication skills, being positive about family needs, and being hopeful. Blackford’s findings indicate the positive aspects and extraordinary gifts brought forth by having a parent with a chronic illness.

Significance of the Study

Findings from this literature review indicate that there are negative implications of living with a chronic illness which can include emotional distress, isolation from family and the community, difficulty adjusting, and the need for social support (Rolsand et al., 2012; Rosenfeld et al., 1983; Schrag et al., 2004; Smith & Friedemann, 1999). These consequences often entail physical, psychological, and emotional adversities and impact the family as a whole (Blackford, 1999; Kean, 2009; Mukherjee et al., 2002; White et al., 2011). Kean

(2009) states, “the voices of children from families affected by chronic illness remain unheard” (p. 267). Furthermore, Ashton (2004) indicates that families affected by chronic illness need support and additional resources.

At first when I began reading the research about being a child of a parent with an illness, I was deeply pained by many of the findings discovered. I am nervous about how my daughter will perceive my chronic illness as she grows. Will she be at risk for so-called problem behaviour (Schrag et al., 2004)? Will I adequately prepare her for the complexities of my illness (White et al., 2011)? How much will my illness impact her day-to-day life (Mukherjee et al., 2002)? These questions loom in my mind. But hope remained when findings indicate the strengthened family relationships and bonds between immediate family members (Blackford, 1999; Kean, 2009; Mukherjee et al., 2002).

In this dissertation I endeavor to reframe the understanding of chronic illness by revealing the strengths and gifts of living with a chronic illness. I have been inspired by Armstrong’s (2010) concept of the extraordinary gifts that are received from those who are “neurodiverse,” a term that represents individuals who are neurologically different, and advocates for neurological variations to be reframed from strength based perspectives. Neurodiverse conditions can include “attention deficit hyperactivity disorder, autism, dyslexia, mood disorders, anxiety disorders, intellectual disabilities, and schizophrenia” (Armstrong, 2010, p. 8).

Armstrong (2010), an educational consultant who both believes in and practices sharing the strengths and talents of students labeled as struggling or troubled, describes Autism, ADHD, Dyslexia, and other brain differences in a strength-based approach. His premise is that by focusing on the details of individuals’ lives abilities, strengths, and intelligences will be revealed. Armstrong states, “I am convinced we need to reject the

‘disease-based’ thinking that too often dogs the lives of labeled individuals and embrace a more positive vision of who they are, and who they can become” (2010, p. viii). The definition for “neurodiversity” is intended to convey Armstrong’s stance against focusing on individual deficits.

I will share my counter-story that poses chronic illness in a positive light by sharing the gifts my life has received since living with a chronic illness because my story does not reflect the dominant narrative of living with a chronic illness. Counter-stories have been derived from Critical Race Theory (Ladson-Billings & Tate, 1995), and are defined as, “a method of telling stories of those people whose experiences are not often told (i.e. those on the margins of society)” (Solorzano & Yosso, 2002, p. 32). By sharing my counter-story of how I live with a chronic illness, I am “exposing, analysing, and challenging majoritarian stories” (Solorzano & Yosso, 2002, p. 32). I will challenge the dominant discourse about life with a chronic illness through my narrative. Further, I have acquired funds of knowledge from my experiences as an individual with a chronic illness (Moll, Amanti, Neff, & Gonzolez, 1992; Solorzano & Yosso, 2002). In the context of this dissertation, “funds of knowledge” refers to the bodies of knowledge I have accumulated that are central to my functioning and well-being while living with a chronic illness. A few examples of funds of knowledge that I have accrued are: having learned to maintain my health in my home with the support of nursing care, creating an alternate plan to working and being a student, and learning how to balance my health needs with my family’s as both a wife and mother. Teunissen, Visse, and Abma (2013) investigated a counter-story of a patient with a chronic lung disease and findings indicate the dominant stories shared of those with chronic illness do not include the element of learning to live with a chronic illness.

Research Focus

In this dissertation, I will explore the extraordinary gifts that I have received from living with a chronic illness. I will utilize narrative inquiry to share my story as an individual with a chronic illness. Drawing upon the work of Oliver (2014), this dissertation attempts to explain my world of living with a chronic illness and will develop an alternate way of looking at the world. My identity as a mother provides an urgency with regard to admitting and explaining chronic illness to my child that interrupts current disability discourses present in mainstream society by sharing a counter-story.

Research Questions

The research question in this dissertation is: What are the extraordinary gifts I have received from living with a chronic illness? Further I will investigate the following sub-questions: What are my experiences from living with a chronic illness? What has contributed to me positively viewing my life with a chronic illness? How can chronic illness be reframed?

Definition of Terms

The following terms are used throughout the study and have the meanings set forth below:

- Chronic disease: Chronic disease “is defined on the basis of the biomedical disease classification” (Martin, 2007, para. 2).
- Chronic illness (CI): A CI is “the personal experience of living with the affliction that often accompanies chronic disease” (Martin, 2007, para. 2).
- Diffuse Irritable Gastrointestinal Tract Syndrome (DIGITS): DIGITS is classified as a motility disorder, where “the intestinal muscle does not work properly. The contents of the intestine (food or stool) cannot be moved along the intestinal channel, so the

bowel is effectively blocked even though there is no physical kink or twist” (London Health Sciences Foundation, 2012, p. 2).

- Extraordinary: Extraordinary is defined as “unexpected, surprising or strange; not normal or ordinary; greater or better than usual” (“Extraordinary,” 2016, para. 1).
- Gifts: A gift is defined as something given to somebody and is a synonym for present (“Gift,” 2016).
- Ileostomy: A “surgically created opening into the small intestine through the abdomen. The intent of an ileostomy is to allow stool to bypass the colon” (Hollister, 2004, p. 4).
- Ill: Being ill is defined as, “suffering from an illness or a disease; not feeling well” (“Ill,” 2016, para. 1).
- Illness: Illness is defined as “the state of being physically or mentally ill; a type or period of illness” (“Illness,” 2016, para. 1).
- Interstitial Cystitis: A chronic condition that results in bladder pressure, bladder pain and can include pelvic pain, extending from minor to severe pain (Mayo Foundation for Medical Education and Research, 2015).
- Neurodiverse: A spectrum of conditions that include “attention deficit hyperactivity disorder, autism, dyslexia, mood disorders, anxiety disorders, intellectual disabilities, and schizophrenia” (Armstrong, 2010, p. 8). Neurodiverse is a concept that represents individuals who are neurologically diverse, and supports neurological variations be reimagined from strength based perspectives.

- Osteoporosis: A “disease characterized by low bone mass and deterioration of bone tissue. This leads to increased bone fragility and risk of fracture (broken bones), particularly of the hip, spine, wrist and shoulder” (Osteoporosis Canada, 2015, para. 1).
- Port-a-catheter: An implantable venous access system that is implanted under the skin on the chest or arm.
- Stoma: An opening on the abdomen as a result of the ileostomy (Hollister, 2004).
- Self-directed learning: Learning without a predetermined script and finding our own way with our own motivations and passions that includes our self-direction (Ricci, 2012).
- Willed curriculum: A philosophy or worldview to approach learning. “The willed curriculum is about love, trust, respect, care, and compassion. It is about allowing young people to unfold and create themselves in ways that are driven by their souls, their spirits, and their internal motivation. It is about allowing young people, and all people, to learn in a world, to use whatever available resources, methods, and tools the learner chooses” (Ricci, 2012, p. 142).

Chapter 2: Literature Review

Understanding Illness

Understanding illness is central to this dissertation. Being ill is described as “suffering from an illness or a disease; not feeling well” (“Ill,” 2016, para. 1). Moreover illness is described as being physically or mentally unwell. Illness can also refer to the type of illness or refer to the period of time being unwell (“Illness,” 2016). Sontag (2001) describes illness to be an imbalance and that treatment is needed to restore the body’s balance. Further Sontag discusses how illness is used as a metaphor and describes how illness is relevant in the lives of all people,

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick.

Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

(2001, p. 1)

Illness impacts every individual, whether they have the illness or someone close to them has an illness. Identifying perceptions and definitions pertinent to chronic illness are central to this dissertation, but it was also imperative to explore what illness means and how illness has come to be understood in present day. This section will investigate the history of illness, expand on the definition of chronic illness, explore being an individual with a chronic illness, and will attempt to redefine health through seminal literature. The second section of this chapter will examine the theoretical approaches that have informed this study. The theoretical approaches that will be discussed are the social and cultural construction of disability, critical pedagogy, wellness studies, and the willed curriculum.

History of Illness—Chronic Illness Defined

There is a lack of clarity in defining chronic illness. For this dissertation, chronic illness will refer to the “stories of experiences that make up” my life with a chronic illness (Clandinin & Connelly, 2000, p. 20). Chronic disease is the biomedical description of the disease. When exploring the definition of a chronic illness, there are many issues associated with what constitutes the latter. Concerns with this definition are the numerous illnesses that fit this description, and often that the definition does not capture any of the symptoms, consequences, treatments, and maintenance of the chronic illness (Walker, 2001). Examples of varying descriptors of a chronic illness include an illness that persists for longer than 3 months, longer than 6 months, can be categorized with particular illnesses or diseases, cannot be cured, or will not kill the person at the time of diagnosis (Edwards, 2013; Newacheck & Taylor, 1992; Wendell, 2001). Edwards (2013) describes the complexity of chronic illness and the difficulty in defining chronic illness with one shared understanding: “chronic illness is a phrase with no end of meanings, one definition stretched over thousands of diseases. It will seep into all of our lives at some point” (p. 207). Chronic illness also may not be the term preferred by the individual with the illness since some people prefer to use chronic condition or chronic disease instead of chronic illness. All of the variation in terms contributes to the complexities in defining a chronic illness (Edwards, 2013).

Regardless of the definition preferred to describe a chronic illness, upon diagnosis individuals will live with the chronic illness. Chronic illness can eventually kill the individual by different means such as exhausting the individual’s health or by life-threatening incidents as a result of the chronic illness (Wendell, 2001). Whitsitt (2010) states that society not only needs to include the medical and biological descriptors but also the cultural experiences of

illness for both the patients and families. This change in how society views illness is a postmodernist view realizing that the medical component of the illness is not the whole story and there is a need to value the patients' experience of being ill. A postmodernist lens refers to a time that "creates a context of doubt, in which all methods are subject to critique but are not automatically rejected as false" (Wall, 2006, p. 2). The intention of postmodernism is to question power and demonstrate there are many ways to acquire and share knowledge (Wall, 2006).

Walker (2001) states that it is doubtful a universal definition of chronic illness will be accepted, but further refining chronic illness will improve the understanding of chronic illness and aid those who are affected. Without having a clear focus of what defines a chronic illness, it is extremely difficult to establish presence in society for individuals who have been diagnosed with chronic illness. This insufficient definition of chronic illness both influences and contributes to a lack of understanding about what consists of living with chronic illness. No one really knows what a chronic illness is. If no one knows what a chronic illness is, how can people understand what life is like for individuals living with a chronic illness?

Comparable to disabilities, illnesses are portrayed based on appearance (Sontag, 2001). In the instance of having an invisible chronic illness it becomes difficult for others to understand the individual's distress when it is not clearly visible. An invisible chronic illness is defined as "diseases that are characterized by chronicity and symptoms that are not externally manifested" (Donoghue & Siegel, 2000, p. 4). The symptoms associated with an invisible chronic illness do not necessarily reveal to an outsider that the individual is experiencing symptoms. The individual's suffering is not associated with an illness but rather other undesirable personality traits, such as being withdrawn.

Becker (2007) states that individuals have an immense desire for life to be predictable, orderly, and have a presence of continuity. Without this “order” the opposite is present in life, creating disorder and turmoil. Individuals with chronic illness have an immense desire to conform to society’s norm of how life is “supposed” to be lived. Tension exists between the normalcy the individual with a chronic illness is attempting to create and the chaos that exists. The disorder present in lives of individuals with chronic illness often makes it difficult to live independently and to be responsible for one’s health status (Whitsitt, 2010). Individuals with chronic illness have difficulty accepting their illness, that they are not responsible for their illness, and are not less of a person as a result of having an illness.

Being an Individual With a Chronic Illness

I am a person with DIGITS. I am a person with a chronic illness. I am not chronically ill. I am a person first. My chronic illness is not who I am but rather a part of me. What I have described is people first language. Instead of being purely seen as a diagnosis, I am an individual with a diagnosis, and the way in which this is described is known as “people first language” (Edwards, 2013; Snow, 2016). People first language is an important social movement that began with the AIDS movement in understanding that individuals are more than their diagnosis and more than a patient (Edwards, 2013). The word patient is described as “a person who is receiving medical treatment, especially in the hospital” (“Patient,” 2016, para. 1). The Latin origin of the word patient is suffering (“Patient,” 2016) and can also be related to passivity (Edwards, 2013). Boyd (2000) describes how patients are most often described as having a disease, being ill, or sick. Edwards (2013) describes the numerous roles an individual with a chronic illness has that include making choices about the illness, being

“experts” with their disease, seeking collaboration with professionals, and still being a patient, “being expected to be patient” (p. 165).

In the medical setting, as a patient I am classified as having a chronic illness (Boyd, 2000). Every time I meet a new doctor my history solely includes my medical history which is problematic because I do not only want to be identified by my chronic illness. It is only when the doctor and I establish a relationship that further insights about my identity are added beyond my medical history and diagnosis. As a patient, I regularly receive medical attention; however, I do not see myself as someone who is suffering but rather someone who is happily living. As a young person with a chronic illness, I am supposed to be young and healthy, not young and sick (Edwards, 2013).

Outside of my immediate family, people really do not want to hear about my experiences with illness and the symptoms I continuously feel. Being young with a chronic illness adds to the complexity in people understanding my life. I am young and yet I have chronic illness with no cure in sight. In addition, at times I do not even want to discuss chronic illness. I have experienced the deteriorating relationships within my family and peers from me “never getting better.” Illich (2013) describes how those who are ill are perceived by society as “those who are sick and tired of society that is they who are ill, impotent, and in need of technical repair” (p. 9). People do not want to see illness, hear about illness, or talk about illness; especially when so much of my chronic illness is gastrointestinal and involves stool. Edwards (2013) writes how those with bowel disease may not feel comfortable talking about their symptoms and illness. Also, as previously mentioned my chronic illness is largely invisible. Much of the effects of my chronic illness are not observable unless I share that I have an ostomy or if I am hooked up to my intravenous. The invisible aspect of my chronic

illness means that unless I remind people that I have it, people minimize it, forget it, or tell me to “get over it” (Wendell, 2001, p. 21). According to Wendell (2001), people do not want to keep reminding others of their impairments. Heilbrun (1988) states, “I sought another identity, another role” (p. 114). I did not want people to view me as sick or disabled. Wendell (2001) discusses that “solidarity between people with chronic illnesses and people with other disabilities depends on acknowledging the existence of suffering that justice cannot eliminate. It also depends on acknowledging that illness is not just suffering” (p. 31). Wendell (2001) shares that living with an illness means different ways of being. Similar to Heilbrun, I know that my different way of being left me desperately wanting to create space for me to live, and the only way for people to understand how people live differently is through patient awareness, advocacy, and sharing their stories. Only then will the barriers be broken (Crow, 1996; Edwards, 2013)

Redefining Health

Health is another concept that has been defined with different meanings and understandings of what it means to be healthy. The World Health Organization (WHO, 2016) defines health as follows:

Good health is a state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity. Health is a resource for everyday life, not the object of living, and is a positive concept emphasizing social and personal resources as well as physical capabilities. Health is a fundamental human right, recognized in the Universal Declaration of Human Rights (1948). (para. 1)

Critics of the WHO’s definition believe this definition to be idealistic, utopian, and overambitious, and that the definition refers to happiness more than health (Boyd, 2000).

Illich (2013) defines health as “simply an everyday word that is used to designate the intensity with which individuals cope with their internal states and their environmental conditions” (p. 7). Further, Illich states that “medical nemesis is resistant to medical remedies. It can be reversed only through a recovery of the will to self-care” (2013, p. 35). The varying definitions associated with the term health reveals the complexity in understanding what health is. What does it mean to be healthy? This is a question I often pondered and for a long time I did not believe that I was healthy. I was only classifying my health according to the biomedical approach.

Illich (2013) describes how individuals damage their health when they believe that they are incapable of coping with their illness without a doctor. I believed I was an unfortunate person who did not possess health and needed the assistance of doctors. I realized that I too could be healthy. Illich states people do not want to be sick; they want to be healthy. Convincing myself that I was healthy started by having a note posted on my mirror that stated, “I am healthy.” I also had this phrase written in my journal and would say it to myself multiple times throughout the day. I realized that being healthy is a state of being and goes beyond the simple idea that health is the absence of disease. Yes, I do have a chronic illness but I am still healthy. Historically, the word health is derived from the Old English *hoelth*, which referred to wholeness within the body (Dolfman, 1973). Depending on an individual’s perceptions, their health changes whether or not they think of themselves as healthy, leading boundaries of health and disease to become blurry (Boyd, 2000). As Boyd (2000) describes,

To be healthy is not to correspond with some fixed norm, but to make the most of one’s life in whatever circumstances one finds oneself, including those which in

terms of some fixed norms may seem severely impaired or unhealthy. (p. 14)

According to Boyd, being healthy is the ability to recover. If I were to compare myself to a typical 32-year old female, my health greatly differs but my ability to recover from the significant health implications I have experienced has fostered my belief of me being healthy. The relationships with my doctor(s) now follows the model of participatory medicine which understands the necessity to empower patients and value their experiences and input. I also know that from my experiences of living with a chronic illness I have become health literate (Edwards, 2013). I know the needs that I have, the medications that are required, and that I need to maintain a unique diet and light exercise. Illich states that to recover health, individuals need to “act so that the effect of your action is compatible with the permanence of genuine human life” (2013, p. 268). The delicate balance of my lifestyle in maintaining my health has greatly contributed to me being healthy and hopefully to sustain a full life.

Theoretical Approaches

Since I have established a historical basis from which to explore health, it becomes necessary to develop the theoretical approaches used in this study as each apply to current literature on health, and as each apply to my own journey as a person with a chronic illness. Discovering the theoretical approaches for my dissertation has truly been a journey and I have learned a great deal about how and why I share certain worldviews. Sharing my story in my dissertation has not come easily but I know that in order to be authentic, sharing my story was necessary in revealing how I have come to my place of being. My experiences have fostered the lens through which I view the world; my all-encompassing worldview (Morgan, 2007). The following descriptions reveal the theoretical approaches that have informed this dissertation. Wendell’s (1996) social construction of disability resounded true to the many

aspects of my life with a chronic illness and the barriers I try to overcome. Freire's (1985) critical pedagogy deeply resonated with me because living with a chronic illness is embedded in who I am; I cannot assume a neutral attitude. I have realized that if I, the researcher, am not willing to share my story and to be vulnerable, I cannot in good conscience ask others to be vulnerable (Gorad, 2014). Therefore, my dissertation research is heavily rooted in critical pedagogy (Freire, 1970). Further, wellness studies relate to my dissertation because I realized I have the ability to heal despite having an incurable illness. Lastly, the willed curriculum (Ricci, 2012) has been applicable since I needed to love and appreciate who I am physically, emotionally, and spiritually. It is only when I began to treat myself with kindness and love that I began to learn how to live with a chronic illness. Further, it is necessary to continue to explore the theoretical traditions that support and inform my research project.

Social Construction of Disability

The premise of the social construction of reality is that reality is based on socially constructed understandings and thus has been created and has fostered shared ideas about reality (Hewitt, 2001). To have a chronic illness is to vary from the norm with an impairment and abnormal health and therefore implies that a normal state of health exists without any impairment (Walker, 2001). Wendell (1996) states that disability is socially created and further defines the social construction of disability as, "the interaction of the biological and the social to create (or prevent disability)" (p. 57). The social construction of disability relates to how obtaining employment with a disability is complex since people with a disability may not be hired as quickly as individuals who do not have a disability (Edwards, 2013). Within the social construction of disability is a pace of life factor. This factor is often taken for granted by people without a disability whereas people with a disability are

incredibly aware of how it marginalizes or threatens to marginalize. The pace of life factor also includes “the social construction of disability through performance” which emphasizes the importance of people being able to perform all tasks in their lives (Wendell, 1996, p 58). Accommodations can counterbalance improvements to accessibility for people but for those who require more time, or those who have limited energy, social events remain inaccessible. In the instance that individuals are able to keep up their pace at work, the resulting fatigue may limit their participation or even exclude them from other life events. Additionally it is important to note that “expectations of individual productivity can eclipse the actual contributions of people who cannot meet them, making them unemployable when they can in fact do valuable work” (Wendell, 1996, p. 59). Disability is also socially constructed in the instances when people are not given the opportunities to participate in all of the main aspects of life. Wendell (1996) does not claim that disabilities are solely socially created but rather, “many of the struggles of people with disabilities and much of what is disabling, are the consequences of having those physical conditions under social arrangements” (p. 61).

Cultural Construction of Disability

According to Wendell (1996) there is also a cultural construction of disability. This is not only evident in society’s omission of stories of those with disabilities but also by stereotyping those with disabilities, stigmatizing, attaching meaning to different illnesses and disabilities, and excluding people with disabilities. The impact of these actions contributes to Otherness of people with disabilities. Further, Wendell (1996) argues that this othering occurs through “encouraging the assumption that their lives are inconceivable to non-disabled people’s fear of disability by suppressing how people live with disabilities” (p. 61). In accordance with the inability to imagine life with a disability, there is also “the belief that

life would not be worth living with a disability. ... This belief is fed by stereotypes and ignorance in the lives of people with disabilities” (Wendell, 1996, p. 67). Additionally, the stigma that is associated with the word “disability” prevents people from using the word even if it describes their situation (Edwards, 2013; Illich, 2013). Initially, when I was first experiencing the symptoms of my chronic illness, I was consumed with what I did wrong to acquire this illness because I could not live with a disability. I favoured a behaviourist model towards illness (Walker, 2001). I believed that poor behaviour was equal to poor health and because I was engaged in a healthy lifestyle that I should be healthy. At the time I believed a healthy lifestyle included being physically active and following a health-conscious diet. Over time I have realized that I now defy this behaviourist model. Individuals with chronic illness are viewed as passive and dependent on the assistance of others and social assistance (Walker, 2001). In order to change these stereotypes, disability needs to be deconstructed. Participation is not about people with disabilities surmounting their disability but rather being able to participate in the activities of life. Having a chronic illness is not about fixing the individual but rather about enabling the individual (Rosenbaum & Gorter, 2011).

Being an Individual With a Healthy Disability or Unhealthy Disability

Continuing with the discussion of disability being a social construction, Wendell (2001) differentiates the difference between being a person who is healthy with a disability and a person who is unhealthy with a disability. From an activism stance it is considered to be safer for people to focus on individuals who are healthy disabled. Wendell (2001) defines healthy disabled to be “people whose physical conditions and functional limitations are relatively stable and predictable for the foreseeable future” (p. 19). Individuals with chronic illness would be considered to have unhealthy disabilities. Being an individual with an

unhealthy disability means being surrounded by people who are full of suspicion. People wonder how ill they are, what makes them ill, and whether or not they are really doing all they can to become well, and why they are not helping themselves. People wonder if they can trust someone with a disability and at times the individuals with a chronic illness “pass” involuntarily or voluntarily by not wanting to not draw attention to their disability (Wendell, 2001, p. 29). Wendell (2001) describes how fatigue is often one of the most misunderstood aspects of living with a chronic illness. As humans, every activity one engages in necessitates energy. When one has chronic illness, fatigue is not healed by a “good night’s sleep” but can require further interventions (Wendell, 2001, p. 25). What is needed is to reframe how people think about energy, contributions, time, and pace because going beyond what people with chronic illness are able to sustain means the consequences are greater. Examples can include relapse, hospitalization, and permanent damage to their bodies.

When relapse occurs, and is assured, individuals with chronic illness are expected to have some form of control over their illness (Wendell, 2001). Being a person who is unhealthy disabled entails “living with pain, fatigue, nausea, unpredictable abilities, and/or the imminent threat of death creates different *ways of being* that give valuable perspectives on life and the world” (Wendell, 2001, p. 31). Using Wendell’s (2001) definition of unhealthy disabled, I can identify with being an individual who is unhealthy disabled although as I have previously stated, I do not view myself as unhealthy. As an individual who is unhealthy disabled I do not regret having the chronic illness I live with.

Critical Pedagogy

Giroux (2004) states that critical pedagogy calls for researchers to “redefine and transform the connections among language, desire, meaning, everyday life, and material

relations of power as part of a broader social movement to reclaim the promise and possibilities of a democratic public life” (p. 46). Freire’s (1970, 1985) critical pedagogy starts with where people are in their current state of being and moves them to a critical consciousness. Critical consciousness enables people to understand their experiences of oppression. My critical perspective is rooted in the experiences I have confronted; it is deeply grounded in the questions I have regarding the ways people living with chronic illness live. I rely on my experiences from living with a chronic illness and Freire’s (1970, 1985) interpretations of critical pedagogy. Critical pedagogy is embedded in sharing the perspectives of people in a particular context. This is essential to framing my doctoral research because of how critical pedagogy references my own place within my research process.

My ability to come forward and believe that I am able to interrupt conceptions of how people with a chronic illness live has taken much contemplation and courage. I was never confident about the knowledge and experiences I have had. I did not value the experiences, nor believe they held meaning. I typically ignored the idea of sharing my story and anomalies (Morgan, 2007). Freire (1970, 1985) believes that within the oppressed is the oppressor. Greene (2009) describes how individuals who are oppressed internalize the systems that view them to be weak. In addition, individuals who are oppressed are unable to uphold the societal expectations of control over their lives and sustain the productivity of society (Greene, 2009). Allman (2009) also describes how the oppressor penetrates the oppressed ways of thinking, aspirations, and behaviours, and how the oppressed “have no model, other than the oppressor, of what they might aspire to be” (p. 429). Over time my views have changed and I have moved to a critical consciousness. I believe there is a great need for individuals with

chronic illness to share their stories. Freire's (1970) assertion that "almost never do [the oppressed] realize that they, too, 'know things' they have learned in their relations with the world and with other men" (p. 51) resonated with me as I considered telling my personal story of living with a chronic illness. Allman discusses the need for dialogue to give opportunities for people to experience alternative stories. In alignment with Edwards (2008), I am an expert regarding my health whether I seek the distinction or not and there is a need for dialogue concerning those who live with chronic illness.

As an individual with a chronic illness I have spent a lot of my time dependent on the assistance of others such as doctors, medical professionals, and family members. Not only am I dependent on people but also on things such as equipment and medications. This continued dependency contributed to my feelings of inadequacy—I always needed people and things that others did not. I felt I was forever dependent, as Freire noted "for the oppressed, at a certain point in the existential experience, *to be* is not to resemble the oppressor, but *to be under* him, to depend on him" (1970, p. 51). As I learned to live with my chronic illness I became aware of how interrelated living with a chronic illness was with politics and power in broader society (Giroux, 2004). The relations I had to form with institutional forms for support were not only complex but often contradictory to the help I needed. I needed to think about how I was engaging as an individual and how I was being perceived (Goffman, 1959). I came to realize that similar to Becker (2007), I needed to think about alternative ways of thinking and speaking about specific subject matter.

My non-neutral attitude towards my life involves uniting action and reflection, also known as praxis, that has and continues to lead to my transformation in attempts to share an alternative perspective of life with a chronic illness (Freire, 1985). My life and understanding

of life with a chronic illness contrasts with the crystallized knowledge that has historically contributed to understanding life with an illness (Guba & Lincoln, 2005). Freire (2009) states, “Yet only through communication can human life hold meaning” (p. 55), revealing the need for people to share their stories and that “Oppression—overwhelming control—is necrophilic, it is nourished by love of death, not life” (p. 55). People need to have opportunities to develop their “creative power” (Freire, 2009, p. 55), as well as their passion. Passion has been referred to as the “power of possibility” and passion, “signifies mood, emotion, desire: modes of grasping the appearances of things. It is one of the important ways of recognizing possibility” (Greene, 2009, p. 85). By nurturing individuals passions, Greene writes how spaces can be opened and a better society can be imagined since it is “only through the projection of a better social order that we can perceive the gaps in what exists and try to transform and repair” (2009, p. 95). Greene urges people to invent ways to free people and to create spaces to “refuse the silences” (2009, p. 96).

Critical Disability Theory

Only upon my reflections of being excluded from mainstream society and not being able to contribute the way I had prior to the onset of my chronic illness did I become critically aware of the ways in which I did and did not belong (Goffman, 1959). Stemming from the numerous limitations and exclusions I have encountered, I have never felt I wanted to stop living because of my chronic illness, nor did I want to stop participating in society in ways that those without chronic illness participate. Instead, I have carefully thought about how I would continue my journey and what it would take to pursue my goals and aspirations. Berger (2014) describes a narrative of Phillips to illuminate the plight of amputees in relation to disability studies. Phillips seeks meaning in his life by continuing to question, and has

changed lives as he created a prosthetic limb that provided more flexibility than previous prosthetics had. Furthermore, Phillips refused to accept life as an amputee and states “I bit my tongue. I knew he was right, in a way—I did have to accept that I was an amputee. But I would *not* accept the fact that I had to wear this foot” (as cited in Berger, 2014, p. 12). Phillips, in his refusal to accept his presented reality is described as an “innovative questioner” who seeks answers to questions that make people in professional domains uncomfortable (Berger, 2014, p. 12). These questions are central to the innovative questioner’s understanding and without the courage to ask, outdated and possibly wrong information can result (Berger, 2014). Throughout this research, I intend to seek answers to these difficult and uncomfortable questions.

Pothier and Devlin (2006) define disability studies as a “theory that emerges from the bottom up, from the experiences of persons with disabilities, rather than from the top down, from the disembodied ivory tower. As such, it is a form of embodied theory” (p. 9). Pothier reveals her experiences with her own disability and her restraint from sharing her needs in certain settings; this is referred to as “passing.” She advocates for people with disabilities to interrupt and to stop trying to fit the environment, and instead to focus on how the environment should be open to varying disabilities (Pothier & Devlin, 2006).

Ware (2009) states the need for further conversations regarding disability studies and notes how long overdue this dialogue is. Silence contributes to the continuation of stereotypes throughout society that are based in beliefs of inadequacy and dependency (Ware, 2009). As Pothier and Devlin (2006) describe, “the struggle over definitions and categories is important because, historically, we have tended to adopt a binary conception of disability: there are the disabled (them-us) and the able-bodied (us-them)” (p. 5). Further,

when considering a healthy person there are positively viewed descriptors attached to ability. Wendell (2013) states that “the public world is the world of strength, the positive (valued) body, performance and production, the non-disabled ... weakness, illness, rest and recovery, pain, death, and the negative (devalued) body are private, generally hidden, and often neglected” (p. 483). Help for those with a disability is often needed to overcome socially created problems. People with disabilities are not in alignment with the dominant citizens and therefore they struggle with the socially constructed ideal of normalcy (Wendell, 2013).

As a Mother With a Chronic Illness

I now view the world through the lens of not only of a person with a chronic illness but also as a woman, parent, wife, friend, sister, and daughter with a chronic illness. My body is different from the norm. I have been defined by an illness. My body “disrupt[s] the rules” (Frazee, Gilmour, & Mykitiuk, 2005, p. 224). I struggle with how my daughter will see me. How will I foster how she views the medical interventions that are a daily part of our lives? I am concerned with the harsh phrases, “Mommy is sick”; “Mommy has a chronic illness”; and “Mommy has a disability.” I never intended for my daughter to think of me as sick, having a chronic illness, or having a disability. I intend to change the language for our lives. The medical needs I have are necessary to maintaining my health and function in accordance with who I am— this is how “Mommy” is. Kean (2009) investigated young people’s strategies to access information when a family member has a critical illness. Kean’s findings revealed that parents controlled information as a means to protect children to keep normalcy in their child’s lives, how children sought information by utilizing different strategies that can include being present with the parent who is ill and/or supporting the parent who is ill,

and children using both direct and indirect questions to their parents. By composing my narrative I will be investigating how I share my chronic illness experience with my daughter.

Kurz's (2012) findings investigated adolescent experiences with parents who are transplant patients, and revealed key themes that include the adolescents' need for normalcy, feeling the impact of the parent's illness, worrying about their parent, and trying to cope with their parent's illness, and their ability to maintain their health. I hope that I will be able to offer my daughter an alternative way to view our lives with my chronic illness beyond the negative effects of living with a parent with an illness. Vallido, Wilkes, Carter, and Jackson (2010) examined mother experiences affected by illness. Vallido et al.'s findings indicate that mothers feel tension and guilt when they are not able to care for their children both when they are present with their children and when they are not able to be present (due to hospitalisations, appointments, and fatigue). Mothers wanted to protect their children from the realities of their illnesses and to prepare them for situations if they were no longer with their children. Mothers described that they were "living to mother, mothering to live" as a motivation to be well (Vallido et al., 2010, p. 1443). Vallido et al. further state the mothering needs to be redefined by focusing on the positive aspects on their life with an illness, and how mothers with illness need further support from the health care community.

My discovery of taking alternate paths to living my life with a chronic illness has been stimulated by my own personal determination and self-directed learning. As Clare (2013) describes,

I am looking for friends and allies, for communities where the staring, gaping, gawking finally turns to something else. ... Places where strength gets to be softened

and tempered, love honed and stretched. ... Places where our bodies begin to become home. (p. 501)

Now that I know what I know, I must continue to pursue possibilities (Berger, 2014). I intend to change perceptions about how living with a chronic illness is perceived. The words “chronic illness” often include negative connotations. Furthermore, the media has been instrumental in perpetuating negative stereotypes towards disability (Ware, 2009), portraying those with disabilities as “dependent, morally depraved, superhumanly heroic, asexual, and/or pitiful.” (Wendell, 2013, p. 485). Knowledge about how people with disabilities live is suppressed and consequently, fear about the thought of living with a disability results (Wendell, 2013). In line with Ware (2002, 2009), I believe disability studies should be grounded in how bodies are viewed as opposed to something being wrong with bodies. I intend to reveal how chronic illness can be viewed through a lens fostering positive growth in times of adversity. By fostering a positive lens, I am not suggesting I will inhibit my daughter from understanding the realities of my chronic illness, but rather, I will pose my life in a positive light so she does not fear my diagnosis and health needs.

Wellness Studies

Throughout my life journey, I no longer view my life with an illness as a burden. As Ricci (2015) states, “We should be offering people our hearts and pulling them up, instead of pushing them away” (p. 4). I sought to create a life that embedded wellness by immersing myself in positive healing strategies. I know I have gained “extraordinary gifts” (Armstrong, 2010) from living with a chronic illness. As Berger (2014) states, “but when we want to shake things up and instigate change, it’s necessary to break free of familiar thought patterns and easy assumptions. We have to veer off the beaten neutral path. And we do this in large

part, by questioning” (p. 6). A major change in my life where “shaking things up” and “questioning” took place was when I became pregnant for the first time.

It took me time to realize that I could have an identity that extended beyond that of a sick person. Palmer (2003) reminds us about how we cannot affirm the identity of others without affirming our own. My wholeness does not mean that I am perfect; I need to embrace my brokenness as a part of who I am (Palmer, 2003). As my daughter grows, she patiently waits for me to access and de-access my intravenous daily. She knows about how gentle she needs to be in touching my port-a-cath, and how careful she needs to be with the intravenous tubing. She can sleep to the soft hum of my pump, and has become accustomed to the irregular beeps and alarms of the machine. She curiously watched my nurse access my port-a-cath. I wonder about the questions she will ask and how I will respond. I do not want my health to be a burden in her life. I have realized the delicacy of my health but also the need to share my health issues with my daughter in a positive light so she can be strong and empathetic (Nolte, 1972). Palmer (2003) writes “we cannot conceal our true identities for fear of being criticized” (p. 6). Further, Armstrong (2010) that one “one important ingredient in the alleviation of all of this suffering is an emphasis on the positive dimensions of people who have traditionally been stigmatized as *less than normal*” (p. 6). Although Armstrong is referring to individuals who are neurodiverse, I propose the need to focus on the positive aspects and gifts of living with a chronic illness.

The Willed Curriculum

There is much more to me beyond my chronic illness. I am not an illness and I intend to encourage a holistic understanding of our mind, body, emotions, and spirit. I believe the presence of balance, inclusion, and connections are all foundational in understanding who we

are (Miller, 2008). A holistic perspective is grounded in the interconnectedness of life, the transformational component of learning, and the importance of relationships (Miller, 2008). Additionally, it is important to acknowledge the presence of love. Love is embedded in holistic education, and is a foundational pillar of the willed curriculum (Miller, 2008; Ricci, 2012). In my journey with a chronic illness, it is relevant to further explore the willed curriculum which is fostered with love, trust, respect, care, and compassion (Ricci, 2012).

Love. Love is central to a holistic curriculum and is foundational with respect to the willed curriculum (Miller, 2008; Ricci, 2012). Further, Ricci (2012) describes that “Love is at the center and drives and controls the willed curriculum. Without love the willed curriculum becomes an externally driven, externally imposed chore” (p. 58). By persevering and learning to live with a chronic illness, I have experienced the connectedness between love and learning.

Having love for others and love for myself is just as critical. By learning to love myself I have learned about respecting my body, mind, spirit, and emotions. I have learned to be kind to myself, to let love guide me, and to protect myself from harm. As Ricci (2012) describes, “love excites and encourages us to pursue our dreams and reach our potential” (p. 69). Love for me has been a difficult journey; it has been hard to love myself. To this day, there are times when I wish I was cured, stronger, and more independent. I still have to take time and remind myself that I am enough.

Trust. Before I could begin to heal emotionally, physically, and spiritually, I needed to trust myself. It was imperative for me to believe that I had the ability to create a life for myself that was worth living. I had to embark on a new path and embrace a new journey as I knew I could never return to the life I was living prior to the onset of my chronic illness. I

slowly learned that I could not continue to live without the dominant medical presence my life had come to know. I began to pursue an unknown path where I discovered what I needed to learn. I had to trust myself to create my own self-directed willed curriculum. By trusting myself I have created a life I did not know was possible (Ricci, 2012).

Respect. Respecting the needs for my body with a chronic illness has been a challenge. I now know that the interventions have truly enhanced my life but valuing my difference can still be challenging. Ricci (2012) states that “Our goal should not be to ... try to make everyone the same, but to support and understand the value in diversity” (p. 81). In my past, I desperately wanted to be the same as I was before the onset of my illness. I did not want to be different. Further, I did not know how to value the life I had, more specifically, my new place of being. I was desperate to do all of what I could prior to my illness (Illich, 2013). Only when I began to appreciate the experiences my body had endured did I begin to respect myself and the positive components of the interventions that have become part of the life I know (Ricci, 2012).

Care and compassion. As I reflect on the time it took for me to learn how to live with my chronic illness, I am saddened by the pressure I felt to conform to the expectations of others. I believe that if I would have had more care and compassion for myself, my recoveries would have fostered more healing. My past has included numerous instances when I have needed large amounts of time to heal as a whole. Having a chronic illness is time consuming (Wolanin, 2013); I wanted to return to my fast paced normal life (Wendell, 2013). I was haunted by comments such as, “You are not in school or working; what do you do all day?” I dreaded social functions. Nobody wanted to discuss my ongoing medical escapades nor did they want to talk about how I was learning to care for myself outside of the

hospital setting. I was vulnerable to perceptions about taking too long to get better. Clearly, I was doing something wrong. Insensitive comments and limited understandings of chronic illness from both me and others fueled my insecurities. Unfortunately, I was not handling my chronic illness in a way that fostered wellness. I was sensitive to being perceived in a negative way, as someone with a chronic illness. I was afraid of my chronic illness defining me. I was not giving myself the care and compassion I needed to heal, nor was society.

“The willed curriculum is a philosophy, a worldview, a way of life. It can take place outside of formal schooling or within. It allows the learner to decide what type of curriculum he/she would like to subscribe to” (Ricci, 2012, p. 141). It has been through the willed curriculum that I transformed into a person who can appreciate the experiences I have had and can ultimately grow. My worldview has changed. I no longer view myself as damaged or unworthy. I believe that I can foster wellness in my life. I know that I continue to be shaped by my chronic illness and I also know that I can no longer separate myself from my illness. Much of my identity has been created from my experiences of living with a chronic illness and the extraordinary gifts I have received from living with a chronic illness.

This dissertation endeavored to combine these theories in attempts to identify the extraordinary gifts I have received from living with chronic illness. Gaps in the research suggest there is a need for alternate stories for families experiencing chronic illness, and thus this dissertation aims to contribute to the literature investigating families impacted by chronic illness.

Chapter 3: Methodology

I have explored living with a chronic illness through a qualitative paradigm. The methodological approach for this dissertation was narrative inquiry (Czarniawska, 2004; Polkinghorne, 1988; Wiebe, 2009). Based on the understanding that as one lives, “we are the meaning makers—every one of us. ... To try to make sense, to construct stories and explanations, and to share them with others in speech and in writing is an essential part of being human” (Wells, 2009, p. 313).

Through the use of narrative inquiry, I have shared my counter-story of life with chronic illness. In this dissertation I have aimed to reframe the understanding of chronic illness. I believe living with my chronic illness has provided me with gifts, not just deficits. Heilbrun (1988), writing in relation to women sharing an alternative narratives, notes that “the price is high, the anxiety is intense, because there is no script to follow, no story portraying how one is ought to act” (p. 39). I have explored the extraordinary gifts I have received from living with a chronic illness. By sharing my narrative I explored how I have made meaning (Polkinghorne, 1988) of my life with a chronic illness. I investigated how I have created the life I have with an unhealthy disability (Wendell, 2001). I have explored the extraordinary gifts that I have received in my life in relation to my chronic illness and that I believe to be the most meaningful aspects of my life. The research question was: What are the extraordinary gifts I have received from living with a chronic illness? I also investigated the following sub-questions:

1. What are my experiences from living with a chronic illness?
2. What has contributed to me viewing my life with a chronic illness positively?
3. How can chronic illness be reframed?

Narrative Inquiry

For this research study it is imperative to define narrative inquiry. Narrative inquiry is a methodological approach that is interdisciplinary in nature (Wiebe, 2009). Narrative inquiry studies and analyzes stories from life experiences (Schwandt, 2007) and seeks to understand certain life experiences that consist of an individual's history (Wiebe, 2009). Bruner (2004) explains the history of the self-told narrative is "ancient and universal" (p. 695). The capability of individuals sharing their stories through the use of narrative crosses both time and borders (Bruner, 2004; Wells, 2009). I have used the terms narrative and story interchangeably to refer the "story" of my life (Polkinghorne, 1988, p. 14).

Narrative inquiry may include a biographical element of sharing stories. Through narrative, stories are shared in response to how one experiences the world (Merriam, 2009). Based in truth, narrative inquiry gives voice to stories (Denzin & Lincoln, 2002). Kimpson (2005) shares her experiences with narrative: "Giving myself the authority to value my own insights and to focus on my knowing undeterred was transgressive, a stepping off the road" (p. 176). Higgs, Horsfall, and Grace (2009) reveal that "whether inside or outside of formal research institutions—[narrative inquiry] is a gift given in a spirit of generosity, even of love, from one person to another" (p. 81). Similar to life experience narrative inquiry is "ever-changing" that ultimately may lead to changes in research questions and purposes (Wiebe, 2009, p. 2). What is noteworthy throughout the research, as Thorne et al. (2002) indicate, is that narrative is a less prominent methodological direction used in the exploration of the lives of those living with chronic illness. Narrative inquiry may include one or a few participants. For this dissertation I have shared my life experiences with a chronic illness. I have revealed my experiences with a chronic illness from an individual intrapersonal perspective and from

a perspective situated in a family setting. Sharing my autobiographical narrative has portrayed my “life as unified and whole” (Polkinghorne, 1988, p. 36).

Barthes (1974) describes how narratives achieve significant purposes that allow people to narrate their lives, potentially identify their future journey, and collectively share values. Further, Barthes states that a text does not include one meaning but rather there is a need to “appreciate what plural constitutes it” (1974, p. 5). When exploring a narrative text Barthes uses *lexias* to describe the smaller “units of reading” that comprise of the master text (1974, p. 13). Each *lexia* may have three or four different meanings and can contain as much as a few words to a few sentences. Each time the text is read additional meaning comes forth. Barthes describes five narrative codes that include the following: *hermeneutic*, *proairetic*, *semantic*, *symbolic*, and *cultural*. The hermeneutic code is the meaning the author presents but is not immediately revealed to the reader; it will be revealed at a later point in the text. The proairetic code is the sequence of the story, taking the reader through the story. The semantic code adds an additional literal layer of meaning to the text. The symbolic code is the antithesis and division of opposites within the story. The cultural code refers to the shared knowledge that exists outside of the text itself. Using Barthes’s narrative codes was significant since it provided the opportunity to examine what the text endeavors to illuminate. Furthermore, understanding Barthes’s narrative codes in my methodology expanded my awareness of the *plural* meanings that are present throughout my narrative.

Polkinghorne (1988) identifies five barriers when studying narrative meaning: meaning is not a fixed tangible thing, we only have access to our own meaning, linguistic statements may lose meaning, linguistics may be interpreted differently, and meaning is a complex interconnection of “modes of presentation, such as perception, remembrance, and

imagination” (p. 8). Noting the barriers in narrative inquiry and in conveying meaning is important since I needed to comprehend these problem areas to ensure I understood the complexities involved in narrative meaning and to further ensure I conveyed the meaning I intended to throughout my narrative.

Data Analysis

In narrative inquiry “data results in a collection of stories” (Polkinghorne, 1988, p. 177). For this dissertation, I have written my story of living with a chronic illness in chronological sequence to expose my understandings of my life (Wiebe, 2009), and have constructed my identity through text (Czarniawska, 2004). My story of living with a chronic illness is a narrative I have lived for a long time that “deserves careful attention” (Czarniawska, 2004, p. 46). When retelling my narrative I have used metaphor in my writing since, narrative inquirers generate research texts that reveal the multifaceted storied way of experience, and through this, research texts are created that represent the composite of people’s experiences (Clandinin & Huber, 2010). Furthermore, Wiebe (2009) describes how narrative inquiry can explore life experiences that are absent in academic writing. Sharing the extraordinary gifts that I have received from living with a chronic illness is lacking in academic writing (Blackford, 1999; Carel, 2008).

My narrative inquiry has been informed by the collection of field texts from my life. The data in my narrative inquiry included journals, autobiographical writing, photographs, and memories from living with a chronic illness. The memorabilia has been collected for the past 11 years beginning from the onset of my illness. Photographs have been included as field texts because photographs can be utilized in narrative inquiry to emphasize changes in individual lives and to illuminate aspects of their lives. When incorporating multiple forms of

data, narrative inquirers generate research texts that reveal the multifaceted ways in which people naturally use stories to capture experiences (Clandinin & Huber, 2010). Furthermore, incorporating my journals, autobiographical writing, and photographs will aid me in representing my experiences with a chronic illness. These sources helped create meaning in the world, contributed to learning, and enlightened my narrative (Clandinin & Huber, 2010; Connelly & Clandinin, 1990), adding further richness and complexity to my memory (Chang, 2007). It is important to note that “memory includes an occurrence that generally has a beginning, middle, and end, even if the end is temporary or dynamic, and can be altered at any moment” (Kizel, 2014, p. 425). Barthes (1974) and Heilbrun (1988) suggest using caution when sharing autobiographical narratives, since as Heilbrun questions,

How much would have vanished or been distorted or changed, even in our memories?

We tell ourselves stories of our past, make fiction stories of it, and those narrations become the past, the only part of our lives that is not submerged. (1988, p. 51)

Furthermore, personal memory does not separate narrative and self (Kizel, 2014) which reinforces the need to use field texts.

Once I had compiled my narrative, I utilized thematic analysis to code the data (Ellis, 2004). Thematic analysis entails identifying themes present in the retelling of my narrative about living with a chronic illness (Ellis, 2004; Wiebe, 2009). The intention of a thematic analysis is to illuminate the content within the story (Ellis, 2004). By reading and rereading my narrative, I deconstructed my narrative with the themes and the sub-themes present throughout my story that related to the extraordinary gifts I have received from living with a chronic illness. As a step-by-step process I composed my narrative exposing a counter-story to life with a chronic illness, and then I coded the data by clustering themes and sub-themes

relating to the extraordinary gifts my life has received. I read and reread my narrative during the coding and I made a list of emerging themes that were weaved throughout my composed narrative.

Autoethnography

Since I have composed an autobiographical narrative it was imperative to understand autoethnography. Autoethnography aids individuals to make sense of who they are, as well as, generalized others, and provides new approaches to thinking and feelings (Ellis, Adams, & Bochner, 2011). Rooted in revealing “cultural understanding underlying autobiographical experiences” (Chang, 2007, p. 4), autoethnography understands research as acts that are political and social. Wolff (2009), with regards to autoethnography, shares that when writing about one’s Self it is imperative to acknowledge the Other, as it is based on moving from Self and Other. Further, Wolff writes that “More importantly, without *consciousness* then cannot be *self-consciousness*. Consciousness-for-oneself always and already is consciousness-for-the-Other” (2009, para. 12). Autoethnography provides a means for people to empathize with those who are different and allows for individuality, feelings, and the researcher’s influence on the research. In addition, autoethnography provides the opportunity for texts to reach larger audiences as the texts tend to be more accessible, potentially laying the foundation for personal and social change (Ellis et al., 2011).

The form of autoethnography that particularly relates to my dissertation is personal narrative. Personal narrative allows authors to “[view] themselves as a phenomenon and write evocative narratives specifically focused on their academic, research, and personal lives” (Ellis et al., 2011, para. 24). Personal narratives provide the opportunity to understand the self within a component of life. Engaging in writing personal stories is therapeutic because

“we write to make sense of ourselves and our experiences” (Ellis et al., 2011, para. 25). I wrote to make sense of my experiences with a chronic illness and have shared the extraordinary gifts that I have received since I have lived with a chronic illness, through narrative inquiry.

Ethical Considerations

I have completed and submitted the research ethics application, *Protocol for Text Analysis, Self-Study, Arts-Based and Arts-Informed Research* to Nipissing University’s Research Ethics Board (REB). This dissertation research study was approved and adhered to the ethical requirements of Nipissing University’s REB and The Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada (hereafter the Tri-Council). To inform the ethical considerations in this study, I have used Clandinin and Huber’s (2010) three components related to narrative inquiry that impact ethics: temporality, sociality, and place: Temporality includes the past, present, and future of those involved in the study; sociality includes both my personal conditions and social conditions; and place links experience to context. I have composed my narrative by focusing on my understandings of my life with a chronic illness and how it came to be. Temporality, sociality, and place have been weaved throughout my ethical considerations. What follows is a description of the ethical considerations that have been relevant to this dissertation.

This dissertation is minimal risk research, as deemed by the Tri-Council (2010). Minimal risk research is defined as possible harms by participation in research that, “is no greater than those encountered by participants in those aspects of everyday life that relate to the research” (Tri-Council, 2014, p. 22). Using the term minimal risk “does not imply a

lower level of adherence to core principles. Rather ... to ensure adequate protection of participants is maintained while reducing unnecessary impediments to, and facilitating the progress of, ethical research” (Tri-Council, 2014, p. 9). This research study involved addressing personal stories of my life with a chronic illness and how it has impacted my family. This may have evoked different emotions pertaining to difficult experiences and responses by the medical, educational, and/or social communities. Participants were informed and provided with the opportunity to review how they were being represented in my narrative and had the opportunity for input. I acknowledged and had compassion for the experiences the participants have endured. I allowed the participants to openly share their thoughts and experiences without any judgement or prejudice. In the instance the participant evoked more serious emotional responses, names and contacts for psychological support would be provided.

I have shared the narrative of my life with a chronic illness and this involved sharing experiences of individuals in my immediate circle. Since I am coming forward and sharing my story, readers may be able to identify who my immediate family members are. I have not shared the direct identities of those in my narrative except for my husband, Rob, and my daughter, Cecelia. This research study utilized narrative inquiry and sharing the stories of my life was essential for this investigation. I needed to ensure my immediate family members and physician were each aware of the details of our family life being shared in this research study. The participant information letter clearly identified the objectives of this study. Since I composed my story, my relational ethics are increased. Not only did I involve myself but I have also implicated my immediate family and physician. This revealed the need for me to

reflect on the relational concerns involved in my story (Ellis et al., 2011). My participant letters stated,

I am writing a memoir of her life with a chronic illness and may mention individuals in my life who may appear in my recollections. I sought consent to include such memories in my dissertation. The objectives of this research study are to reframe the understanding of chronic illness by revealing the strengths and gifts of living with a chronic illness. I will share my story that poses chronic illness in a positive light by sharing the gifts I have received since living with a chronic illness. (See Appendices A and B)

Refer to Appendices A and B for further information on the participant letters used for this research study.

I clearly explained and described my objectives to each family member impacted by my chronic illness when I obtained consent. I also ensured I considered relational concerns to see how participants felt about how they were being represented and provided the opportunity for them to respond to how they are being represented (Ellis et al., 2011). Tolich (2010) states that “the self is porous, leaking to the other without due ethical consideration” (p. 1608). I needed to be mindful and so I shared my writing with those represented in my narrative. Participants had the opportunity to review how they were being represented in the story, offer input, and/or omit certain information that pertained to them.

To achieve informed consent as described by the Tri-Council (2014), participants needed to have the time and opportunity to understand the information provided verbally and in the consent, ask questions, and discuss the details of their potential participation. I shared with participants the nature and objectives of the research study, the risks, and benefits of

participation in this study. I clearly explained to participants that since I am sharing my personal story, a reader may be able to identify them based on their involvement in my life. Participants had the opportunity to review my narrative and were able to change or omit aspects of my story that related to them. I disclosed to participants that they are able to withdraw from the study at any time.

Confidentiality was relevant to this research study as the researcher is to safeguard entrusted information (Tri-Council, 2014). The researcher and consent letter informed participants that they may be identified by their participation in the research study since the study involved a personal narrative of my life with a chronic illness. I am sharing my story and participant information may be identifiable through my narrative. Tri-Council (2014) states that “Information is identifiable if it may reasonably be expected to identify an individual, when used alone or combined with other available information” (p. 59). Further Tri-Council (2014) describes identifying information as “Indirectly identifying information—the information can reasonably be expected to identify an individual through a combination of indirect identifiers” (p. 59). The participants in the research study have been integral to my life with a chronic illness. Participants were informed that by sharing my story they may be indirectly identifiable. I had ethical approval to use my husband’s and daughter’s first name since the “research in which the probability and magnitude of possible harms implied by participation in the research is no greater than those encountered by participants in those aspects of their everyday life that relate to the research” (Tri-Council, 2014, p. 22).

For security, I was the only one who had access to the data. The data, as well as identifiable information of participants, such as my family and physician, was stored in locked filing cabinet in my office to maintain confidentiality. The data will be kept until

approximately 5 to 10 years after the study is published. I will retain the data from the study because it includes personal memorabilia. The types of information for this dissertation will include direct identifying information such as names, and indirect identifying information such as being known to have taken part in a specific situation since I am sharing my story (Tri-Council, 2014).

The benefits of this study include advocacy and awareness about living with a chronic illness within my family context. I intend for this dissertation to inform my daughter's understanding of chronic illness and potentially for other children with parents with chronic illness to experience a similar result. Participants in this study had the opportunity to reminisce and reflect on past experiences potentially providing opportunities for self-awareness and growth. Based on my understanding of narrative inquiry, this methodological approach was most suitable to investigate my research question and corresponding sub-questions.

Chapter 4: Narrative Inquiry—My Fight to Get Better

It has been challenging to reflect on my life with a chronic illness. I have been reliving my life through previous journals, medical notes, and photos—remembering times that have been forgotten and reliving moments of my life that are hard to believe were mine. And then I am reminded of my present life. My daughter Cecelia is a soft spoken but articulate little girl. She toddled through our kitchen saying “Mama, Mama, Mama” as she chased our dog Gemma. We were waiting for my husband Rob to come home from work, a typical evening in our home. I am filled with gratitude and love.

Prior to the onset of my chronic illness I was living with my dad and sister. I was 20 years old and healthy. I was in my second year of university, worked part-time as a server, and seasonally in a proshop at a local golf course. I was engaged to a man I loved very much, enjoyed an active social life with my girlfriends from high school, and participated in physical activity regularly. I saw my life in a linear progression and I was happy with the direction in which my life was going. I was getting married, was in university to be an elementary school teacher, and had a group of friends I believed would be there forever.

When I started experiencing discomfort in my lower backside and tailbone, I initially thought I pulled a muscle. The next day the pain had exponentially progressed. I now had severe pain, was having difficulty transitioning from different positions (sitting, standing, laying down), and had difficulty walking. Over the next few weeks I had doctors’ appointments and had been to the emergency room at our local hospital multiple times, all with no answers. Finally, at one more trip to the emergency room, I was given an ultrasound that focused on my backside, and the doctor believed I had a large abscess growing at the base of my spine. He sent me home that evening and I returned the next morning for a second

opinion. That morning the doctors had confirmed I had an abscess at the base of my spine. I was scheduled to have emergency surgery that night to remove the abscess. The surgery went well and I was released from the hospital shortly after. With the help of a community nurse, my wound was left open to heal from the bottom up and needed to be packed and cleaned regularly. It was expected that I would return to my daily activities within a few weeks' time. Once I was home from the hospital my family was very relieved. It had been a long 3 weeks to diagnose what the problem was but now that the abscess was removed, all that was needed was time to recover.

The day I was released from the hospital, my fiancé had a weekend trip away with his family. I was hopeful that he would stay home to help me recover. Instead, he decided to go away for the trip. He had shared with me that I was now recovering and my family was there to help. Although I understood his desire to go, as his fiancé, I worried about how often I would be left alone if I was unwell in the future, but I told myself I was going to get better and all would be well again.

My wound continued to heal but I was still experiencing a lot of sharp pains in my lower back and tailbone. Sitting was very uncomfortable and I was unable to return to my usual physical activity. I went back to the surgeon and shared that I was still experiencing a lot of difficulty with pain. He instructed me to give my body more time to heal since I had such a large abscess. A few weeks later after my incision had completely healed, I returned to the surgeon again, describing the pain I was experiencing. The surgeon scheduled a bone scan to see if I had contracted an infection from the cyst. My scan results did not reveal any infection, and there was nothing more he could do. The surgeon suggested I return to my family doctor to receive further support.

I was devastated that I had not healed to what I was before the surgery. I wanted to return to my life and all that I loved, being with my fiancé and friends, going to school, and working. Even though my incision healed, I was filled with pain. I would get into bed at the end of the day and I would cry because of the pain. I didn't understand where all of this pain was coming from. I never felt comfortable enough to admit to the people around me the amount of pain I was in. I was supposed to be better and wasn't, I didn't understand why this was happening to me. *Why me?* was a question that would continue to plague my mind in the coming months.

Over the next few months I continued on with my school and work responsibilities. It was difficult but I persevered. I dropped a course to make my workload at school more manageable; I reduced my work hours; I started to use a pillow to support me when I sat; I would stand in my classes to help with the pain; and I was being prescribed narcotic pain medication. I did not make all of these decisions at once but over time I needed to withdraw more and more from the life I had known. I was afraid that I would not return to my normal healthy life and was desperate to get better as soon as possible.

My fiancé and I were in the midst of planning our wedding but because of my continued physical ailments, our families suggested that we postpone our wedding that was planned for the upcoming summer. When my fiancé suggested that he thought it was best if we waited to get married until I was better, I was crushed. I felt I was no longer worthy to be his wife. I wasn't the person he loved but rather a sick and helpless individual, not someone who could be a bride. In response to our wedding being postponed, now more than ever I was determined to resume my health. I needed to get better to be able to get married to be the wife I wanted to be, and to be loved by him—that was what I wanted the most. How was I

going to get better? And even more frighteningly *What if I didn't get better? Would he still love me?* I could not have a new normal in my life, I needed what my life was before I had the pain, and a new normal was not an option. Although I did not know it at the time, this was the start of our fragile relationship deteriorating.

While I was living with my dad, I would have regular phone conversations with my mom. I remember crying to her and asking, *Why is this happening to me? What did I do to deserve this?* I desperately wanted an answer. *How could this happen to me when my life was going so perfectly?* I struggled with wondering why this had happened to me because I was trying to attach a reason to why I was experiencing this pain and an undiagnosed illness. At that time I couldn't understand that my life had the potential to still be full of gifts that included, meaning, love, and wonder. I was consumed by the pain I felt. All I could see was pain.

My family doctor continued to refer me to doctors who would provide assessments to see what could be causing the pain. Because all of my tests were coming back normal there was no immediate rush for a doctor to see me. I was forced to wait. I didn't understand—my life had ultimately stopped—how could I not be a priority? I was 20 years old and on narcotics to manage the pain I was experiencing. In my mind this was worst case scenario.

My parents decided to utilize a private agency and paid to find a doctor who would provide further assessments and help. Although the appointment was 4 months away, I was desperately waiting for this doctor to help me. The next few months were extremely difficult for me to manage my pain. My pain medication was increased, I had to quit my part-time job, and I withdrew from university. Everything I had known was disappearing. I returned to my family doctor for further support as the pain medications were not as effective. I had been

prescribed anti-inflammatories, Tylenol 3, Percocet, Oxycontin, and finally on an increasing dosage of hydromorphone (since my tolerance was increasing). My family doctor had a discussion with me stating that sometimes pain doesn't have a physical cause and can be something that we make up in our heads. He then proceeded to suggest I start taking antidepressants to help overcome the pain I was feeling. I was overcome with fear from this discussion with my doctor. *How could I be making this pain up? And if I was making the pain up, how was I going to stop it if I didn't know I was doing it?* This conversation was extremely disturbing to me—that my body had the ability to betray me into thinking I was in pain when in reality I wasn't. I couldn't believe this to be true, and worse *what if it was true and I was making the pain up?* In desperation to get better, I began my journey with antidepressants. I started with a small dose and gradually went up hoping the pain would subside. In the beginning I didn't notice any changes with pain, all that I knew was that I was living in a fog, was extremely groggy, and gaining weight. It was like the me I knew was now trapped in a box inside my body and I couldn't find my way back to myself because of the deep fog I was now living in.

During this time I remember getting together with a group of my high school girlfriends and they were asking about how I was and what I was doing with all my time. I didn't have an active social life anymore and quite frankly had ceased to exist socially. This was the first time with all of my friends that I realized that I was no longer one of them. I was an outsider. My life no longer included the typical *what should we do tonight?* My life clung to a doctor being able to fix me. I was no longer in school, I didn't work, and my social life had disappeared. Although my fiancé still spent time with me, he was still very active with

his friends, and we began to spend less time together. I was lonely. The pain I felt was mine and mine alone.

My fiancé and his family suggested that I start seeing a counsellor to help me cope with my pain. I was very unsure about needing the support of a counsellor but I was desperate to get better and I was willing to try anything. I still desperately wanted their approval. My life had consisted of making those around me happy and I felt I needed to do this for them. Once I started having sessions with a counsellor I found it to be profoundly helpful. I had someone to talk to and I could voice my deepest fears without worrying about the implications of what I was saying. I had the opportunity to openly share my feelings. The counsellor had me participate in a sleep therapy program to help improve my sleep quality. I began my journey with guided imagery meditations, and she encouraged me to pursue other holistic healing strategies like yoga. Meeting with a counsellor had fostered immense changes in my life because it was the first time that someone discussed with the idea of holistic wellness with me: physically, emotionally, and spiritually. I became aware of the need for whole body healing. I was purely thinking of my pain as physical and if the pain went away my life would return to normal. I had not considered the events that had occurred as a result of my physical condition that would inhibit my life from returning to normal.

In the spring of 2005 my appointment with the specialist my parents had privately accessed had finally arrived. I was naïve in thinking that this appointment was going to change my life and I would leave with the answer to return to my previous life. I couldn't have been more wrong. The doctor didn't know what was causing the pain and I would need to go through a series of tests before anything could be determined. A few months later after all of the tests were complete and the doctor had reviewed my results, he diagnosed me with

coccydynia which could be treated by removing my coccyx through a coccygectomy. The doctor shared that it may help but it may not. The reality was I would probably always have discomfort in my lower back and tailbone area. *Absolutely not!* I thought. This information was completely unacceptable to me at the time and I was very hesitant with the idea of having a surgery that would not guarantee a 100% recovery. I wanted to resume the life I had. I would not accept that I had to live with pain.

Letting Go of the Me I Knew

Once I had let this specialist's advice percolate, I began to realize that the chance of me returning to my life prior to the onset of the pain was beginning to seem unrealistic. I was also struggling with being able to discount the experiences I had with my fiancé and friends. I was alone and their lives were moving forward. The phone calls were fewer and fewer, the invites out were non-existent since I was still sick, and my day-to-day life was pretty bleak. I was on an array of different medications trying to help with pain and was struggling with how to function on all of these medications while still feeling much pain.

I was also beginning to see that I could not be the person my fiancé had proposed to. All the ways in which I defined myself while I was healthy had disappeared. Nothing about my life was the same and neither was I. I didn't know exactly how I had changed, but I knew I had. I no longer wanted to be an elementary school teacher, I was angry that our wedding was postponed, and I was lonely. *So what if I was sick, shouldn't he still want to marry me anyway?* I worried I was no longer good enough for him. I couldn't live up to the standards of my healthy self and the life we had planned. It seemed to me that his life was going forward unaffected by my undiagnosed illness, but my life had halted. I started to wonder even if I could resume the path I was on, *would I want to?*

These initial days, new to chronic pain, were gruelling. I didn't have the capacity to engage in all of the activities I used to and my days were empty. I had gone from being extremely busy to having days that now were wide open. *Wide open for what? To be stuck in pain?* Each passing minute seemed like an eternity. I didn't know what to do with myself or how to help alleviate my pain. It was like I could hear the slow tick tock of our kitchen clock. The days dragged. All I believed I could do was wait—wait for the next doctor to see me and tell me what was wrong. My life was dependent on the medical community fixing me. I now reflect on this period of time where many transformations were happening that I was not aware of. I was secluded and hurting but this time fostered my independence and forced me to really think about who I was and the path I was on. I didn't know who I was. I had defined myself by who surrounded me. I began to search for my own identity. This time contributed to me realizing that.

When I first started experiencing my symptoms I would have given anything to return to the person I was and life I had. But now I didn't want to be that person anymore. I couldn't be that person anymore. I had experienced too much pain and now needed to prepare myself to be able to live with pain. I needed to find a new way to live. I started experimenting with holistic alternatives. I began to consider my emotional and spiritual health not just my physical ailments. I had been consumed by focusing on the physical aspects of the pain and had not considered how my pain and experiences had impacted my spiritual and emotional health. I started attending restorative yoga and meditation classes to introduce my body to relaxation and healing that was outside of traditional medicine. In these restorative yoga classes I was amazed to find that my body still had abilities and there were comfortable ways for me to be. I was beginning to see that I could experience personal wellness. I loved

attending my yoga classes and I often left class feeling much better than before I arrived. I met a yoga instructor who provided me with much insight and support for years to come. She accepted my body for what is was right then in that moment and believed that there were ways to find comfort and healing. Continuing to engage in yoga and meditation has been a wonderful addition to my life by helping me learn about love, being kind to myself, and opening myself to healing.

Although I had stopped working as a server, I had planned to return to the golf course and work for the summer of 2005 with the accommodations that included shortened shifts and breaks as needed. Even though I was being supported, I was very hesitant. I had worked there the previous summer as a full-time seasonal employee. I worked in the proshop and occasionally on the beverage cart. It was a fun summer job and I had met a lot of wonderful friends. I had kept in contact with one of the assistant golf professionals, Rob. He was understanding and willing to accommodate my health needs to try and see if I was able to still work in the shop a few hours a day for a couple of days a week. I tried for a few months but unfortunately needed to stop because of my discomfort, and it was difficult with all of the medications I was being prescribed. I was living in a completely different reality. I had also become withdrawn and insecure because of my physical condition. I was ashamed of who I had become and the struggles I was facing with pain and illness. My outgoing demeanor had become shy and withdrawn. I didn't know how to be and was uncomfortable with my own body.

During this time my fiancé gave me a book about how chronic illness affects family. He had read parts of it and placed sticky notes to show me the areas of the book where he believed our relationship was suffering because of my pain. I was both furious and saddened

to be given this book. I felt he had saddled me with the responsibility I now had as someone with an illness, as if I could control what was happening. I would not be the burden that I felt this book portrayed people with illness as. *How could he believe that I was solely responsible for the unraveling my life had experienced now that I had been living with an undiagnosed illness?* I realised that this was his way of trying to make sense of our experiences but I internalized this as my pain and illness being all my fault. Now this book is a reminder for me to realize that yes, I do have an illness but I am also an individual and shouldering the responsibility is not fair. I know that having an illness affects the lives other than my own. People's lives affected by chronic illness but I would not take my illness out on my family. I would not destine my family to hardships because of my illness, there would be much more to my life.

The surgery to have the coccygectomy was still an option to assist with my pain. Ideally the surgery would remove some of the pain but it was not a definite diagnosis. The hesitation and skepticism of family members loomed all around me. Some of my immediate family members were still very much concerned that I had nothing physically wrong and that all of my pain was mental. I knew I wasn't making this pain up but hearing so often that the pain I was experiencing had no physical origins and required psychological support was infuriating and emotionally damaging. Their doubts crept into my thoughts and I greatly feared that they were right, but I couldn't and wouldn't let myself believe their presumptions. It saddens me that many of the doubts I was exposed to altered some of my family relationships, because, again, no one was seeing me, they were listening the untrue assumptions that others were making.

One day my fiancé called my parents because he was concerned and believed that

further psychological support was needed to help combat my “psychological” pain. This act absolutely destroyed me. The person who I was certain would forever love me for who I am did not believe me. I felt betrayed. His actions reinforced my fears that I had been living alone with pain. I needed to find a way for me to heal by myself. My life had changed so much and, to me, this action meant we were no longer right for one another. I would not return to the person I was and it was time for me to let go. I could not be his fiancé. I could not commit to the life we had planned. Despite what I could not do anymore, I was beginning to plan for a new life and I felt calm knowing that I could move forward, just in a different way. I did not know who I was or where I was going, and I could not be an elementary school teacher, but I knew I would pursue higher education, maybe a PhD, maybe related to health. I could not be an elementary school teacher.

The Beginning of Redefining Myself With an Illness

I soon decided I would pursue higher education. I continued to research graduate programs that I thought were interesting, I looked at medical school, and I attended a naturopathic school orientation. I remained full of hope even though I had just taken a medical leave from school for the upcoming fall 2005 term. I believed that at some point in the future I would be able to pursue my new dreams whatever they may be. Hope helped me to get through those early days of pain.

At this time the narcotic dose I was being prescribed could not be increased—it had ceased to help my pain, so I decided to stop taking it. I had no idea how physically dependent my body was on narcotics. I initially tried to slowly decrease my dosage but I would just keep taking an increased amount. I finally had to get rid of it. I stopped cold. I had terrible withdrawal for a couple of weeks consisting of nausea, vomiting, hot flashes, chills,

headaches, and increased pain. The benefit to all of this was I finally felt a little piece of myself return. I was present. I knew I needed to cope with the pain and narcotics were not the answer. I continued trying chiropractic therapy and acupuncture but did not find the relief I needed. I also began my journey with receiving Reiki treatments and persevered with my own personal Reiki training. I had found a healing strategy that I felt many benefits of and this was the start of a practice that would continue for years.

I was still living with my dad at the time and spent a lot of time trying to learn about strategies to help live well. It was hard because I was still in limbo, not knowing what was officially wrong. My surgeon had provided me with information about an online support group for people who had been diagnosed with coccyx pain. I had the opportunity to read other peoples' stories, questions, and concerns. It was helpful to connect with people and ask how they were doing. I read as many self-help and wellness books as I could. I craved inspirational stories and healing. I wanted to know how others were living and how they came to be.

With reservation I elected to have the surgery to remove my coccyx. The surgery was scheduled for September 2005. Although my fiancé and I were no longer together, he still wanted to be there for the surgery. I wondered *why now?* He did not believe I had a physical cause to my pain and I had spent much of my time in pain by myself. Since my fiancé and I had been together for years my parents thought I should be kinder and allow him to be there because we had been through so much. Reluctantly, I listened to my parents and had him there. Terrible. Terrible. Terrible. It was awful because it sent the wrong message. He ended up overstaying his welcome in my parents' eyes and then I was suddenly responsible for his presence while recovering from surgery. *Perfect.*

I was released from the hospital a few days later. Although I primarily lived with my dad, my parents thought it would be best if I stayed with my mom in London, Ontario after my coccygectomy. I resented how dependent my health issues had made me. Previously, I had lived on my own in first year university, was financially supporting myself, and could come and go at my leisure. I no longer possessed these ways in which I defined my independence. I was lonely. I did not know how to find a new way to live and define myself. I was not used to having to spend so much time with myself. I was still caught up in trying to be who I was prior to my chronic illness. The daughter, friend, and fiancé I used to be. Now it was time for me to step outside of what I knew and what others knew of me and redefine my life because I knew I could not continue with the path I was on. While healing from my coccygectomy surgery I firmly decided that I was not the same person who my fiancé had proposed to and that I needed to find ways for me to cope with pain. I needed to heal. I needed to find new ways to live.

For a long time I was angry about how my relationship with my fiancé had ended. I was angry because I did not feel he could see past my pain and symptoms. I was angry he wanted me to be who I used to be. I am no longer angry. I have very fond memories of us dating and spending time together. I am grateful to have had the opportunity to be a part of his and his family's lives. I loved their family dinners and being at their house. His family offered me support and stability while I adjusted to my new family life since my parents had divorced and found new partners. Both my fiancé and his parents encouraged me to study and helped me apply for university. I am grateful for the love and support that I received during that time in my life. They were there to support me and provided care in during a time I could have quite easily been lost.

Losing my financial independence was incredibly debilitating. I was in grade 8 when I began my first part-time job in the restaurant business. I worked as a busser cleaning and setting tables. I was used to having access to money that I had earned. Not working from being ill was causing me to be financially dependent. Once I began to realize the longevity of my health situation and the difficulty I was having in managing my pain and symptoms, I decided to apply for the Ontario Disability Support Program. This was a big process and it took a lot of time for me to apply. I had never accessed a social support program before and was not at all familiar with the process. The first time I applied, I was denied as I did not have a specific diagnosis. Because I had since had my coccygectomy, I decided to appeal the decision.

Although I experienced mild improvements in my lower back pain after my coccygectomy my chronic pain symptoms returned and continued to advance. In addition to the lower abdominal pain I was experiencing, I also started to have a lot of acid reflux. I had been to my family doctor a few times and I continued to try different types of medications to assist with the gastrointestinal symptoms. Despite the medications and increasing doses, my acid reflux and irregular gastrointestinal symptoms continued to worsen.

In the late fall of 2006, Rob and I started dating. I had known Rob for 2 years by this time. Prior to the onset of my illness, Rob had hired me to work at a local golf course. He was the assistant golf professional, and he was one of the people I had worked with before the symptoms of my chronic illness had begun. During the previous summer I was in need of a second job in addition to serving and at the time, working at a golf course seemed to be the perfect fit. That summer I worked a lot, days at the golf club and nights serving. But I recall thoroughly enjoying my time at the club. I had met a new circle of friends and was really

happy being surrounded by the people who I worked with. Many of us spent several summer evenings together, and friendships that were created that summer continue to be strong friendships today. Rob knew that I was not well and continued to reach out to me and see how I was doing. He would call every couple of months to see how I was and chat with me. I always looked forward to our conversations.

One day Rob and I were chatting on the phone and he asked if I would be interested in accompanying him to his work Christmas party. I was absolutely delighted! Following that conversation I called Rob and asked if he wanted to get together one evening. I was so excited. Despite all of the pain and obstacles I was facing, whenever I spoke with Rob he treated me the way he always had. He did not remind me of who I used to be and what I used to be like. He accepted me for me in that moment. From that first date Rob and I have been together ever since. We seem to just fit, and being with him is the most natural part of my life. Rob and I started our relationship despite the medical needs I had. He saw me as his partner, not a person who had now been defined by pain and an unknown illness. To this day, I know I have an incredible partner in life. Rob knows that I have a chronic illness and the realities of my illness but that never has influenced how he sees me. He is full of kindness, love, and compassion and he is incredible mindful of my well-being. To be quite honest, I think he knows my needs better than I know my own and he is the first to ensure we keep our life balanced.

In the winter of 2006 I enrolled in two distance education courses for my undergraduate degree. I felt I was at a point where I could reintroduce school into my life despite the medical challenges I was experiencing. At first I found online courses difficult in terms of determining what was expected but I continued to learn and adapt. Being in school

remained to be difficult. I did not achieve the grades that term that I was used to but it felt like I had never been to school before. I was relearning how to be a student with health needs and that was challenging for me to accept. I did not want to be defined as someone with needs. I struggled with self-identifying as someone with a disability.

Even though I had my coccyx removed I was still feeling pain. I returned to the surgeon and I had more tests done to find out that I also had arthritis. I started taking different types of anti-inflammatories but had allergic reactions to all of the anti-inflammatories prescribed. I continued with yoga and meditation as the primary method to cope with the pain. The surgeon suggested I try corticosteroid injections, and in the spring of 2006, I received my first injection.

Rob and I continued to date and spend quite a bit of time together. I did not feel like a person who was sick with him. We continued to do lots of different experiences together despite how sick I was. We were creative about how we could do things. Being with Rob gave me confidence. He helped me believe in myself, and he accepted me for who I was. He understood that my stamina was weaker, that I needed time away from school, that working was unattainable at the time, and that some days my symptoms were at their worst. Rob has been an instrumental individual in my life. We have both cried many tears and had many moments of frustration resulting from my illness but those moments never have influenced how he sees me.

That spring my dad decided he was going to move in with his partner so my sister and I would need to find a place to live. Without a job and unable to support myself because of my health situation I moved back to London with my mom and her partner. I found this move to be very difficult. I found the days to be isolating because when I was living with my dad, I

had established a bit of normalcy for myself and I was also able to be closer to Rob and my sister. In London, I felt isolated. Although I participated in recreational programs, I was struggling.

I had been referred to a pain clinic to help me cope with my pain management. My mom took me to the pain clinic. Prior to my appointment, I was filled with hope that I would be provided with these incredible strategies to learn to live with pain and help reduce my discomfort. But because I did not have a set diagnosis, the feedback I received was extremely limited. Basically I left with the message, “learn to live with it.” I was so angry that this was the feedback I received. Living with the pain I was experiencing was still not an option. I wanted more than that; I wanted help, support, and strategies. I was not ready to hear that living with pain was now my reality. I still required a lot of support.

I was referred to an anesthetist to administer a corticosteroid injection. During my first injection, the anesthetist also prescribed a nerve block medication. Prior to leaving I had scheduled my next appointment but was in hopes this was the answer to help with the pain. With little relief from the first injection and nerve block medication, I returned for my second injection. The anesthetist started to ask me questions about my pain and what tests I had. I shared with him my story and he simply asked, “Has anyone looked at you from the front?” My response was no. He asked about my bladder, and gastrointestinal symptoms. Of course I had been having troubles but my primary discomfort had been from my backside. Because some of my gastrointestinal symptoms were being monitored by the family doctor, this doctor referred me to an urologist to help with my bladder symptoms. I had been experiencing pelvic pain, frequency, and urgency issues.

I met with the urologist in May 2006. He suggested conducting a scope of my bladder

and I agreed. Once I had the scope, the urologist shared that I had interstitial cystitis. I was prescribed gabapentin to aid with the discomfort but was also encouraged to try bladder instillations. This would entail going to the hospital and having the urologist use a catheter to instill antibiotics into my bladder to hopefully help with the pain and bladder symptoms I was experiencing. I would need to travel to an out of town hospital once a week for 12 weeks.

In June 2006, Rob and I purchased a townhouse together in Kitchener. It was quick—we had only been dating 6 months but the decision was easy for me. I was thrilled to be moving in with him. Our decision to move in was mixed with both support and reservations from our families. I still was not working, did not qualify for disability support, had not resumed my full-time status in my studies. Rob had started his first year at a different golf club, and we did not have a lot of money. But, despite the drawbacks of our situation, we proceeded to prepare to move in and our families began to help us prepare for our move. We moved in together in August. When I moved in with Rob it felt like I was finally home. Since it was summer, Rob worked a lot as a golf professional. He worked 6 days a week and on most days left early in the morning and returned at dark. Regardless of his long hours, we continued to create our home and life together.

After a few months of living together, I was informed that I qualified for 6 months of financial support while I lived with my dad. But because I purchased a townhouse with Rob, I no longer qualified for ongoing ODSP. Although the money from living with my dad was welcomed, Rob and I still did not have a lot of money. He was seasonally employed and we did not have benefits. I was encouraged to apply for support from the Canada Pension Plan. I began preparing my application only to be rejected because in order to qualify for the

Canadian Pension Plan I needed to contribute by working for a certain amount of time. Because I was young, I had not worked long enough to qualify.

I had bladder instillations every week. It was awful. Each week I would go into the hospital, register and wait. Then I would be called to get changed into a hospital gown and wait in a waiting room outside of the operating room. I would wait with many other women who were all experiencing the same pain from interstitial cystitis. It was frightening—many of these women had been coming for these treatments on and off for a long time. I did not want to have to come back. I wanted this to help and then be on my way. I could not imagine these instillations being a part of my week to week life. This is when I really began to understand the chronic part of having an illness. Chronic meant relapse, it meant recurrent, it meant here to stay.

Part of having the bladder instillations is to hold the antibiotic in your bladder for as long as possible to allow for the most relief since the medication has more time to work. I was having major difficulties holding the medicine in. One day the doctor suggested he use a clamp so I would not have the option to urinate. The clamp would force my body to hold in the antibiotic, so I agreed. Once he was done, I was to return to the waiting room to wait. I was assured all the liquid in my bladder would stay there. At this point the pre-op waiting room was full and there was standing room only. I was extremely uncomfortable and struggling to stay standing. A nurse noticed and was going to bring me a stretcher. In the time it took her to find the stretcher, I had essentially peed all over the floor. My body had found a way to move the clamp and I had peed on the floor. I was humiliated. The nurse brought the stretcher over was filled with words of comfort but I did not hear anything. Again, I felt my body had betrayed me.

In November 2006 I received my last bladder instillation. My dad regularly would take me to the hospital for these procedures. He would pick me up at my home and we would head to the hospital together. He would patiently wait until the procedure was done and then we would head back home. I often would fall asleep in the backseat of his truck surrounded by my pillow and blankets. Instead of dropping me off at home that day, we attended my sister's graduation. In honour of my sister, we went out for dinner to celebrate her achievements. I returned home late that evening and Rob seemed completely out of sorts. I had returned home later than he anticipated and had not called. I did not sympathize with his concerns and told him I was exhausted and was going to go and get ready for bed. I put on my pyjamas, had washed off my make up, and was brushing my teeth. Out of the corner of my eye I saw Rob kneeling in the doorway. He held a small open box in his hand that held a ring. As soon as I turned to look at him, he asked if I would marry him. Toothbrush in hand, and mouth full of toothpaste I gave him an enthusiastic hug and said yes. Only then did I rinse my mouth out! Even now when I think back to Rob proposing, I am in awe of how it did not matter to him that I was still struggling with procedures to help my symptoms, it did not matter that my day had been spent in the hospital, and from celebrating with my family I was exhausted and sore. He saw past all of that. He believed we would create a life of love that was filled with meaning. He could not have been more right.

I was having little success with the bladder instillations and still experiencing much pain. Once I had received 12 weeks of therapy my urologist believed that I had other issues beyond coccydynia, arthritis, and interstitial cystitis. Because of my continued uncontrollable pain I was prescribed a very high dosage of Percocet. I was taking three Percocet every 3 hours. He proceeded to refer me to a gynecologist.

When I met with the gynecologist he was confident that I had endometriosis and I was scheduled to have a laparoscopy to remove the scar tissue. *What, endometriosis? Would I be able to have children?* I was so worried and all was unknown until I had the surgery. I felt all this time had been wasted while all along I had this. *Why didn't anyone look at my pelvis?* I was so afraid. I did not want to tell Rob. *What would he think? What if I can't have children? Would he still love me?* I was so nervous about this surgery, *what would the doctor find?* I had the surgery and I did not have endometriosis. At that point the doctor suggested I pursue other avenues. I was then discharged from the hospital. I was so relieved but again *now what? What was going on? How could I be in this much pain and there be no reason for the pain?*

I did not recover well from that surgery. The laparoscopic surgery seemed to escalate my gastrointestinal symptoms. My acid reflux over the past months had worsened and at times I would vomit. After this surgery it seemed to have accentuated my symptoms. I was not able to keep anything down, not even fluids. Rob and my mom took me back to the ER at the hospital where I had the surgery. The gynecologist who performed the surgery was paged. He came and did an assessment. I did not have endometriosis and as far as he could tell nothing was wrong with me. He suggested I pursue psychological support, because in his opinion, I was anorexic. *What? Where did that come from? I most definitely was not anorexic!* He believed I had manipulated my parents and Rob into believing I had something physically wrong when in fact I was psychologically unwell. *What was happening?* I had been upfront about all of my digestion issues. And yes, I got upset at doctors' appointments because I had been in pain for years and no one knew why? *Did that make me anxious?* Hell

yes it does! *Was it depressing to talk about?* You betcha! *Was I anorexic and manipulating my family?* No.

Not knowing what to do, I told my nurse that I was also a patient of an urologist who worked out of the hospital I was currently at. She had my urologist contacted and he came to see me shortly after. I was fortunate to be in this doctor's care from that point forward. He firmly believed that there was a larger overarching issue and all of the other problems like the pain, interstitial cystitis, and arthritis were secondary to a bigger problem. I spent the next 3 weeks in the hospital while my urologist attempted to have different specialists come to assess me but this was proving to be difficult. My charts at the hospital had included descriptors that stated I was anxious when I talked about my pain, that I was extremely emotional, and potential psychological issues were present. These statements contributed to assessments by doctors with follow up statements of "I am not able to help you." I still was unable to keep any fluid or food down. I kept trying and the results would be me projectile vomiting. This was a horrific time. I was in incredible pain attempting to be controlled with Demerol injections and was only receiving intravenous fluids to keep me hydrated. A gastroenterologist doctor came to see me and concluded from the numerous test I had which had not indicated any issues, that again my issues may be psychological. Christmas was only a few days away and I would need to wait until the New Year for further support. Until then I would remain in the hospital waiting.

Writing about this time fills me with overwhelming sadness. So many of the conversations I had with medical professionals were harsh and disconnected. They did not see me. They saw someone who had psychologically created the issues I was experiencing and who had manipulated my family into believing I had something physically wrong. The

only doctor who believed me was my urologist. I am still moved by the kindness he displayed. He repeatedly stated that there was a primary issue that had yet to be uncovered. He referred me to many doctors outside of his specialty in attempts to find the primary cause of my symptoms.

The Christmas season is my absolute favourite time of the year. Even as a child, the first of November meant putting all of the fall decorations away and decorating my bedroom for the holidays. In my childhood bedroom I used to string colourful lights all along my ceiling, I had a garland for my window, and a mini Christmas tree. Being in the hospital during the month of December was awful. It was my first Christmas with Rob in our townhouse and I was not home. Prior to my laparoscopy we had brought home a giant real Christmas tree (it took up about a quarter of our living room) and had spent the day decorating in anticipation of Christmas. It was extremely sad for me not to be at home. My mom came up with the idea to bring Christmas to me while I was in the hospital, and every day she brought the magic of Christmas with her. While I was in the hospital, we celebrated each day. She had brought me festive socks, pajamas, and ornaments to celebrate. She refused to let me believe that being in the hospital would interfere with the magic of Christmas.

On December 22nd, my mom, Rob, and I all decided that if nothing was going to be done in the hospital I was in until the New Year, I might as well be in a hospital closer to home. Although Rob and I lived in Kitchener, we decided to try a hospital by where my mom lived. I had been previously to our local hospitals in Kitchener and had not had much success. Most recently to that time when I was having incredible pain, Rob brought me to the ER, the doctor shared he would not give any pain medication to a drug addict.

Prior to leaving the hospital, my mom asked if I could have a barium swallow done, as that was the only test I had yet to have. We thought maybe that I had a blockage and that was contributing to the projectile vomiting I continued to display. The barium swallow was scheduled, and we planned to leave shortly after. We would be taking the results of the barium swallow with us. Preparing for the barium swallow was very difficult because I could not keep any of the barium down. I was violently ill and vomiting. I had one nurse who was absolutely furious I was not keeping any of the barium down. I was crying and telling her I was sorry and trying to keep it down. Another nurse overheard us and came over to see if she could help. She suggested I drink a small amount at a time and walk to help the barium move through my digestive system. This strategy helped a lot. Although I had not drank the required amount of barium needed, the nurse had the x-rays done to see if I had ingested enough barium. Once the radiologist had interpreted the images, the nurse brought out my x-rays and shared a narrowing had been revealed on my x-ray. *Finally!* We didn't know what this meant but a test result had at last been indicative of something physical and not psychological. I was so relieved! My urologist also wrote a letter for us to take to the hospital I was going to next.

Chapter 5: Narrative Inquiry—In Pursuit of a Diagnosis

When we arrived at the hospital closer to my mom's home, my desperation and naivety lead me to believe that the doctors at this hospital were going to see my x-ray results and respond immediately. My admittance was not at all what I had envisioned. The words anorexia, anxiety, and depression all lingered in the air. There were grave concerns about the quantity and frequency of the narcotics I was using. I still felt no one was listening. *What about the x-ray that had indicated some kind of narrowing and potential blockage?* Yes, a narrowing had been documented on my x-ray but it was still difficult to see. I was admitted to the hospital and was being referred to various specialists who might know what was causing the narrowing. Again, I had made the mistake of displaying too many emotions and there was much discussion about my mental health and anxiety. The immediate course of action was no more narcotics and instead I was given sedatives to help. At home I was being prescribed three Percocet's every 3 hours for months.

I had been in the hospital for three weeks receiving Demerol injections in my thighs. My thighs were filled with bruises and welts from the many injections. I had lost quite a bit of weight and was around 95 pounds from my usual 110 pounds. I am at a loss for how to describe the withdrawal that I experienced. I was freezing. I was sweating. I was dry heaving as I had not been able to eat in weeks. My whole body shook. I was in bed out of bed, in bed out of bed. My bowels were stimulated. I couldn't sleep. I was completely delusional and not in touch with reality. All of these symptoms were happening in tandem. My family refers to this time as my poltergeist days. *Never again. Never again would I ever use narcotics as a pain maintenance strategy.* From my terrible withdrawal symptoms I was giving increased doses of Lorazepam to help me sleep. It took days for my body to start responding to this as

initially the Lorazepam did not even put a dent into my withdrawal symptoms. My withdrawal symptoms had come with a vengeance and the only element that contributed to these symptoms lessening was time.

Christmas passed. I am so grateful for my mom celebrating Christmas with me throughout December because I do not even remember the actual days of Christmas that year. Those days are mixed with memories of pain and suffering. This was the first of three Christmas seasons in a row I would spend in the hospital.

It was late at night, a few days after Christmas, I came out of the bathroom in my hospital room and saw a tall man in sage green scrubs. He asked me to tell him my story. After he had listened to my story he shared with me that I might have Superior Mesenteric Artery Syndrome (SMA). SMA syndrome is characterised by the aorta and superior mesenteric artery collapsing on part of the bowel. Most often SMA is caused by weight loss and can be seen in individuals with an eating disorder. He believed this to be a secondary condition to a bowel issue that could potentially be a severe form of irritable bowel syndrome. Dr. T. also continued to tell me that SMA syndrome is difficult to diagnose because it rarely shows up on tests because of the difficulty of tests seeing the blockage, and consequently SMA syndrome was not a definite diagnosis. Ultimately, it was going to take time to diagnose. More time—it seemed that my pain and symptoms included taking away my time. I had not been home in over a month. Rob had been commuting from Kitchener to Toronto and now from Kitchener to London to spend as much time with me as he could while I was in the hospital. Because we did not have a lot of money and Rob supported us both, it was imperative that he keep working despite my long stay in the hospital. Friends

came over to see Rob a few days after Christmas and helped him take down our first real Christmas tree.

Once I stabilized and my withdrawal symptoms had dissipated I was discharged from the hospital with a prescription of Lorazepam and a medication to help my stomach empty. I was not to take any narcotics. I saw Dr. T. every few weeks for the next few months to monitor my progress. I continued to vomit when I tried to eat and therefore was losing weight quickly.

Although I was now in the care of Dr. T., I was frustrated by the actions of doctors that I had seen previously and I felt they could have supported and helped me more than they did. I decided to file a complaint with the College of Physicians and Surgeons of Ontario. I shared my story from my perspective about what I had experienced. I received feedback from the College and letters from each of the doctors I had complained about. All of their feedback included an empathic response to the duration of my symptoms without a definite diagnosis. Although their responses were thoughtful and acknowledged my struggles, I did not understand why they did not display any empathy when I met each of them in person. When I received letters from the College of Physicians and Surgeons, I did not feel any better. I had complained because I did not want someone in my situation to be treated the same way that I was—I did not want a statement that defended their stance and finally acknowledged my pain. I wanted them to realise that not knowing what was physically wrong did not mean stating harsh assumptions about my way of being. I did not know how to be, I wanted to be fixed, and I was desperate. I was trying my best to live and no one in the medical profession was seeing that. I was doing what I had been told to by other professionals. In my mind, doing what the doctor said was the way one pursued getting better.

By April 2007 I was so malnourished and had lost so much weight that I was readmitted into the hospital. I now weighed less than 85 pounds. My doctor decided then that I would have surgery for SMA syndrome. The problem was I too malnourished to even have surgery. I had a nasal feeding tube put in but I still vomited because of the blockage. I then had a PICC line put in to administer Total Parental Nutrition. I would need a few weeks of nourishment prior to having surgery. The surgery I would have would essentially re-route my bowel around the blockage by my arteries. Dr. T. continued to prepare me for the fact that SMA syndrome is often a secondary condition.

Having surgery is always difficult for me, I wake up in recovery extremely distressed. This surgery was no different but this time I was in incredible pain. The realities of using narcotics for long periods of time had affected my liver and ultimately my tolerance. I needed large amounts of narcotic medication to control my pain and even then it did not work well. Consequently I had a lot of difficulty managing my pain and required frequent support from the pain team. It was the middle of the night when I was transported from the recovery room to my room. I was in incredible pain and when they had to move me from the stretcher to my bed, I was in uncontrollable pain. My mom and Rob were asked to leave the room. My screams filled the hallways.

I always have the same recurring dream from my childhood when I am given anesthetic. I am in a beautiful meadow filled with tall grasses. The air is warm from the sun and I can feel my hair blowing in the breeze. I am always sitting on the grass and visiting with different family members and our family dog Deja. I never want to leave this place. The dream always ends with me being urged by those family members to return.

To help my stomach empty, Dr. T. had put in a g-tube in my abdomen. That way if I

was nauseous I would be able to open the g-tube and empty my stomach contents. Once I had recovered enough, I was able to reintroduce food back into my life! I was able to eat small amounts again with a high fluid diet and needed to walk a lot to help my body digest. I was released from the hospital in May.

Rob and I had been continuing with our wedding plans. Rob had taken on the task of packaging and mailing out all of our invitations. We were both adamant about having our wedding in the upcoming July. Our family was very concerned about my health and ability to participate in the day but there was no stopping us. We simply felt we would be able to accommodate my health needs. Instead of meeting with many of the people in person, we planned our wedding over the phone.

Our stag and doe was at the beginning of June. I was still recovering from surgery and still required my g-tube and many medications but I was very excited about our stag and doe. I went and purchased a shirt that was loose and comfortable around my g-tube and pants that I could tuck my g-tube into. I also still had my PICC line in my arm. Although my ultimate hope was that I would no longer need this support, none of this took away from the wonderful party. Regardless of the support I needed, I was able to attend and celebrate. I saw family and friends we had not seen for a while and I was able to be part of the joy of the evening.

Our wedding came together beautifully and I would not change one aspect of how we planned our day. My only desire was to celebrate our love. I was so grateful to have Rob in my life, I did not want to delay being his wife. We had seen firsthand how unpredictable life is and we saw no reason to wait. *Wait for what? What if that moment was the healthiest I would be?* We wanted to live in the moment and were grateful for the love we shared.

Planning our wedding gave me something to look forward to. Rob reminded me that I was enough and that he loved me regardless of my health situation. His ability to see who I am despite the symptoms I experience has been a gift that encourages me to persevere because I am not an illness.

We left for our honeymoon early in morning after our wedding day. We planned a trip to British Columbia that included renting a loft for week on Vancouver Island and spending a few days in Vancouver. We had a magical honeymoon enjoying our time together. The loft was ideal because we were able to grocery shop and meet my dietary needs. When we were in Vancouver we learned a very valuable lesson about traveling. With only a standard hotel room booked, it can be difficult to find venues that meet my dietary needs. On the last few days of our honeymoon, we tried a restaurant that we were unsure of would meet my dietary requirements. Well I tried and was sick for the next few days. Even when experiencing the drastic symptoms of my gastrointestinal illness on our honeymoon Rob was full of kindness and compassion. He was content to watch movies and lay low despite being in city we were eager to explore.

From my continued gastrointestinal symptoms it was determined that I had a severe motility disorder—a motility disorder that at the time did not have a name, did not have a set treatment, and did not have a cure. There were no support groups. I left the hospital knowing little other than I would live with this forever. I was to walk a lot to help digestion, eat small meals, and continue with the help of medications. I would continue to see Dr. T. regularly. I was devastated with the reality of not only knowing I had a chronic illness but I had a chronic illness that little was known about. *How was I going to continue my life? When would the illness stop? Would it continue to advance? What would my life look like?*

Since my diagnosis of a motility disorder had been confirmed, I continued to talk with Dr. T. about the need of a support group and platform for other patients to access. Dr. T. continued to pass along my contact information to newly diagnosed patients so they would have someone to talk to when facing such an overwhelming diagnosis. Dr. T. would later name the motility disorder I had been diagnosed with as Diffuse Irritable Gastrointestinal Tract Syndrome (DIGITS). I would continue to talk to many patients, and I would eventually team up with other patients and start a DIGITS website and support group. We would continue to fundraise for DIGITS and my mom and I would take on the role of planning two galas all in support of DIGITS. Learning my role within DIGITS advocacy and fundraising has been difficult because ultimately I am an individual with DIGITS. It has been challenging for me to realize my own needs and I am quick to sacrifice my own in order to help others. I want desperately for DIGITS to be recognized as a legitimate medical diagnosis that all medical professionals would be informed about, and cause to fundraise for. But what I did not realize at the time was that I cannot do it all by myself. It has been challenging to continue to find support and understanding of DIGITS because it is so rare. Since DIGITS is in the motility disorder family, it is hard to diagnose and little is known about motility disorders. Learning my role as a patient advocate has taken time for me to establish and to realize that I need to have boundaries to maintain my own health and wellness.

I decided to return to university in the fall of 2007. I had enrolled in a few online courses for my Bachelor of Arts degree and I now felt I was able to continue with my Bachelor of Education classes, even though I did not want to. I had met with program coordinator during the summer and had intended to drop out of the program. She insisted I stay in the program and finish. I was half way and just because I was in the Faculty of

Education did not mean I had to be a teacher. The realities of my chronic illness were setting in and I knew that even if I wanted to be a teacher, the likelihood of me being able to sustain a full-time teaching position with my body was incredibly unrealistic. But from the supportive conversation with the coordinator, I decided to remain in the Bachelor of Education program.

I was still struggling with my symptoms of having difficulty eating, vomiting, and very frequent episodes of diarrhea but I continued to pursue classes. Because I had taken a 2-year leave, I had been enrolled in a new cohort. I returned to university very shy and withdrawn. I did not know anyone and was insecure about my chronic illness. I sat by myself in all my classes and when I was sitting in a group, I was not part of the group but instead, was an outsider sitting there. We had many group projects and peer evaluations. I always had to ask to join a group and the answer was usually no. In the instance it was a “yes,” it was met with reluctance.

Throughout that fall term, I continued to vomit with extreme episodes of diarrhea. I continued to lose weight and by the end of November 2007 I was not keeping food or fluid down. The ongoing progression of my symptoms after my SMA syndrome had been surgically corrected further indicated the severity of the motility disorder with which I had been diagnosed. Without the ability to hydrate and nourish myself I had a central line put in and was on Total Parental Nutrition. I had decided to name my central line “Henry.” I wanted to name my central line to eliminate the use of medical terminology. I was more comfortable with family asking about Henry, rather than my central line. At this time, the feeding tube was permanent and there was no answer to whether I would be able to eat again. If being on a feeding tube for the rest of my life meant having the opportunity to live my life, I was good

with that. I just wanted to get out of the hospital. Because I was on a feeding tube that went directly into my bloodstream, I was at a heightened risk for sepsis. Living in the community and not in the hospital was met with reservation.

I was determined to go home. I did not want to stay in the hospital. I was willing to learn whatever I needed to do so I could be able to be on a permanent feeding tube and continue to live my life outside of the hospital. I participated in training where a nurse with specialized knowledge and care of central lines and feeding tubes educated and trained me to care for my line. Before I was released from the hospital I needed to know how to care for, and be comfortable, caring for my line. I would also require the support of a home care nurse. At first I would have a nurse come every day and then over time my visits would be reduced to two times per week. With perseverance and determination I was discharged from the hospital to live at home with a permanent feeding tube. When I left the hospital I thought I would be able to live forever with TPN. I thought I had found a way to live with DIGITS, the answer I had been searching for with regards to living with a chronic illness. The first couple months on the feeding tube seemed to pass without any major issues. I had figured out a routine but I continued to struggle with the symptoms of my chronic illness.

When I was on TPN, I had difficulty with daily functioning. During this time of my life I have a lot of foggy memories and do not remember a lot. It is odd because once I had the feeding tube for a bit, I was nutritionally at my best. I would have blood work taken every week and the nutrition I received intravenously was catered to my levels based on my weekly bloodwork. On paper I was the healthiest I had been in years. But my memory was terrible, I was exhausted, and struggled to find enough energy throughout the day. My TPN was administered 12 hours per 24-hour period, and I also required additional intravenous fluids

for hydration. I would typically hook up from 7:00 or 8:00 in the evening until 7:00 or 8:00 the next morning. I also required intravenous hydration halfway throughout the day. Waiting until the night for fluid was too long. I would become dehydrated during the day and needed to hook up for intravenous fluids mid-way through the day.

I wanted to return to university in January but I needed to be able to hook up half way through the school day to ensure I would not become dehydrated. Prior to making any plans I needed to meet with the program coordinator and placement supervisor to see if being able to hook up during the day could be accommodated. My health situation was met with both concern and kindness. I am grateful to recall the compassion and encouragement I received to enable me to continue with my studies. At this point I had many health interruptions and accommodations needed so I also met with accessibility services to help support my success. During classes I was able to be hooked up safely so long as no one would trip or be able to accidentally disconnect my line, which would be very dangerous. As part of my Bachelor of Education program I had a teaching practicum one day each week so during this time, I would hook up during my lunch break in the staff room.

My mom and I found a suitcase with wheels that had a telescope handle. The handle raised high enough to hold my fluid bag and intravenous pump. At the time, the pumps in the community were quite large and heavy. I also needed to ensure that the IV bag hung higher than the IV to work and to keep air from entering the IV line (and thus my bloodstream). When I was hooked up I would extend the handle and hang my IV bag with a hanger and the pump would sit in the bottom of the suitcase. My pump had the battery power to last most days without having to plug it in. On days when I had more classes and did not have enough

time at home to charge the pump I would need to plug it in. I was always embarrassed and apologetic when my pump would beep during class time.

I was still very shy and insecure about my health needs. Although I was grateful for the support I was receiving, I had difficulty connecting with others. I no longer had many friends and my reality was quite isolated. My life required needing to be home for 12 hours straight to hook up. I could not eat which made social gatherings with food and attending restaurants uncomfortable. I was especially anxious when a server would ask me if I wanted anything. I was extremely worried about how people would perceive my health needs. I was very quiet during classes and had little contact with peers.

There were numerous peer evaluations and at one point a professor pulled me aside and asked me why I was being rated so poorly on peer evaluations when my independent work did not reflect how my peers were evaluating me. I did not know but I suspected it had something to do with the fact I was not viewed as a peer. I continued to question why I was in the Faculty of Education. I clearly was not part of the teaching clique and now more than ever my health accommodations were too much for me to work as a full-time teacher. It is also important to note that when having a central line, sepsis, is huge risk factor. In the instant bacteria enters the bloodstream, it will migrate to the central line (foreign object) and cause a serious life threatening blood infection. So again, working with children in the school system where illnesses are prevalent was not an ideal setting for me. My family kept reminding me that I was so close to finishing and I should just to keep going, but I hated it. I absolutely hated attending the Faculty of Education.

As the winter term went on, my symptoms continued to worsen even though I was not eating and my body was not responding well to TPN. I needed another intervention to help

me be able to live with this motility disorder. The problem was at that time, my doctor was not entirely sure what would help. Dr. T. began to discuss the potential of removing my colon resulting in an ileostomy. He thought that majority of the motility disorder was in my large bowel and if it was removed, hopefully my gastrointestinal system would function better. But this was an experimental option. The worst case scenario was that I would be on TPN with an ostomy. The reality was that my body was not tolerating TPN well and I would not live a very long life. I did not know what to do.

I was petrified about the option to have an ostomy. Removing my large bowel was a foreign concept to me. My parents were still bewildered because I grew up a healthy child. *How could this be an option?* I was 24 years old and the decision was up to me. This was a hard decision because I was putting my trust and my life in Dr. T.'s hands. I had multiple appointments with Dr. T. discussing having an ostomy. He even connected me with another patient who had an ostomy so I could talk with her about her ostomy. This was a pivotal conversation because even though she had an ostomy, she was still in the hospital struggling with the symptoms of this motility disorder. I needed to prepare myself for the reality of still being sick with an ostomy. I was very confused about how I felt about an ostomy. I was nervous about how it would alter my body and I was concerned with what others would think if they knew I had one. I had asked my immediate family not to share with anyone that I had elected to have the surgery.

During this time, I was referred to a lawyer to potentially assist me with my ODSP application. Because of my continued health needs, Rob and I were acquiring a lot of medical debt. This lawyer met with me for over a year and helped pursue and appeal decisions with ODSP. We went to appeals together, he compiled medical documentation, and wrote

numerous letters. But in the end we remained unsuccessful. Since ODSP is part of social welfare, Rob and I were considered a family unit in the program. It did not matter how much debt we accrued because we owned our house. If I wanted to financially qualify for ODSP because I had been recognized as an individual with a disability, we would need to sell our house to pay our debt and then rent, and/or divorce my husband so I would qualify. We ultimately decided to stop pursuing ODSP for support at that time.

While I researched and considered if I would have surgery to have an ostomy, my symptoms continued to worsen. I continued to struggle with spasms and severe pain. I elected to have the surgery with mixed emotions about the success and trust of my new doctor. I ended up being admitted to the hospital in June earlier than my intended surgery date. My symptoms had progressed so much it became evident that a colectomy and ileostomy was my only option. I desperately wanted the social participation that comes with eating. I wanted to enjoy meals with Rob. I missed eating. More than that I wanted to create the life Rob and I hoped for and had dreamed of. My most cherished dream of being able to have a child and be a parent with Rob. What I hoped for and envisioned was not our present life. I was determined to try anything in pursuit of our life dreams.

My dad and I had an argument one day on the phone when he shared with me that he had spoken to other family members and they were all concerned with the trustworthiness of my doctors and alluding to the necessity of needing to remove my large bowel. I was furious with my Dad that he had shared my health situation with others. It was none of their business and I had been living with the symptoms of my illness for almost three years now with little support from our extended family. I was not at all receptive to hearing their opinions at this point. This was one of the worst fights I have ever had with my dad. My dad shared that my

family was concerned with the drastic measure of needing to remove my large bowel and the resulting permanent ileostomy. *Really?! How? My survival depended on an alternative to the permanent feeding tube! I had been struggling for years now, and maybe this was exactly what I needed.* But the disbelief of me being diagnosed with a physical gastrointestinal motility disorder continued to loom. *Was Dr. T. reputable? Could he be trusted? What is a motility disorder anyway?* These were questions that I continued to face and attempted to answer. Even with a diagnosis hesitations filled the air since many believed my illness to be psychological in origin. I knew after the heated conversation with my dad that I needed to make the decision for myself based on my thoughts and feelings and I needed to trust the expertise of Dr. T. I realised that I completely trusted Dr. T.; he had listened, investigated my symptoms, and he saw me as a human being with a complicated physical illness. I consented to the surgery. Rob had continued to support me and the idea of having an ostomy. He had seen the effects first hand of my illness. I would continue to dry heave and vomit even though I could not eat and I continued to have irregular bowel patterns. He saw the pain. He understood my day to day life and the need for intervention.

I ended up being admitted to the hospital prior to my surgery date to have a colectomy. I was unable to control my pain and continued to have many uncontrollable gastrointestinal symptoms. With one final consultation with Dr. T., I decided I would go ahead with the surgery immediately. Even though I had discussed having an ostomy and had researched what an ostomy was, it was still difficult to imagine what my life would be like with it. I worried that I would still need to be on TPN and that even with this surgery, my ability to live would not be possible. Not only did I question if I could live but what about life with an ostomy? I wondered what clothes could I wear and how would they fit? Would

people be able to notice my ostomy? Would it stink? Would it be loud? Would this make my symptoms more controllable? Would I be able to have children? I was full of questions but there was no definite answer. Surgery at this point was experimental and I was all in.

Even though I had previous surgeries and knew what to expect, I still struggled with waking up from anesthetic. I have such a difficult time. I know the importance of preparing for a surgery and being calm and relaxed and yet I still wake up hysterical. This surgery was no different. I woke up in recovery frightened, and my pain was uncontrollable. The damage to my liver from long term narcotics use had caused my tolerance to be dangerously high, and it was consequently difficult to find a safe narcotic dose to ease my pain. Again, recovering from this surgery was incredibly intense since it was extremely difficult to manage my pain.

When I am in the hospital I never want any visitors outside of my immediate family. I used to hate it when people would want to come visit. I never wanted anyone to see me at my worst and make small talk. I saw the way they looked at me their eyes filled with gloom. I felt their tense and worried energy. I sensed the discomfort of being in a hospital setting. All I wanted was them to see me, the Taunya they knew and who was still alive inside me. What they saw was the physical changes I could not control. Because of this I really struggled with giving people the opportunity to see me in the hospital and I absolutely hated surprise visits. It has taken me a long time to articulate why I did not want visitors in the hospital and why I was only comfortable with certain guests. Although I still prefer not to have a lot of visitors in the hospital I am no longer as regimented in my views. I am appreciative of people coming to the hospital to visit and I understand that is their way of showing they care and acknowledging my health needs. I have been in the hospital with

many roommates and have seen the isolation and despair people experience when they are alone all day and all night. I still do not love surprise visits and many visitors in the hospital but I no longer respond by being angry but instead by being welcoming to their care and concern. I used to fear people seeing me as sick and seeing what I looked like as a sick person. I did not like looking in the mirror, and I most certainly did not want people to be looking at me when I could not look at myself. I was still struggling with the betrayal I felt towards my body for having an illness. I struggled with what I looked like sick. I did not resemble myself but rather was a weak, gaunt, and frail version of myself. I was ashamed of what my body had become and did not want anyone to see me and validate how much I had changed.

Because of the long stays I have had in the hospital, I have also spent many weekends there. I recall numerous occasions where Dr. T. would come in my room and Rob and I would be watching a movie on our portable DVD player. Dr. T. would often joke about our “Date Nights” but such nights served a far greater purpose than simply passing the time. It was our way of adapting to our situation and my health needs. It never stopped us from pursuing what we wanted in our life. A date night in the hospital is not ideal but it contributes to memories I cherish because I have a partner who sees me, and not the body that continues to require many medical interventions. Rob’s presence in my life has been an extraordinary gift because he has shown me how to love myself by sharing what he sees in me. He has continued to remind me that I am not an illness and it took years of his gentle reminders before I started to believe that I was more than a person with an illness.

After having a colectomy, my ileostomy was covered with an ostomy appliance but it had a clear bag so the medical professionals could monitor how my ostomy was functioning

without taking my appliance off. I was very self-conscious of anyone seeing my abdomen because of the clear bag filled with stool. I asked Rob one day what he thought of my ostomy. He lifted up the sheets and bent down and kissed my stoma. I knew in that moment he had accepted my ostomy without reservation and was grateful. Rob was quicker to accept my stoma, newly named Oscar, than I was (Named after Oscar the Grouch, Oscar was my new trash can).

As I recovered, I passed the ice chip and water stage and I was able to start other clear fluids. What a wonderful experience to be able to start the process of eating again. From clear fluids, I went to a fluid diet, and then to solid foods! I could eat! I was ecstatic! From not being able to eat for so long my tongue swelled up from my taste buds being incredibly sensitive. I was able to eat again, I was so grateful. Not only was I thankful for the ability to eat but for opportunity to experience food, preparing, tasting, social gatherings, and celebrations.

Even though I was incredibly grateful to be able to eat and be rid of TPN, I still struggled with my body image now that I had Oscar. I also still required a central line. Oscar continued to be overactive and staying hydrated was difficult. It didn't matter how much I drank my body did not absorb the fluid. I now used my central line, my Hickman, Henry, solely for hydration purposes.

When I finally returned home and was recovering from my colectomy, I spent a day with my mom going through my closet. Having an ostomy had altered my body and changed how my clothes fit. I was extremely self-conscious about anyone knowing that I had an ostomy and was adamant about anyone being able to detect my ostomy under my clothes. I had difficulty adjusting to Oscar because of the high position on my abdomen; my stoma is

actually higher than my belly button. Not only was my stomach still healing and sore from surgery, I was not used to the way an ostomy felt. I was hypersensitive to the bandage and my ostomy bag filling up. I got rid of many of my clothes. I did not want to be reminded of what I used to be able to wear. Prior to having surgery I had an assessment done that considered my body in various positions for the ultimate placement of my ostomy. Once I received my permanent marker dot of where my stoma would be I was very surprised and worried—this was not at all what I anticipated. When I met an individual with an ostomy, her ostomy was quite low and closer to her hips. I was told that because of me being short and petite, my stoma placement considers all positions and cannot be blocked or compromised when my body is in various positions. Oscar was placed in a position that was more visible and I found it to be more difficult to hide than I had anticipated.

My central line, Henry, was used to administer TPN for my nutritional needs and fluid for hydration. Now Henry was only used for hydration purposes which entailed approximately 2 to 4 hours of IV per day. My overactive ostomy also meant that I had to wear large ostomy bags. All the research I had done prior to having surgery suggested that there were options to wear these cute little ostomy bags; I could not wear these at all. Oscar would fill these bags in no time and they would pop off. I needed to wear the large bags which hung down my leg. When I would try to wear small bags they always ended up bursting, leaking or forcing me to mad dash to the washroom. It took me a couple of years to accept the fact that I needed to wear large bags.

I was also very self-conscious about my ostomy around Rob. Even though he was incredibly sensitive and understanding of me having an ostomy, it took me a long time to be comfortable with having an ostomy and with him seeing my new body. I still remember the

first time I let Rob see me with my ostomy. My acceptance did not have anything to do with Rob but was about me being comfortable that I had an ostomy, and being seen with an ostomy.

I had one year remaining of my Concurrent Education program to finish my Bachelor of Arts and my Bachelor of Education degrees. I was determined to finish. My postsecondary journey had been long and I was ready to graduate. I dreaded starting school again, I had yet to make any friends, and I found the experience to be isolating. I continued to require accommodations for my health since maintaining my nutrition needs was still difficult. I was drinking expensive partially digested drinks that tasted like metal in hopes to aid in improving my nutrition and weight. My stamina was weak and I was still learning how my body was functioning with an ostomy. My physical education class was difficult to participate in and I ended up requiring additional accommodations to complete course work. When I did participate and we had to change for our physical education class, I would arrive early and stay late to change or I would change in a bathroom stall. I was completely ashamed of what my body had become. I was so thrilled to be eating and experiencing an improvement in my symptoms, but I was not ready to acknowledge that my ostomy was responsible for the improvements my life had.

My last year of the Concurrent Education program proved to be quite different from the previous year. One day in class a professor asked me a question about my classmates' names and I replied that I did not know. He asked why, since I was in my graduating year. I explained I had recently joined that class and did not have much contact with my peers. This in passing conversation, was the most profound influence on my postsecondary career. This professor continued to ask me questions about why I had joined the class and what my

experiences were. I shared that I did not understand why we learn about the importance of inclusion and I did not have one friend. My needs were obvious. I knew I was different—I had an IV pump attached to me regularly. I felt that if these teacher candidates did not have compassion for a colleague, how would they appreciate differences in children? Our conversations continued and I ended up completing a research project as part of my physical education course about the school experiences of children with chronic illness. Not only was this professor kind, but he helped me see that despite my health conditions, I was still of value in the educational community. From my perspective, I was planning on graduating from the Concurrent Education program but I had no idea what I would do after. I knew full-time work was out of the question. The best case scenario was supply work but I knew I did not want to do that forever. My conversations with this professor encouraged me to continue to learn and grow as an individual. This professor advocated for me to present at a conference at the main campus that was held for my peers and other teacher candidates. I would share my experiences and the findings from the project I had been working on about the school experiences of children with chronic illness. I was extremely excited about this opportunity but very nervous about sharing the experiences I had about my life with a chronic illness. Up until this point in my life I remained very quiet about my personal experiences.

News about me presenting at this event had traveled quickly among my peers and the night before the key note, for the first time, Rob and I were invited out by school mates. Sharing my story at this event was my first academic experience. I was surprised by the responses from all of my colleagues. Many came forward to chat with me after and I realized the importance of people sharing stories. This was the beginning of my becoming an

advocate and realising that people really do not know what life with a chronic illness is like. From that day forward, I had friends in my program. It took time to establish relationships but from putting myself out there, I received support and the beginnings of many strong friendships were formed. Speaking at this conference ignited a passion within in me. I was eager to research about chronic illness and with encouragement I ended up applying for a Master of Education graduate program.

During my last term in the concurrent education I had my first sepsis infection in my Henry, my central line. I had started my second last practice teaching placement for my Bachelor of Education Degree and thought I had come down with the flu. I had to miss a few days but despite not feeling well, I thought it was best to try to attend. I felt awful. I had wicked chills, was incredibly nauseous, in pain, and weak. At this point, I realized I needed further medical help. I went to the doctor and blood cultures were ordered. I received a call the next day from a doctor informing me that I was septic and needed to go to the hospital immediately. This was the first of many sepsis infections I would continue to battle with from having central lines. Once I was admitted to the hospital, I received antibiotics and Henry was surgically removed. I would require peripheral intravenous until I was well enough to have a new central line surgically implanted.

After I had recovered from this infection I began my final placement. From the previous infection I had lost a considerable amount of weight and was quite frail. In the initial days of my placement, my associate teacher asked if I was alright and if we could chat about my wellbeing. I said sure and that I had a chronic illness that had been causing me difficulties and was happy to chat about it. He then proceeded to tell me that other teachers had been saying that I was anorexic and were concerned about me working with children. I

was angry and disappointed by the assumptions and judgments people were making about me. *Why was no one asking me? Why would they assume they knew my story when they had not even spoken to me?* One day at my placement I was eating lunch and an educator walked by me and said “*well if I ate like a bird I would be as thin as you are too.*” Not once did this person consider the potential of dietary restrictions as the reason I looked the way I did. I not only felt uncomfortable but I was ashamed of my body and how I looked. I was trying really hard to live and be healthy. I was eating and that was a success but this person did not see that. I knew I could not keep ignoring these statements and needed to speak up. I was invited to attend one of our staff meetings. At that meeting I shared that I had a chronic gastrointestinal illness and if that anyone was concerned or had any questions I would be happy to answer them. After the meeting many staff came forward and shared with me that they had no idea that I had an illness and appreciated my sharing.

I graduated from the Concurrent Education program in the spring of 2009. I had seriously doubted that I would ever be able to finish those two degrees but I did and I was full of emotion. *It was finally over!* I had completed what I had started six years ago and I was ready to move on. As a graduation gift and in hopes of my health stabilizing, I really wanted to extend our family to include a dog. I had wanted to bring a dog into our family for years, but the reality of my long hospital stays and Rob working so often led us to the decision that we could not care for a dog. With my increasing hope and knowing that I was off TPN and now eating since having Oscar, we started to look for a puppy. We met our little Gemma and she became our furry daughter. She is a small dog with a gentle demeanor and the perfect fit for us. Having Gemma in our lives has been and continues to be an incredible gift. I spend much time at home recovering and living with the symptoms of my illness while

Rob works long hours to support us. Gemma has brought much joy and comfort to me. She is incredibly intuitive and knows to be careful around my intravenous lines. She has never jumped on my abdomen when I have had a surgery or procedure and instead seems to know that she should curl up beside me. Gemma is full of love and is extremely aware and sensitive to my needs. Gemma continues to fill our life with joy and love. She is the first to jump into bed for a nap and is thrilled to accompany us on a family walk. But most importantly, Gemma has allowed me to be me in whatever capacity I can. Regardless of what we do or do not do in a day, she accompanies me.

Chapter 6: The Realities of My Chronic Illness

From 2008 to 2012, I would have numerous central lines, and I would have eight bouts of sepsis. I would continue to struggle with how I could live with my chronic illness. My infections would increase in severity and the questions about how long I would be able to live on the path I was on continued to surface. I had many assessments and consultations about having a central line and how to reduce line infections. During these years I would experience many surgeries to implant and remove my central line. I would experience doctors trying to remove the line by pulling it out of me when it required surgical intervention because it was attached to tissue in my chest. At one point I would I would walk out of an operating room, refusing to let a doctor inappropriately remove my line. I was deemed as “refusing care.” Cycles of infections continued. One big realization for me was that working in the school system was contributing to my infections from my weakened immune system. So although newly hired to the occasional teaching list, I took a medical leave to explore further options.

I was accepted into my Master of Education program of choice and I started attending classes in the fall of 2009. I was eager to start my Master’s. I was a full-time funded student who was ready to learn more about research and how I could contribute to academia. I was in a small cohort and a few of the teacher candidates I had met in the previous year had continued on with their Master’s as well. My supervisor was the professor with whom I had completed my first research project. For the first time in a long time, I felt that I had friends at school. I carpooled with two peers regularly and participated in social events. I really enjoyed this time because I was starting to feel comfortable with who I was. We were a

close-knit cohort and they knew about my illness but were beginning to see me. I was also now eating more and gaining weight.

Since I had stabilized and was out of the school system, I was eager to discuss the potential of having a baby with Rob with Dr. T. He shared that he could not see why we would not be able to have a baby and that I need to be prepared that getting pregnant could be difficult. I was thrilled with the idea that we could officially start to try for a baby! Being honest and realistic about my needs continued to be a struggle for me. I had a difficult time sharing when I was not well enough to do certain things, I never mentioned if I was not feeling well, and I still needed to learn the importance of balance. I finished my Master's program within a year, attended conferences, and presented at my first research conference. I was also septic three times which means many lines implanted and removed. When I reflect on this year, I am amazed that I survived. I wanted desperately to control my illness. I thought that if I acknowledged that I had an illness, and I knew the research about living with a chronic illness, that naturally I would be able to live how I wanted to. But what I did not understand was that I could not control my illness. Despite what I thought, I needed to have accommodations in my life. I needed to not only acknowledge my illness, but I needed to find ways that I to live with my illness without experiencing life threatening infections.

Rob and I decided to sell our townhouse and we had a brand new two storey home built. When we decided to go ahead with the purchase, I was in the hospital with a line infection. Rob brought the purchase agreement to the emergency room for me to sign. Moving from our townhouse into a home to me revealed that despite my health conditions, we were making it in life. Despite all of the adversity we experienced, we were still pursuing the life we wanted. At the time for us, this included a big shiny new house. The house would

be built in the winter and ready for us to move in that spring. I was super excited that we bought the house. Rob was working two jobs and we were able to afford the life we wanted. I was on my way to completing my Master's degree and we were very eager to start our family.

We were very proud to move into our new house. We thought this would be the house that we would continue to expand our family in. We believed that this house meant we had come to understand my illness, but that we could also move past my illness and control our future. Our move proved to be quite hectic as I had another line infections so we needed extra help and support to move. We were fortunate to have the support of our family. We closed our townhouse on the same day we received possession of our house, and even though our new house was not far from our old home, the moving plans were incredibly unrealistic with my ongoing health issues. I needed to have the flexibility of timing and we did not plan for me to be unwell.

While we unpacked and settled into the house I continued to work on my Master's thesis. I was eager to finish and excited to share my research findings. The hardest part of my Master's degree was compiling my narrative which informed the topic of my thesis. Continuing to share the realities of my story has been difficult because it has meant acknowledging what has happened.

I defended my thesis in July 2010. I continued to write and adapt my thesis for publications. I believed that it was imperative for people to know about the stories of those with chronic illnesses and specifically gastrointestinal illnesses. Over the next year I continued to publish and apply for doctoral studies. I was also offered my first teaching position at the same Faculty of Education I graduated from. I was thrilled to be offered employment at this institution because I was able to continue with what I was most

passionate about—research. Since my Master’s was funded, I was required to do a research assistant (RA) position. I had participated in my first research projects as an RA and loved being immersed in learning about the research process. I was hungry to learn about what research projects entailed and the topics of study I was participating in. I had two professors who had different stances on research and topics of interest. It was a fascinating experience to learn about approaching research.

As a part-time faculty member I remained keen to continue to participate on research projects with various full-time faculty. I continued with my role as an RA and was also paired up with another RA who was in the midst of completing her Master of Education. I did not know it at the time but I would soon develop a meaningful friendship with her both personally and professionally. We began jointly working as RAs together on the same research projects. We not only learned about the research process but also how to work effectively and efficiently as RAs. We learned to trust each other professionally and we began to share the details of both our personal and professional lives. We soon realized that we had a lot in common and that we aspired to the same goals. We both wanted to pursue careers in academia and would need to continue on with our Doctorate degrees. Together we learned and supported each other’s personal and professional aspirations.

In my first year of teaching at a postsecondary institution I continued to struggle with central line infections and had my line removed over the holiday break, requiring surgery to put a new central line in in January. I had needed to take a few days off work but I returned to teaching soon after my procedure. I went to work and sat in a chair to deliver the content needed. I still remained afraid of having to say, *no I am not well enough*. I was sensitive to the stigma of how people viewed me with a chronic illness. I wanted them to know that I am

committed, strong, and able to handle my responsibilities. I was immersed in my new position as an aspiring academic. I was eager and hungry to learn and grow as a scholar. I wanted to experience all of the potential opportunities I could by being an RA, attending conferences, seeking publications, and being a part-time faculty instructor. At the time, I thought that meant returning quickly after an invasive procedure to surgically place a new central line. I sought to become an expert in understanding life with a chronic illness and if I could consume all of the research and apply it to new research studies and then I would have figured out how to live with a chronic illness.

In pursuit of a career in academia, I applied for doctoral studies in January 2011. I was both anxious and hopeful that I would be able to continue my journey in academia and contribute to research about the realities of living with a chronic illness. I checked the mailbox every day eagerly awaiting a large envelope, which would imply an offer of acceptance. I was also very involved with a team of individuals with DIGITS (and their mothers) and we had planned a gala to fundraise for our newly named motility disorder DIGITS. Deciding to fundraise and create a fundraising effort for DIGITS was an incredible commitment. I learned a lot about working with other individuals with illness and about my abilities. Although I was incredibly passionate and fully supportive of our DIGITS fundraising it was very difficult to maintain my needs. I thought since the gala was our major fundraising endeavor that I would be able to rest and recover after the event. One snowy day in the early spring, I received my offer of admission in a large envelope to begin my doctoral studies. Around the same time, Rob and I saw the gynecologist and we began using Clomid to help us conceive. We were thrilled to be actively pursuing parenthood. Already, it had felt it was taking so long for me to become pregnant. While we continued to be optimistic about

having a child, I completed my first year as a part-time faculty, and I was hopeful I would be offered a teaching opportunity the following year as I continued to aspire in academia. I had been accepted to a full-time doctoral program that was out of town and came without funding. Over that summer I had planned to continue to seek research contracts and work as an RA to support my doctoral journey. My life with Rob had been going extremely well and it seemed we had established some sense of normalcy. I felt I had figured out how to live with a chronic illness.

Unfortunately, this sense of normalcy was short lived and my body had other plans for me. As soon as I had completed my fall faculty teaching contract I was admitted to the hospital, struggling with line infections. My gastrointestinal symptoms were heightened and I was in a lot of pain. I could not seem to keep my symptoms controlled and my lines continued to get infected. Because of the abrupt onset of my line infections I was taken to a local hospital by ambulance. Unsure of my rare illness and understanding of sepsis, Dr. T. was contacted and I was transported to London to be in his care.

Once again, I viewed my life to be on hold again. I missed my Master of Education convocation. I had to cancel summer family plans that had been made far in advance. I had to decline some of the research contracts that I had been offered, or take on roles with fewer responsibilities for the time being.

One of the effects of being on TPN can be developing gall stones in your gallbladder. I had not only developed gallstones but it was predicted that my gallbladder was no longer functioning properly, contributing to my recurrent line sepsis. My gallbladder needed to be removed but there were literally obstacles in the way. My stoma was directly in front of my gallbladder. In between my gallbladder and stoma was the bypass I had from my SMA

syndrome. So my gallbladder was going to be very difficult to remove and would require a major surgery. I remained in the hospital. I was having difficulties eating and because of my constant line infections, I could not have a new line put in. I was rapidly losing weight and weighed less than 80 pounds. I was on the emergency surgery list. One night I was wheeled down to the operating room and being prepped for surgery. But while being prepped, I developed a high fever. My blood work revealed that I was not well enough to have the surgery. We needed to wait. In the meantime, TPN would be administered peripherally but it was very painful and was hard on my veins. My veins would not tolerate the TPN. We continued to wait for my fever to subside and levels to improve. A few days later, I had cholecystectomy surgery to remove my gallbladder.

Similar to my previous surgeries, this surgery remained difficult for me to wake up from and again my pain was uncontrollable. Dr. T. had now realised the pattern of my pain being difficult to control and had arranged for me to receive nerve block injections every 24 hours to help me in the initial days after surgery. This was the most difficult surgery I have ever recovered from. The frequent sepsis prior, the experience of being in the hospital, and the actual surgery, had left me feeling incredibly depleted. I had become so malnourished. We had recently started Clomid to become pregnant but I was grateful we had not conceived from my recent infections and surgeries. I was so discouraged. I was frightened by how quickly I could become so ill and by how few options remained for my survival. I continued to struggle with pain and recovering from this surgery.

I returned to see Dr. T. in late July. I was worried about being able to start my doctorate and returning to work. I was still in so much pain. I did not understand why it was taking me so long to recover from this surgery. Dr. T. explained to me how severely ill I was

and the seriousness of the surgery I had. He described how difficult it was to remove my gallbladder when my insides had adhered together from previous surgeries and scar tissue. He described how all of my organs needed to be cleaned off and were then put back in, and that is why I was still in pain. Although I felt comfort in his explanation and reasons for my pain, I remained discouraged about living with this chronic illness. I struggled with how I would continue to create a meaningful life, especially when I could become so ill so quickly. Although I was extremely discouraged about my ability to live, I learned that I very much wanted to live. I had not been committed to my life because I never thought I would survive. I knew from this point forward that I believed in my ability to live.

Rob continued to work a lot since I was unable to work over the summer. He would work 6 days per week. He worked one full-time position and then would add in three extra shifts on top of his work day at a golf course as a golf pro. I am grateful for Rob's determination to support us and at times I found it very difficult to watch and be helpless to financially contribute. I saw him working so often and felt that this was all my fault. *If only I could work more, if only I was better, if only I didn't get so sick then he wouldn't have to work so much.*

I continued to recover slowly but that did not mean I would delay my September commitments. If I could resume my responsibilities and start working, we would be able to financially catch up from my summer episode of being unwell. Even though I was still struggling, I would carry on as if I was well. I would not mention how ill I was—I was very skilled at keeping the realities of my illness a secret. I started my second year as part-time faculty and began my doctoral studies. Rob and I returned back to our gynecologist and at this point our gynecologist decided it would be best if we sought consult from a fertility

clinic and offered us a referral. Now that my gallbladder had been removed it was thought that my risk of sepsis had been substantially reduced.

During that fall, I commuted to my faculty teaching position two times a week in one city, I commuted to my classes for my doctorate in another city, presented at conferences, and I had resumed my research contracts as an RA. I was busy and I was determined to do it all. Every day had a different schedule with multiple tasks. I believed I could live with an illness, be a student, be an employee, be a wife, and pursue motherhood. I thought by doing all of this, I was proving my self-worth. I was not getting it at all. I continued to ignore my body, my symptoms, and my intuition.

I knew I should not feel less of a person because I had a health issue, and yet, I hid my chronic illness. I felt ashamed that I was not healthy. *Why does my body not work the way it is supposed to?* I conformed to thinking I was lesser of a person as a result of my illness. I believed I was inferior to the healthy individuals who surrounded me. I hated my scars. I should not have hated my scars, the scars are results of life-saving measures, and still I could not look in the mirror. Why are my scars ugly and not beautiful? The scars represented my life being able to continue. I always thought if I could, I would have plastic surgery in a second to remove the many scars from my body. It was upon much reflection that I realized if I removed these scars I would be conforming to society's view of scars being ugly and undesirable. The scars on my body were symbolic of me living, my triumphs, and my ability to heal.

I am not sure if I was naïve about starting my doctoral studies or if I simply had a different idea of what it would be like. Since I was commuting out of town, I would arrive on campus early in the day to prepare for classes and then I would attend evening classes and

commute home after. The program I was enrolled in was a “flexible” education program. As I continued on in the semester, I was frequently reminded about the process in which a doctorate was completed, and the rites of passage that I would need to complete. Although I never admitted out loud, in the back of my mind I worried about my ability to continue with standard doctoral requirements. I was taking both mandatory and elective courses and I struggled to meet professors who were the right fit for me—someone who understood what living with a chronic illness was like and the flexibility I may need to continue my education. Instead I put on a façade that I was not affected by my chronic illness. I was not my illness and there was no way that I would let my illness interfere with my aspirations. I continued to enroll in courses for the fall, winter, and spring semesters.

I hid the inability to control my symptoms and make myself better. I tried as much as possible to hide the effects of my chronic illness. When my symptoms would be revealed, I was infused with guilt and the constant need to apologize for my body’s inadequacies. *Why could I not be stronger, fight through the pain and symptoms? Why could my body not perform better? Why did I have to feel my illness every day?* I regretted the limitations my chronic illness caused in my life and in turn in my family. I wished I was better because they deserved better. I felt responsible for the failures of my body as if I could control my chronic illness. At times when I would go to bed I would be amazed that I had made it through the day despite the pain I experienced, the exhaustion I felt, and the ability for Oscar to be so active. I felt completely depleted. I did not know how I would be able to recover. It was beyond needing sleep to restore myself. I continued to expend myself far beyond what was repairable and even though I questioned how I would be able to live, I kept going. My ability

to carry on was the only way I knew how to cope. This was my way of sustaining the life I knew. And so that is exactly what I did—I did not ever stop.

When our consultation for the fertility appointment came I was so excited to resume our journey to having a child. I had spent the years prior journaling and seeking wellness support for becoming a mother. Our first consultation involved sharing my complicated medical history. We left our consultation with hope but the journey was still going to take time. Our fertility doctor wanted to make sure that I was healthy enough to be pregnant and that involved more assessments and tests. We met with numerous doctors, making sure I was mentally well enough, ensuring I was able to nourish myself despite the gastrointestinal illness I had, and testing to assess my current state of health.

I was grateful for this doctor's approach to us pursuing becoming parents. I felt his caution was needed to ensure my health and the health of our unborn children. Although I was eager to move forward, I understood the reasons for the measures that were in place. The appointment I was most nervous about was when the doctor proceeded to ask me how I would cope with the effects of my chronic illness as a mother. What would our life look like? How was I going to live with my chronic illness as a mother? I did not know this at the time but the questions that I was being asked then are the questions that have informed my research questions for my dissertation. *How would I share with our children the realities of my chronic illness?* My answer then was my ability to love our children would not be affected by my illness. My ability to love supersedes my illness. My ability to continue to live my life despite my illness would not stop. Although I needed to have a different way of life compared to a healthy individual, Rob and I would raise our children aware of my needs but not in a way that our children would fear or be hindered by my chronic illness. After this

appointment we had all but one last doctor to sign off on us pursuing fertility treatment. Because of my malabsorption of nutrients and fluids our fertility doctor had ordered a bone scan. This scan would reveal that I also had Osteoporosis in my lower spine and hips. We met with this doctor and he still signed off on us pursuing fertility treatment.

Our first treatments were intrauterine inseminations (IUIs). We started our treatments in the winter of 2012, with our first few cycles that winter and spring, we did not get pregnant. I was devastated. All of the daily injections, the early morning trips to the clinic for cycle monitoring, and the preparation for the day of the transfer, had all failed. We still were not pregnant. Not only were we not pregnant, but the financial realities of fertility treatment had quickly added up, and we did not have benefits that would cover any portion of our treatments. We needed to evaluate our finances to see how we could continue to afford fertility treatment.

I was still instructing at a university, working three research contracts, continuing my graduate studies, and attending many fertility appointments. Rob kept communicating to me that he was seeing lots of red flags with how much work I had committed to and how my symptoms were acting up, but I did not listen. I proceeded with a long day at a conference out of town. I was at Union Station waiting to see what platform the train I was taking home would be on and I felt a POP on my stomach. My ostomy bag had popped off. I immediately ran to the bathroom. Since I had taken the train, I had limited supplies and no extra clothes. I only had minimal supplies for Oscar. If I missed my next train, I would have to wait 2 hours for the next one. I cleaned myself up as quickly and as best I could but I was full of stool. I ran to the train with tears streaming down my face. Once I arrived home I walked right into the shower fully dressed and sobbed. Oscar had been extremely active with lots of output and

I could not get to a bathroom quick enough. In hindsight this was another big warning sign.

From the realities of the financial bills we were accruing from fertility treatment and the realisation that I may need to work less, Rob and I quickly decided we would sell the house we had just moved into. We were fortunate since our house sold the day it was listed. We accepted the offer and now needed to find a less expensive place of our own.

That spring I had another line infection. We thought that since my gallbladder was removed that my risk of sepsis had decreased. Unfortunately, we were wrong and I suddenly became quite ill. This episode of sepsis came on so quick that Rob had to call an ambulance. I am so grateful he was home with me. I cannot imagine what would have happened if I was home alone. All I remember is having chills so intense that my body was shaking. From then on my memory is a blur of weaving in and out of consciousness. This was another terrible episode where once again we were grateful that I had not yet conceived and yet heartbroken at the same time. I struggled so much with the realization that my not being pregnant was a blessing. We had just sold our house to free up money to save for fertility treatment. We needed to wait for further consultation with doctors to assess my having a central line. The numerous issues of sepsis I was having were of major concern. Sepsis killing me was my new reality.

Time quickly passed and I was in the hospital for another long period of time. Since we had sold our house we needed to find another place to live. At this time the housing market in our area was very active, bidding wars were common, and a house would sell within hours of being on the market. Adding to the complexity was that we were downsizing and consequently had a limited budget so it was proving to be very difficult to find a house that would meet our needs and our budget. While I was in the hospital, Rob had started his

first year as a full-time golf professional working long hours, spending time commuting to see me in the hospital, and actively looking for a house. Rob had put offers in on houses I had not seen and although we did not end up purchasing those houses, it was a difficult time to be separated for such a significant decision.

This was the eighth time I had been septic and finally I began to see the magnitude of my chronic illness. Prior to this, I knew I had a chronic illness and the realities of my chronic illness but I did not understand how I needed to be one with my body, not fight against it. This was the first time I realised that I had spent years hating my body and trying to prove that I could do everything—that I was stronger than my chronic illness, and I would not succumb to it. I realized that for years Rob and I had been living in homes with stairs, when I regularly needed an IV pole. I would keep all of my medical supplies (IV and ostomy supplies) hidden and located in inconvenient locations in our home. It did not make sense; I used these supplies daily. I had been making my day-to-day living so much harder by pretending my needs were not the reality of my life. All this time I had been telling myself I knew what living with a chronic illness had entailed but I had successfully been ignoring all of the warning signs I needed. A person can die from one bout of sepsis. I had lived through eight. Each time, the infection became more severe and the bacteria more advanced. My survival depended on me changing my life but I was unsure about how to do it.

Prior to being discharged from the hospital, I had met many doctors and ultimately in consultation with Dr. T., I was advised to take time to heal and find ways to sustain a balanced lifestyle to combat the continuous bouts of sepsis I had experienced. Effective immediately, I took a 1-year medical leave from part-time instructor position, my numerous research contracts, and my doctoral studies. The realities of my health situation meant Rob

and I would need to stick to the low end of our budget while we were house hunting.

Although we were encouraged to spend more in order to expand our search, we could not afford to. Rob and I both still held onto to our dream to become parents and even though we needed to take a break from fertility treatment we wanted to ensure that we had money saved for when we could resume trying.

About a month before our house closed we found the house that would soon be our home. Although it was a fixer upper, and would prove to be more of a fixer upper than we planned for, we found the house we would settle our roots into. Some of our immediate family remained concerned about our hasty decision to move and the house that we had selected to purchase. We had just built this beautiful home and now we were moving into a home that did not have the new suburban appeal. The house we intended to move into was dated with old features, and required much work. Rob and I saw past all of this. We saw a house we could afford and one that could potentially give us the opportunity to raise children in. We did not want to live in a big empty house without children. If living in a smaller house meant we could pursue having children, we were grateful to make this house our home.

Our move came together quickly. Because of my latest health complications we decided to hire movers to make the transition easier. We bridged the two houses for a week so we would not be as time constrained during the move. Our inexperience with a fixer upper meant a week was not enough time and it remained difficult to get the house ready for us to move in. Our last day in the house we had built also meant saying good-bye to a nurse I had for more than 6 years. Now that we were moving to a new city, not only would I have a new nurse but I would also be transferred to a different community nursing agency. This was a difficult decision when we were considering where we had moved. My nurse had come at

least twice each week for years; she had become a member of the family, knowing the intimate details of our lives. While the movers were loading all of our items, I sat amongst all of our boxes and required a peripheral IV. I was still healing from my infection and we had yet to decide on the next plan for a central line. Keeping hydrated remained difficult. That day was particularly difficult for the nurse to access a vein and it required numerous efforts. There I sat in the house Rob and I had built thinking about how this house was supposed to be a symbol of our ability to make it in this world. How wrong we had been. My arms were full of IV pokes, bruises, and sores. I had stitches in my chest from my line being removed, and I had lost weight as a result of my infection. I was desperate for change, and my life depended on it. Saying goodbye to this house was easy for Rob and me—the house never even felt like ours. It was time we started living our life fully aware of our realities and that meant letting go of what we knew and starting fresh. We jumped in, hand in hand, and never once looked back.

Chapter 7: Manifesting Wellness

The move to our new to us house was not flawless. The previous owners had left a bunch of stuff in the house, the house was filthy, and our furnace and air conditioning were both not working when we moved in. Despite all of the hiccups, Rob and I continued to be optimistic about our decision. My mom and sister helped us paint, my mother-in-law helped us clean, and my dad helped us navigate purchasing a new air conditioner and furnace. Our families had come together in our time of need to support us in our new adventure. Their help aided us in settling into our new house that would be our home for years to come.

I was worried about the implications of taking a medical leave from my part-time faculty position. I consulted with a mentor and valued friend about how I would proceed about notifying my employer regarding a medical leave. I did not want my employer to know about the severity of my health situation, and I did not want this medical leave to have an impact on my future employment possibilities. Both my mentor and friend were supportive in helping me articulate what information I should share about my health situation and what should remain private. I was granted an unpaid leave and stopped teaching and working on my doctorate but remained informed on research projects. I continued to be informed on the research projects I was working on but took a step back in the responsibilities I originally had. This was a difficult time because I felt all the hard work I had completed was now for nothing. Everything I had worked for was slipping away—I was no longer able to contribute in the ways I thought I would be able to. I was angry. I was disappointed. I struggled with how I would create meaning in my life. *How was I going to live day to day?*

I went back to strategies that I used when I had been discharged from the hospital. I started with making “to do” lists. Whether that included going for a walk with our dog

Gemma, reading, having a shower, and/or making dinner, I wrote it all down and I crossed it all off as I completed these tasks. Making these lists helped me feel a sense of accomplishment and that my time was not just passing with me being sick. Instead I showed myself evidence that I was living.

With further consultation and in need of a central line, I was presented with the option to try a different type of line called a port-a-catheter. A port-a-cath had the potential for me to be accessed and de-accessed through a needle. The ability to de-access meant a decreased risk of sepsis. I was on board for this new line; I would try anything. Living with a chronic illness was one thing but this constant threat of sepsis was a whole other level of challenges. *How was I going to live with the constant threat of sepsis?* I wanted to eradicate my risk of sepsis.

I started to think about all the time I had been sick; all the time I had been so sick and had given myself no time to heal. I was exhausted. I reflected on how I would not only quickly return to commitments but I would overschedule and not adhere to my bodily needs. Despite loving my occupation and being a graduate student, I was completely drained. Having a conversation with Rob was incredibly difficult because I was so tired. When I reflect now it was not surprising I had so many line infections, it was painful truth to admit to myself. *What had I been thinking?* I had spent 8 years fighting my body. Being angry and trying to control it. I worked too much, would get too sick, and then I would start the cycle all over again. *What was it going to take for me to really start paying attention to the needs I had?* I needed to start listening and being mindful of the body I had. It was about this time when I started my blog “Manifesting Wellness” as a way to document my journey to healing.

I had surgery to implant my port-a-cath. Unfortunately, I had a reaction to this port—

we did not know what was happening at first but my chest filled up with fluid and my port-a-cath site was not healing. The first time my port was accessed, fluid leaked out from the needle prick. I had been in communication with an IV nurse at the hospital as well as regular visits from my community nurse but no one knew what was happening. I returned to the hospital to see the doctor who implanted the line and upon assessment it became evident I was having an allergic reaction to the port. I was allergic to polyurethane. This was a challenge because majority of central lines are made with polyurethane because of its ability to resist bacteria, which allows for a lower infection rate. I would need a port-a-cath made of silicone similar to my previous Hickman's. This was difficult since not a lot of companies were using silicone to make port-a-cath's anymore. It took some time but my radiologist was able to find and order in a port-a-cath made of silicone. I had the port I was allergic to removed and would have to spend some time healing before a new port would be inserted.

Prior to having the port-a-cath put in, I had an appointment with the radiologist about the necessary care for my soon to be new line. He explained to me the importance of being aware of how other medical professionals handle my line and the importance of protecting my line in order to protect my life. He went over the strict instructions of line care he would be sending to my community nursing agency and the importance of my intervening if someone was engaging line care that compromised the sterile field. It was challenging for me to realize the importance of my authority of my health and that I needed to intervene when my line care was being compromised. This was a new concept to me at the time because I had been following the advice of the medical professionals. I did not think of myself as an expert responsible for my own care. I never thought that I would need to, but I did have to intervene on more than one occasion. At first, I was timid about questioning a medical

professional's actions but over time I realised the absolute necessity of my intervention because my health, my life, depended on their actions. Sadly, this would be true on more than one occasion. I recall one memory where I stopped a nurse from flushing a line full of air into my port-a-cath. I gently reminding her that she needed to prime the line (fill the line with fluid) first. The nurse was apologetic after I had shared this with her but nonetheless I was forced to ensure that my care needs were being met.

Once my second port was inserted, I felt I was holding my breath while this one healed. Another reality of having had so many lines was that there was a lot of scar tissue in my neck and chest, making it difficult to find a clear pathway for my latest port. This was another hard truth, I had not had a central line last much longer than 6 months, and I could not keep having new lines put in. Eventually there would not be any place to put in a line and at that point my life was dependent on having central line. This new port-a-cath needed to last. Gratefully, my new port-a-cath, named Hope, healed and I was adjusting to having the port in my life. Hope was bulkier than my Hickman's (Henry) and more noticeable on my chest. I had always been very cautious about anyone being able to see Henry. But because of the bulk of the Hope it was very uncomfortable to wear clothing covering up the line. Clothes would tug on the needle making my chest sore and uncomfortable.

While on my medical leave, I worried about people asking me questions about why I was not working. *Why I had stopped school?* I did not want to feel their judgment or pity. I recall a conversation when an individual said to me, "it must be nice to be able to afford staying at home; I wish I had a health condition." This comment has been made in varying ways over the years and other statements such as: "It must be nice to be so skinny"; "It must be nice to be sick"; "Must be nice to have the time off"; "What do you do all day?" I was so

frustrated, angry, and disgusted at their lack of understanding. They had no idea about the realities of my life and the implications my illness was having on my family life. I had to come up with an answer to all of these statements and my answer to this day is “I am focusing on getting healthy.”

Listening to my body proved to be a lot harder than I thought. I continued to exhaust myself with projects at home and writing to do lists that are far too long. I had some setbacks where I injured myself and jeopardized my newly inserted line because I was trying to fill my recovery time with senseless household chores. Still I struggled with listening to my bodily needs. I felt guilty if I didn't have my day completely accounted for. My husband was working long hours, the least I could do was be productive at home. I needed to continue to work on acknowledging how my body felt that day and give myself the permission to rest and heal.

I started to be more upfront about the realities of my life with a chronic illness. I did not see the need to hide my ostomy. I started writing a blog that shared I have a chronic illness and that my health has been a struggle, but it also focused on sharing that I was endeavoring to bring wellness into my life. I had previously worried if people thought Oscar was gross or if people could smell the distinct odor from Oscar. In our home, I no longer hid my ostomy supplies. The odorizer I use for Oscar remained on the counter in our home at all times. Not only was I admitting to others that I had an ostomy but I was admitting to myself that I had an ostomy. I realized that these fears had stemmed from previous conversations I had with family and friends. I had been letting their judgments and misconceptions inform how I viewed myself. I had been asked if Rob thought an ostomy was gross. My response was “No, but do you?” I had also been asked “Is it weird looking?” “Does it stink or leak?”

No an ostomy is not weird looking, it saved my life. Oscar is quite beautiful actually. And of course it stinks, doesn't all poop? Finally, yes it leaks, technology always has the capacity to malfunction. I continued to struggle about being honest with myself about my chronic illness but I had learned to become more comfortable with my needs and communicating my needs to others without feeling guilty or that I was less of a person. I struggled with always apologizing for the need to accommodate my health.

Since I had been off work and school for over 6 months I continued to experience comments that I struggled to find answers for and always felt I need to justify myself. “You don’t look sick.” I never intended to look like a sick person—I want people to see me. And quite frankly if one really looked, I had scars, an ostomy, and a port-a-cath. I questioned what being sick looked like. “You must be getting back to normal by now and getting better.” I have an incurable illness that includes an uncontrollable ostomy with many other severe symptoms from the illness, and a port-a-cath I used daily. I guess in a sense I was finding my normal but generally my normal was a lot different from what the people asking these questions expected.

Rob had realized the challenges of him working 6 or 7 days each week as a golf professional and the need to find alternative employment that provided support and flexibility for my health needs. Not only had my health been a challenge for him to receive support in the workplace but our quest to continue on with fertility treatment would require more time at home. For us, that meant Rob would leave the golf industry and return to school to pursue a new career. This was a difficult journey for us financially but it was a much needed change to improve our family life.

I was becoming more confident in my advocacy and awareness for those living with a

chronic illness. I continued to advocate for DIGITS awareness and my mom and dad were integral advocates for fundraising. My mom led fundraising for our gala and my dad inspired many donations and sponsors. I participated in awareness campaigns for people with chronic illness and ostomies. Finally I was being honest with myself and honest with others. I no longer felt that I needed someone to fix me but that I had the ability to actively participate in my care. I was finally learning how to live with a chronic illness and giving myself the much needed time to heal.

One day my dad asked “Wouldn’t it be nice if you were better?” Without DIGITS there would be no spasms, pain, cramps, overactive or underactive stoma, nausea, vomiting, bladder pain, incontinence, frequency and/ or retention, food sensitivities, medications, dehydration, osteoporosis, malabsorption, sepsis, and infertility. But then I would not be the person I had become and I was beginning to really appreciate my voice and provide myself with care and compassion. I was not afraid of DIGITS, I was not angry with my body. I was finally appreciating my story. This was the first time I did not know if it would be nice that I had not had the experiences that made my story.

Rob and I started to resume our fertility treatments in the late winter of 2013 and we still struggled with becoming pregnant. Since our IUIs had been unsuccessful, we began to prepare for the possibility of invitro fertilization (IVF). Pursuing IVF was a difficult decision because of the financial strain. We had already spent \$15,000 and would need at least another \$10,000. I was high risk for IVF because of my dehydration and a potential life threatening side effect from IVF treatment is ovarian hyperstimulation syndrome (OHSS). With careful monitoring and consultation we proceeded for with our first cycle of IVF. This first cycle ended quickly when my ovaries did not respond with enough eggs to harvest, resulting in us

cancelling the cycle after paying the costs of services and drugs we had accessed. We needed to take some time to free up additional money and I needed to take time away to allow my body to heal from the cycle I had just experienced. In that time away I decided I would return to work part-time and that I would continue with my graduate studies.

I once again tried to apply for ODSP for financial support through the upcoming summer months prior to me returning to work in the fall. Yet again, I was denied and a social worker shared with me that I am just one of those people that falls through the cracks. That was the last time I applied for ODSP funding and I again was reminded of the need for people with chronic illness to share their stories.

In the year I had taken off, I had withdrawn from the graduate institution I was enrolled in since I was facing barriers to being able to complete my doctorate in the ways that the institution had outlined. I needed more flexibility. I needed faculty support that was both useful, authentic, and from people that believed my success was possible as a person with a chronic illness. I did not need people to remind me of all the barriers I experienced because of my chronic illness and I did not want people adding new barriers. I decided to apply to the institution where I had completed my Bachelor of Education and Master of Education, where I felt faculty would support my endeavors as a graduate student with a chronic illness and appreciate the individual I am.

Embracing the Life I Have

I was hoping to resume working as a research assistant and had committed to returning as a part-time instructor in the upcoming fall. I had been accepted into Nipissing's doctoral program and would start my first residency in July. Rob and I had decided to start our second attempt of an IVF cycle in May. At this point I had no idea if we would get

pregnant but I continued to have hope and I continued to believe that we would have children. What I could not predict was how children would come into our lives.

A few days after my egg retrieval and then embryo transfer I started to experience symptoms of OHSS. I contacted the clinic immediately and I was closely monitored for the next 24 hours. By the next day my nurse had called stating I would need to be admitted to the hospital immediately. Because of the progression of my symptoms, both Rob and I thought there was no way we could possibly be pregnant. But we could not have been more wrong. Not only did I need to be hospitalized for OHSS but I was also pregnant!

I WAS PREGNANT! Both Rob and I were overjoyed! Finally, finally we were going to have a baby! I was in the hospital for over a week and every day I asked for my beta scores to ensure our baby was growing. Every day the nurse would come in and say “Yes Taunya you are pregnant.” While I was in the hospital we decided to share the news with our immediate family. We wanted them to experience the bliss we felt. We decided to wait until the end of our first trimester to tell people outside of our immediate family.

I started to experience pregnancy related symptoms early on but I was so thrilled to be pregnant that I was not about to complain about any of it. Because Rob and I were fertility patients we had an ultrasound scheduled every 2 weeks during our first trimester. Our 6-week ultrasound was when we heard our baby’s heart beat for the first time. Seeing the vibration of our baby’s heartbeat inside me felt like I had been given the greatest gift. Despite all of the health complications I had, I was going to be a mom. I was this little baby’s home, and this baby was our bright light. Over the years I had been focused on what my body could not or was not doing. Now that I was pregnant with Rob and my child, I was observing my body participate in all of these miraculous changes that all signified giving life to our child. I was

suddenly reminded of all the abilities I had, and that extended beyond the physical changes I was seeing and feeling, and also included my capacity to be well. I began to reframe the deficit lens I had viewed myself with a chronic illness in. My doctor appointments no longer consisted of what was “wrong” with me but rather encompassed all the beautiful growth that was occurring in my body.

I decided I would continue with my doctoral residency which would occur during the last four weeks of my first trimester. My family thought attending my residency was absolutely ridiculous but I was determined to continue on with my graduate studies and so I did. Rob helped move me into residence and I had elected to have a private room because of my health needs. Attending this residency also meant transferring my nursing care for one month. This was a huge process. My line care needed to be perfect and now that I was pregnant my life, and my baby’s life depended on it. Transferring my care was not seamless and took many phone calls, further documentation, and time to set up the care I needed. It was a very disappointing experience because I was trying so hard to continue with my aspirations but I was still being met with challenges. I planned on giving my graduate work my undivided attention for the month of my residency but what I did not account for was my changing health needs from being pregnant with a chronic illness. Not only was I nauseated all the time but it became increasingly difficult for me to manage my hydration needs. Consequently, there was a day that I missed all my classes because I was incredibly dehydrated. I required further medical care during this time. When I returned to classes the next day, while on a break, a professor shared with me that my absences would not be tolerated even if they were due to medical needs. I was reminded of how my chronic illness does not fit in with the professional standards I was required to meet.

During my pregnancy as I continued with my graduate studies and teaching, I realized that there is little information about being pregnant with a chronic illness. I was particularly concerned with being able to breastfeed while having a port-a-cath. I could not find any information about being a parent with that type of technology. My pregnancy went really well in terms of our baby developing and growing and we were elated! But the symptoms I continued to experience were unique to me having a chronic illness. Having access to information and support while being pregnant with a chronic illness would have been truly valuable. I continued to blog and share my experience because I wanted people to be hopeful about have a chronic illness and the potential for others to have a baby as well. I had met so many women who had felt that being a parent was something that was out of their reach and not for them because of their chronic illness. I wanted to share that being a parent is not only possible with a chronic illness, but it is an incredible gift.

I continued to experience negative opinions about being pregnant despite all of my health conditions but I was very quick to share that I had the help of many medical professionals who supported my journey to parenthood. While pregnant our baby hid behind Oscar. To me this meant acceptance and comfort by Oscar. It made us laugh every time we had an ultrasound and our baby would be comfortably tucked away and cozy behind my stoma.

Because of the realities of all the surgeries I had, we planned for a scheduled caesarean section but our baby decided to debut earlier and I had an emergency caesarean on one of the worst snow storms in January 2014. Early on the morning of January 25, we officially met our daughter and she was absolutely perfect. We laughed and cried through the whole birthing process. We were filled with love for her. The most incredible gift was being

her mom and being able to parent with Rob while getting to intimately know this beautiful human before us. I recovered quickly and was absolutely in love with our precious daughter. I learned how to breast feed with a port-a-cath and my worries quickly disappeared. From a very early age Cecelia would find comfort placing her hand on Oscar. She accepted all of me, technology included. I was her mom. I was finally starting to understand that the realities of my chronic illness do not change who I am.

Within the first few weeks of my daughter's life we said good bye to my Oma. I was very close with my Oma and am also very similar to her. She instilled in me the value of family traditions and reminded me of the importance of being a mother. Our fertility journey has instilled in me a great deal of gratitude and I truly view being a mother as the ultimate privilege in my life. My Oma and Opa have provided my sister and I with an invaluable gift—time. It was upon her passing that I realised the magnitude of the gift she and my Opa had given us. They were always there for us, from the day-to-day events, to celebrating the magic of the holidays. I learned about the significance of being together as a family. Since my Oma has passed I miss that the most about her. I miss her presence and knowing she is there. I believe she continues to live in all of us and even my daughter has displayed mannerisms that remind me of my Oma. For those moments, I am grateful.

My sister and my relationship is reflective of what we have learned from our Oma and Opa. She has been an omnipresent individual in my life. Over time we have become intricately connected and are always there for one another. We feel what the other feels and know each other to the depths of our souls. She embodies strength and wisdom, and is always adamant about how I need to protect the delicate balance of my health. At times when I have

been stubborn and unwilling to accept who I am, she has been there to remind me of what I can do. Our relationship is one of my life's greatest gifts.

I do not want Cecelia to live in fear of my chronic illness and I do not want her to fear my chronic illness becoming worse. One of the realities of my illness is there is no cure and for some patients, it continues to worsen. Although a rare chronic illness, the mortality rate remains high. I worry about my impending future. *How will I care for our daughter and myself with all of my health issues? How will I care for myself and our daughter with the health issues that may come?* In response to my fears, caring for our daughter has come more naturally to me than anything I have ever done and I have never felt more grateful for the life I have. Being her mom has been the most incredible gift. Our life is different but we continue to adapt as a family and learn each day.

Prior to giving birth to Cecelia, I thought I had accepted and adjusted to life with a chronic illness but as I reflect on how I viewed my body, I still thought I was broken. I still felt that I needed to be fixed. Cecelia has helped me see and believe that I am not broken but am exactly who I need to be and that I am whole. I am there for Cecelia—every day. She patiently watches as I change Oscar or hook up to my IV. My port, Hope did not get in her way and she spent much time looking at it and touching it. There are times when Cecelia cries through my dressing changes, Oscar leaks at the most inconvenient times, and there are days when I am not feeling well because my symptoms acting up. I feel guilty because of my daily needs as a result of DIGITS. But then, as we both settle down together with cuddles from being upset, I know in my heart that we will get through this together.

Cecelia's first year of life was full of changes in our family. I continued to work as a part-time instructor since I did not have enough hours to qualify for maternity leave. Nothing

could have prepared me for how difficult it was to go back to work after Cecelia was born. Even though it was only a couple times a week for a few hours I still found it to be extremely difficult. The realities of the money we spent on fertility treatment continued to follow us. We needed to start getting ahead and that meant needing work. I had always thought by the time we had children I would stay home but this was not our reality at all. We had spent thousands trying to conceive and needed to combat our debt to keep our family afloat. As much I hated every minute of being away from Cecelia, I knew that I needed more than ever to continue with my schooling and professional aspirations to provide more for her.

Cecelia traveled to North Bay with me while I completed the second doctoral residency of my doctorate program. We had the support of my sister and mother while I was in classes. Rob had planned some vacation time but ended up with an acute illness of his own so we continued to rely on the help of my mom and sister. Completing my second PhD residency was quite the adventure since Cecelia was 5 months old and we were living in residence. Although there were some challenging times with balancing being a new mom with the role of a PhD student in residence, I am grateful for those moments. My mom and sister had the opportunity to bond with Cecelia and we had a lot of fun together. Cecelia adapted wonderfully to residence and we still laugh about her young residence experience.

When Cecelia was 3 months old I applied for a full-time professor position at a local college. I was hoping for an interview, and not only did I receive one but I was offered the position. Cecelia was 6 months old when I began my position as a full-time professor. That position also came with a short out-of-town residency so Rob, Cecelia, and I spent a few more days in residence. I found this experience to be a lot more tumultuous. The days were long and I would rush back during our lunch hour to snuggle, feed Cecelia, and pump. These

days were the longest I had ever been away from her and I really questioned if I was making the right decision. I recall people saying *you tried so long to have her, I can't believe how quickly you are returning to work*. I found this to be a very frustrating observation. Not only had we accumulated much debt from fertility but we did not have a lot of financial stability. I was offered a salary, benefits, life insurance, and a pension. We had never had the security this position offered. I was committed to being able to sustain my role as a mother and wife, graduate student, and now as a professor.

My Expectations or Theirs?

I had once again lost sight of myself. I quickly fell back into my old beliefs that I had to do it all be an incredible wife, mother, and full-time professor, all the while pursuing my doctorate. I had a full-time job and got caught up in external demands. I had wanted to be the best for my family but was relying on measures of productivity to define what best meant. I had forgotten how unrealistic the expectations I had on myself were. The stakes were too high but I did not see it, I did not stop for long enough to check in and listen to the intuition I had nurtured and valued. I had quickly fallen back to old habits I thought I had rid myself of. I was suddenly clinging to what I could do without taking the necessary precautions to sustain my well-being, my health. I felt the pressure of having an incredible job and the requirement of me being able to work the 45 hour work week that came with it. When I was not working, all my attention and energy went to Cecelia.

At times I am able to work from home and also have flexibility of when I work. When I started my position Cecelia was 6 months old. Rob also worked from home at the time. We planned accordingly, and if Cecelia was not with one of us she was with her grandmother for a half the day. I was, and continue to be, completely in awe of her. Many

times I would fall asleep with her at bedtime. Often, after I had fallen asleep with Cecelia for a few hours, I would get up and finish my work day. I am thankful for the ability to adapt when I work outside of class time but working quickly became all-encompassing for me with my health needs. My energy was dwindling rapidly and my symptoms were increasing in severity. I had continual colds that lead to the flu. My life was completely out of balance. I was not taking care of myself. There was always one more thing to do. When I was not at work I was exhausted and our family life suffered because I was not well enough to participate.

In the fall of 2014 I was hospitalized with a severe case of the flu. I was in isolation and was not able to see Cecelia for days. I was still nursing Cecelia so Rob brought my breast pump and supplies. I would pump at the hospital and Rob would bring breast milk home for Cecelia. My sister primarily cared for Cecelia by staying in our house and my mother-in-law also stepped in to help. I felt incredibly guilty for my health. *How could I let this happen?* The reassurance I was given about how “sometimes people get the flu” did not help. I needed to be more mindful of my health. I had failed and I needed to take better care of myself. While in the hospital, I would Skype with Cecelia. It was amazing to see her but difficult because I was not there with her. As her mom, I simply just wanted to physically be with her. She is a radiant human filled with love. I struggled with how I would continue to balance my family life with my work and maintain my health.

Not only did I want to support Cecelia as a mother, I also want to provide for her. Rob and I have lived for years barely getting by and accumulating a lot of medical debt. My position as a professor offered us the financial security we had never had and we wanted this for Cecelia and hopefully for future children. I was more than qualified for the position I was

in but I struggled with the physical realities of my chronic illness. I struggled with the literal time commitment required while trying to maintain my health.

When I returned to work my responsibilities had piled up while I was away ill. My desk had stacks of paper waiting for me. I was extremely overwhelmed and shared this with my superior. From our conversation I learned a valuable lesson about making my position as a professor work for me and being more careful about what I followed along with. If I had an objection that was unrealistic for me, I needed to state it, otherwise I was the only one who suffered. As difficult as my first term was, being sick during that time reminded me of the necessity to stay true to my needs no matter how hard it was to admit as a as new faculty member.

I made it through my first fall term and honestly had the words “never again” running through my head. That term was treacherous and I had learned a great deal about my role and how I would continue as a faculty member. The courses I instructed were now created with both my students and my needs in mind. When I taught courses with other faculty, I ensured that I did not compromise my own needs. The term had a completely different tone and I was keeping myself afloat. Rob had decided to continue his role in the company he was with by working in their office, which meant he would be commuting every day out of town. We had decided this was his best option because this role offered further opportunities for him. We decided Cecelia would start in the child development centre that is provided on campus. Having Cecelia in childcare was a much needed routine for our family. We struggled making arrangements for family to help care for her and we needed a dependable option that allowed for last minute care. I continued to work in the evenings once Cecelia was asleep so she would not be in childcare for too long each day.

We had embryos frozen from our egg retrieval and we wanted to try for another baby. I started hormones in February and we had an embryo transfer mid-February. The day after the transfer I woke up not feeling well. It seemed I had developed another cold. Luckily it was reading week and I had a few days to rest and recover.

What I am about to write about next is the most difficult part of my story because of the realities and truth of the story. To maintain the authenticity of my narrative I have bared it all but what I will share next is the most devastating reminder of the chronic illness I have. I have been avoiding writing these memories. I have had this journal out for days but was afraid to open it, I was not ready. It has taken me much courage to expose this part of me and my life. I was fearful of reminiscing, afraid to relive the depths of my sorrow.

I did not recover from the cold. Instead, I continued to get worse. One night, about a week after the transfer I woke up with a high fever and chills. *This wasn't happening. It was just the flu right?* I immediately took some Tylenol. My fever broke the next morning. I called the fertility clinic and they said I needed to keep my fever down. My regular nurse was off and a nurse came shortly after to access my port. I shared with her my symptoms and she agreed that they sounded like the flu. It was not the flu. I had not realised it yet. The next day, I was still ill. I decided to stay home with Cecelia. Rob said in the morning, "Are you sure you are okay?" "Yes" I had replied, "I will be okay." Since my fever had broken I thought I was recovering from the flu. I decided to hook up for my hydration and then it happened—a dreadful sepsis chill, my whole body uncontrollably shaking, I could barely think, talk, or move. I was home alone with Cecelia. *Need to stay conscious. Need to call for help.* I somehow managed to call Rob. Help was on the way. This was not happening, this could not be happening. Not now that I could be pregnant. *What if I was pregnant? What about our*

potential baby? I was lying down convulsing, Cecelia sat patiently on my lap. I felt her warmth as my body shook with chills. My mother-in-law arrived and she took me to the hospital.

On our way to the hospital, tears streamed down my face. “I might be pregnant” I said. A few moments later I uttered, “We wanted to surprise every one and decided to keep this transfer quiet.” “Oh Taunya” she said. “Hopefully it is just the flu.” I think we all knew at this point it was not the flu. I asked my mother-in-law to stay with Cecelia. I would be fine on my own. “Please just drop me off” I said. By this time my chills had passed and I now had the follow-up sky-high fever. I was overdressed and I needed to get into cooler clothes. When I met the triage nurse in ER I was extremely upset. I was met with no sympathy, no empathy. I asked for a hospital gown to change out of my warm clothes, my fever was dangerously high, my heart was racing, and my blood pressure was extremely concerning. “No” she continued to reply. “I have been through this many times before, I need to try and get my fever down, and can I please have a hospital gown?” I was crying and visibly upset. I would need to calm down she said. *Of course.* Then I shared that even when no beds are available, when sepsis is a potential I usually will have blood drawn immediately. To that I received another “no.”

I was admitted into ER fairly quickly and one of the first questions the doctor asked was have you had blood taken. This was such a frustrating moment because I knew what I needed in terms of my care and people within the medical community wouldn't listen. “Not yet,” I replied. The doctor agreed my symptoms were indicative of sepsis and he was going to admit me and start treating me for sepsis right away. A short time later, the doctor returned and shared with me that I was pregnant. This news came with such joy but was met with concern. I was pregnant and potentially had a very serious line infection. I kept repeating,

“We are safe, we are healing.” The most difficult aspect of having a line infection is the amount of time it takes for my blood cultures. It takes time to see if it will grow in the lab. Although, I was being treated for sepsis with antibiotics, my symptoms continued to rage on. Two days later it was confirmed—my line was infected. It needed to be removed immediately. I would need another antibiotic as the bacteria was not responsive to the one I was on. This was my worst nightmare. My chronic illness had threatened my pregnancy. *How can this be happening?* I did not understand.

Prior to being released from the hospital I had multiple conversations with doctors about the risks of having a central line. Nine times I had been septic. No line was safe for me. What were we going to do? Peripherals were the only safe option. “What about our baby?” I had asked. No one had an answer. I continued to cling to hope. I was released and was finally able to see Cecelia. I missed her so much. My heart ached that this was our reality. We had Skyped and she smiled and would kiss the screen. Yet again, my chronic illness had taken what is most valuable to me. Time.

I had been home from the hospital for 2 weeks, when one morning I woke up not feeling well. But I continued on with our morning routine. Cecelia and I got ready and I headed to work, still not feeling well. *Morning sickness? No, too bloated with major cramps.* “We are safe” I told myself, “the worst is over.” All of sudden I had two sharp pains in my lower abdomen and back; I rushed to the washroom. I was bleeding. *No!* Many tears fell. *What am I going to do?* I called our clinic and left a message for the nurses. I had to leave work. I let the childcare centre know that I would be off campus. “Is everything ok?” I lied and tried to hide my tears. Kept bleeding. *No! Please No!* I pleaded inside. The clinic called, I was to come in for an ultrasound. During the ultrasound, a doctor came in and held my

hand. She said “You are miscarrying.” I was sobbing. This was my fault. No one knew the cause of our miscarriage. It just happened. I was very ill and my fever was incredibly high which is very dangerous for a developing embryo. *My inadequacies, my chronic illness. I am so sorry Baby. Please forgive me.*

When we got home, Cecelia reached for me. She truly is proof of the miracles of life. I was filled with sorrow and gratitude. She was ours. She was healthy and I was there with her. Rob picked up Gemma. “We need a family hug” he said and wraps his arms around us. Tears flowed as I breathed in our family. My sister had called on our way home from the clinic. “Can I come over?” she asked. I told her it was okay that she had a long day from work and commuted so she did not need to come. She said, “I want to come over and just be with you guys.” I understood. “Of course” I said. That night, Cecelia took her first steps. Rob, my sister, and I were all together to share the joy of Cecelia walking for the first time up and down our hallway. A miracle, our darling girl took her first steps. We all held out our arms to catch her and we were filled with laughter and tears.

It took me a week to say the word miscarriage and I still struggle with it. I was blessed to be a mommy to our little baby, even if it was only for 6 weeks. Our baby was here for a reason and has changed our lives. I will forever be grateful for the joy, and faith our little baby brought us during a time that is usually filled with sickness and fear. I continued to have appointments with doctors stating that this was not my fault. But when I thought of Cecelia, I wanted to be there for her in every way that I could. I needed to find a better way.

Creating Space for Chronic Illness

I started to ask myself *what if I stopped trying so hard to be normal and just let myself be. What if I gave myself time to eat, sleep, walk, write, and be with my loved ones?*

Rob, Cecelia, Gemma are part of my identity and how I define myself. Loving them has become as natural to me as breathing. It does not matter how much pain I endured, how much my chronic illness continues to advance because I am living through the beauty of my family. My family helps me be a better human and has given me the gift of unconditional love. Their ability to love me has taught me how to love myself. My most recent infection meant that having a central line was too risky and would ultimately lead to my death. I never want to experience having a line infection again—the risk is too great. Nine times I have been septic. That has been nine times my life came very close to stopping. But I struggle with dehydration—I need to stay hydrated to live.

A new idea was presented; what if my body could learn to absorb more fluid? What if I limited my activities so I did not require as much IV fluids? What if I stopped over extending myself and I learned to live well with my chronic illness. What if I slowed down and I practiced serenity, at all times not just when I was overwhelmed and hurting.

Not having a line meant being able to plan a vacation with Rob, Cecelia, and Gemma. We had not been on a vacation for longer than a weekend in 8 years. My twice-a-week nursing visits made it impossible to plan an extended trip. During this past summer we went away for 8 days to a cottage that we rented. I went swimming for the first time in 8 years. I grew up spending my summers in the water and absolutely love the feeling of being submerged in it. I have missed the weightlessness I feel when swimming, the tranquility, and the healing nature of water. Not only was I able to go swimming on our vacation but I was able to take Cecelia to swimming lessons. The first time I took her, I cried, full of joy. Cecelia was not pleased to be in the cold pool water with the instructor and being told what

to do in the water and still I smiled full of pleasure. We were swimming together. Previously I thought this would never have been possible.

Our vacation took a lot of planning and we still needed to be very mindful of where we traveled. I do not qualify for travel insurance so we opted to stay close to home. Also, I was still having two nurse visits a week but we were able to make a plan for when we left on our vacation with my nursing visit and I had my IV in for longer during our vacation as a precaution to not have to come home early. In the instance we did need to come home early, we were only a few hours away. Going on vacation with our family was absolute bliss. Vacation had become something that was outside of our means both time wise and financially. We were finally at a place where my health care had changed so we could take a vacation and we had the financial means to book a vacation. We savoured being together for uninterrupted family time. Our vacation was truly rejuvenating. So often I hear people complain about where we live and how other places in the world have so much character and places to explore. I have never felt that. I feel fortunate we live in a place where in a 2-hour drive we can escape to cottage country and still have access to medical care. I am so grateful for the close proximity for us to be able to vacation and explore in nature.

While I was on my vacation from work, I realized how much my activity level had changed from not being able to have as much fluid to maintain my hydration. Reducing my activities at home meant reducing my work hours and being more mindful about commitments I made. I had to be more aware of how I exerted myself. I needed time to see how I would manage with smaller amounts of fluid. It was time to slowly wean down the amount of IV fluids I used. I was still in my first year as a full-time professor. I did not want

to be labelled as a professor with a disability. I did not want the baggage that comes with being identified.

My doctor was adamant about being realistic about my accommodations and with my history of not adhering to my own needs, I followed his lead. In one conversation with my doctor I shared how I worried that I was not following the normal workload as a full-time professor. I worried about how I would be judged as less committed to the profession. He simply replied, “Taunya you are not normal. I don’t understand the complexities of your health needs and you can’t expect the people you work with to understand.” This comment was ground shattering to me. All of this time I realised I was trying *so* hard to be normal. I was trying to make my life with a chronic illness fit into the normal I perceived everyone else to have. I had it all wrong!

I never realized how much I needed the flexibility to accommodate my chronic illness *to stay well*. It has been challenging to figure out my fluid needs with peripheral IVs but I have made a lot of progress. I learned that I needed time to be well. I needed to listen to my body’s needs and to attend to my needs. I had severe episodes of dehydration but I began to learn what my norm was through trial and error so I would be able to thrive. I learned that I needed workplace accommodations to sustain my health. My accommodations did not influence my capacity as a professional and did not relate to my commitment or my qualifications.

I needed to reinvent myself. I had reawakened to a new understanding of life. I had finally given myself permission to heal. I had let go of my fears of my chronic illness and opened my heart to love and be loved. Through my personal wellness I was finally able to fully experience each moment of my life. Love has governed my healing. In every moment I

now tried to come from a place of love. When I am not coming from a place of love, I ask myself, *why am I doing this?* Through this process, I have learned it is okay to let go. I have let go of the pain I have endured, I have let go of the anger I have had. I know that the people I share my time with see me for who I am and that over time, the people who do not see me for who I am have faded from my life.

Now I am comfortable being seen with an ostomy. I do not panic if people know that I have one. Wearing a bathing suit does not make me cringe and my heart beat rapidly. I let my bag literally hang out. It is uncomfortable and hot to have it jammed down my leg and the plastic of the bag has cut my leg in the past. There have been times I have gone out to run errands and forgot to tuck my bag back in. The first time I forgot I was mortified. But it has happened again and again and I now think *who cares!* Yes I have an ostomy. I have a life because of my ostomy—my ostomy should be celebrated, not hidden.

I have habilitated my life which has included taking the time I need for my body to be healthy ALL of the time. I never stop telling myself that I am healthy, that I am full of life. It may not be in the way I once envisioned living but I am living! My body is my shell and at times my body has difficulty expressing the essence of who I am but I am bigger than my body. I am grateful for the body I have, the body that has made my life possible. I try my best to live my life one moment at a time. I am still learning how to be fully immersed and present. I used to value my ability to multi-task and do it all. Now I value my ability to attend fully to what I am experiencing. I know my daughter has taught me the value of living fully in the moment. I am a person with a chronic illness and I am in love with the beauty that surrounds me in my life.

My Oma used to always tell me that she wished I did not have to suffer, but through my suffering, great transformations of love, strength, compassion, and wisdom have occurred

within me. My chronic illness has helped me restore my sense of wonder, and live with purpose as a wife, mother, and academic. I define myself as healthy with an incurable chronic illness. I believe I have the tools within myself to continue to live a fulfilling life with much meaning.

Writing this narrative has been a journey that not only involved revisiting, but also reliving experiences that I had not only forgotten but had tried hard to forget. Sharing my narrative has given me the opportunity to view myself and my experiences in an alternative light. I have let go of the anger I had in response to my experiences and have let love and compassion for the experiences I have endured, fill me. I come from a place of love and compassion for how chronic illness has not only affected my life but the lives of my loved ones. I am creating a life that values time, which I am present in, and that includes me living well in my own capacity as an individual with a chronic illness. I continued learning ways to live sustainably to maintain my needs. I know that my struggles have not only been my own, but have had a great impact on my family, especially Rob and Cecelia. I know that hardships will continue to be faced and hard days lay ahead but I also know that the extraordinary gifts my life has been filled with will give me the strength I need to persevere in times of pain and uncertainty. Reframing chronic illness means I never want Cecelia to feel the negativity and burdens that life with a chronic illness can consist of. I hope she sees through the negativity and sees the extraordinary gifts that our lives are full of.

When I reflect on my life, my chronic illness influences much of my life and who I have become. I know that I have become stronger, kinder, more compassionate, more appreciative, and more aware of the life I have. In a strange way, my chronic illness has made my life better. I have experienced how powerful love is, how precious time is, and how beautiful life is.

Chapter 8: Findings

By reviewing a collection of field texts from my life, I composed my narrative of living with a chronic illness in chronological sequence to uncover how I understood my life with a chronic illness. Thematic analysis (Ellis, 2004; Wiebe, 2009) was used to code my narrative to illuminate themes within my story. Thematic analysis edifies the content throughout my narrative and seeks to develop common themes throughout the narrative (Ellis, 2004; Clandinin & Connelly, 2000). Themes were elicited from reading and rereading the narrative in its entirety. Through thematic analysis my narrative was deconstructed into themes and further subthemes. During the coding process I compiled themes that had emerged from the narrative and organized the themes into connected clusters. From coding my narrative three themes emerged, with 12 subthemes. The following table includes the overarching themes and subthemes within this research study. What follows is an explanation of each of the themes identified along with corresponding subthemes.

Table 1

Themes

Issues of Identity	Extraordinary Gifts I Have Received	Tensions in Understanding Chronic Illness
– Fix Me	– Hope to persevere	– My fear of chronic illness
– Identity crisis	– Learning to love	– Provisions for chronic illness in silence
– Searching for myself	– Mindful of my time	– Renewed understanding of chronic illness
– In pursuit of acceptance	– Gratitude	
– Reconciling my identity		

Issues of Identity

My narrative is a detailed account of the experiences I have had while living with an illness. From first experiencing the symptoms of what I believed to be an acute illness to learning that I had a chronic illness, I felt many emotions from fear and hate to love and acceptance. The experiences I have endured from living with a chronic illness have been complex and multifaceted, and have affected my perceptions of myself and ultimately my identity. The subthemes present within the issues of identity theme include: fix me; identity crisis; searching for myself; in pursuit of acceptance; and reconciling my identity.

Fix me. Initially I believed my symptoms were acute in origin and from this presumption, “I told myself I was going to get better and all would be well again.” When I did not recover to my previous state of health, “I was devastated ... I wanted to return to my life and all that I loved.” I was consumed with the physical aspects of being in pain and wanted to be rid of the pain I experienced, while often wondering why this pain was happening to me. My life during this time was concerned with fixing me to return to being healthy. “I was afraid that I would not return to my normal healthy life and was desperate to get better as soon as possible ... in response to our wedding being postponed now more than ever I was determined to resume my health.” I continued to search and anxiously waited for the advice of medical professionals. Whatever they suggested I try, I did. In the beginning their suggestions included many medications and I swallowed each pill hoping it would be the fix but, “I didn’t notice any changes with the pain ... I was living in a fog.” When the initial discussions about having chronic pain emerged I was furious and would not entertain anyone who had that opinion. “My life was dependent on the medical community fixing me,” and so I waited.

When I received confirmations from the College of Physicians and Surgeons and I received thoughtful letters and responses from the medical professionals I had complained about,

I didn't feel any better ... I didn't want a statement that defended their stance and finally acknowledged my pain. I wanted them to realise that not knowing what was physically wrong did not mean stating harsh assumptions about my way of being. I didn't know how to be, I wanted to be fixed, and I was desperate.

I was so consumed with wanting others to fix me. I thought that was what being a patient meant but as suggestions of my symptoms being chronic in nature began to surface, I transitioned from wanting to be fixed to undergoing an identity crisis.

Identity crisis. The identity crisis theme is weaved throughout my initial days of my undiagnosed illness and when I first learned of my illness becoming chronic. There were times when I clung to the characteristics of the healthy person I had been, and times when I questioned the authenticity of the life I had as a healthy person. Although I continued to search for the answer to resume to my previous state of health and life, I slowly began to integrate changes into my life. I reduced my school course load, left my part-time employment position, and began to utilize accommodations in attempt to decrease my current state of pain. When I began to meet with a counsellor and I slowly began to think about all that I had experienced with this pain in my life, if I could return to the life I was living, "Would I want to? ... All of the ways in which I had defined myself while I was healthy had disappeared ... I didn't know exactly how I had changed, but I knew I had." These days were difficult and time passed slowly. I didn't know what to do or how to be. Although I wanted to keep those around me happy, I was filled with loneliness and pain. I realised that I didn't

know who I was and, I had defined myself by who surrounded me ... I needed to prepare myself for being able to live with pain.” And yet, “my outgoing demeanor had become shy and withdrawn. I didn’t know how to be and was uncomfortable with my own body ... and internalized my pain and illness as being all my fault.” The continuous doubt I received regarding the psychological rather than physical origins of my pain had a substantial impact on my identity, “[it] was infuriating and emotionally damaging.” I realised that, “no one was seeing me ... I would not return to the person I was and it was time for me to let go.” It was time for me to explore who I was and to re-create my identity.

Searching for myself. I was relearning who I was and began to understand the importance of self-care, but before I was able to care for myself, I needed to explore who I was and who I yearned to become. When I began to learn about holistic wellness, I realised that pain is not only physical but can include emotional and spiritual health. “I had been consumed by focusing on the physical aspects of pain. ... I started attending restorative yoga and meditation classes to introduce my body to relaxation and healing that was outside of traditional medicine.” Finally I was able to see that I could experience wellness by engaging in certain practices and “there would be much more to my life.” I began to explore options, and “I was beginning to plan for a new life and I felt calm knowing that I could move forward, just in a different way.”

Despite my optimistic beliefs, limitations of living with pain continued to surface. I had discontinued some medications and experienced severe withdrawal. I had become financially dependent on my parents since I was unable to work. I still struggled with finding a way to live and define myself. I returned to school as a student with health needs when I

was used to being a healthy student. “I struggled as self-identifying as someone with a disability.” I began to learn that I didn’t know myself all that well.

Within this theme of searching for myself, my narrative explains that I continued to search for support and help to rid myself of my symptoms. When I had been told to “learn to live with it” at a pain clinic, I still believed this to be an unacceptable option. “I wasn’t ready to hear that living with pain was now my reality.” I continued to experience different treatments, but it was during my bladder installations when I began to comprehend the chronic element of chronic illness. “Chronic meant relapse, it meant recurrent, it meant here to stay.” I continued to view my body as an entity that continued to betray me when treatments did not work, when symptoms progressed, and when questions remained unanswered. During this time period there were many insinuations that my illness was psychological with no physical origins. Although I was displaying highly emotional responses, I was frantic to find the root cause of my physical pain and symptoms when, “the words anorexia, anxiety, depression all lingered in the air.”

Meeting Dr. T. was formative to helping me understand and accept my body. He offered what no other medical professional had; an answer. He was the first to say “I understand.” He recognized that I was a young woman who was both anxious and frantic to resume her life. He provided me with the utmost medical care but also cautiously prepared me for the potential of being diagnosed with a lifelong incurable illness; “Dr. T. continued to prepare me for the fact that SMA syndrome is often a secondary condition.”

In pursuit of acceptance. In pursuit of acceptance is a subtheme that encompasses my quest for acceptance after I had been diagnosed with a chronic illness. What is important

to note is my acceptance of my life with a chronic illness did not occur at once but was fraught with mistakes, relapses, and fragmentation.

Mistakes and relapses. I started to begin to understand the complexities of having a chronic illness when I received confirmation of having the motility disorder, DIGITS. Prior to this time I remained hopeful that I would somehow find a way to avoid living with a chronic illness, which is odd because I had already been diagnosed with the chronic bladder condition, interstitial cystitis. Until I had a full diagnosis of all my symptoms I did not want to acknowledge my life would forever encompass a chronic illness. I left the hospital knowing little other than I would live with this forever. ... *How was I going to continue my life? When would the illness stop? Would it continue to advance? What would my life look like?* I was consumed with trying to find a definitive answer to being able to live with a chronic illness. It was very challenging for me to understand and make sense of the uncertainty that came with the diagnosis of the chronic illness I had.

When I decided to resume my Bachelor of Education, “the realities of my chronic illness were setting in and I knew that even if I wanted to be a teacher, the likelihood of me being able to sustain a full-time teaching position with my body was incredibly unrealistic.” When I was unable to eat and required a central line to administer TPN in the hospital, “I was willing to learn whatever I needed to so I would be able ... to live my life outside of the hospital.” And when I was discharged from the hospital I believed I would live the rest of my days on TPN with a central line. Beginning to accept my chronic illness started to resonate with me internally but “I was extremely worried about how people would perceive my health needs.” I did not want people to know about my chronic illness, and I was not comfortable talking about it. When my chronic illness required further intervention and an ostomy was

suggested, “I was petrified.” When I had I elected to have an ostomy, I did not want anyone to know because I feared their thoughts and judgments.

Not only was I fearful of the judgments of others but I was also fearful of myself. While I could articulate that I had a chronic illness and what my needs were, I didn’t like looking in the mirror, and I most certainly did not want people to be looking at me when I couldn’t look at myself. I was still struggling with the betrayal I felt towards my body for having an illness. I struggled with what I looked like sick. I didn’t resemble myself but rather was a weak, gaunt, and frail version of myself. I was ashamed of what my body had become and didn’t want anyone to see me and validate how much I had changed.

Once I was home from the hospital, I rid myself of all my clothes that I could no longer wear, “I did not want to be reminded of what I used to be able to wear” and I wanted to hide my ostomy. My life with an ostomy had drastically improved my health. I was no longer on a feeding tube but I was extremely uncomfortable with identifying as being person with an ostomy. “It took a long time to be comfortable with having an ostomy and seeing my new body ... I was completely ashamed of what my body had become.”

When I shared my experience with chronic illness with my professor, I encountered a completely different experience than what I was used to. My professor valued my experiences, and “advocated for me to present at a conference.” It was through this experience I learned the value of sharing stories and that my story was not something I needed to be ashamed of. I continued my education because I was curious about how others were living with their chronic illness. I became so immersed that at times I forgot that I too had a chronic illness. “From 2008 to 2012 I would have numerous central lines, and I would

have eight bouts of sepsis. I would continue to struggle with how I could live with my chronic illness.” What I had yet to understand is that although I had accepted and could articulate I had an illness,

what I didn’t understand was that I could not control my illness. Despite what I thought, I needed to have accommodations in my life. I needed to not only acknowledge my illness, but I needed to find ways that I to live with my illness without experiencing life threatening infections.

I continued to persevere with my life goals but “I was sensitive to the stigma of how people viewed me with a chronic illness.” I was not going to let my chronic illness prevent me from the life I wanted and that included pursuing education, becoming a parent, and obtaining a position in academia. “It seemed we had established some sense of normalcy. Unfortunately this sense of normalcy was short lived and my body had other plans for me.” The health lapse that included multiple sepsis infections and cholecystectomy surgery was a compelling reminder of the fragility of my health.

I was frightened by how quickly I could become so ill and by how few options remained for my survival. ... I struggled with how I would continue to create a meaningful life. ... I learned that I very much wanted to live.

And yet, even after this surgery I became immersed in doing too much work and taking on too many school commitments, while also wanting to start a family with my husband. “I was proving my self-worth. ... I continued to ignore my body, my symptoms, and my intuition.” Once again, I became extremely ill with sepsis. “Sepsis killing me was my new reality.”

After having sepsis eight times, I drastically changed my life. I halted my academic studies and career pursuits. I spent time figuring out how I could live. “This was the first time

I realised that I had spent years hating my body and trying to prove that I could do everything—that I was stronger than my chronic illness, and I would not succumb to it.” I started to reflect on how I had lived my life and realised that I needed to change my ways but I was uncertain how. “I struggled with how I would create meaning. ... I had spent 8 years fighting my body.” Even though I knew it was essential that I change my way of life I worried about what others would think, would ask, and even more than that “listening to my body proved to be a lot harder than I thought.” Over time while focused on restoring my health, I became “more confident in my advocacy and awareness for those living with chronic illness.” I also “was finally appreciating my story” and the experiences I had as a person with a chronic illness. I felt comfortable and ready to return to academic and career pursuits, and what I was most excited for was resuming my path to parenthood with my husband. Becoming pregnant and bringing our daughter into my life has instilled monumental changes in learning that “the realities of my chronic illness do not change who I am.”

Our life had a lot of changes during our daughter’s first year of life. I continued to pursue doctoral studies and I accepted my first position as a professor. It was during this year that I lost sight of what I had learned about maintaining my health. I resumed “my old beliefs that I had to do it all.” Once again, “I was suddenly clinging to what I could do without taking the necessary precautions to sustain my well-being, my health.” I was torn between the expectations of being a professor, the security the position provided and maintaining my health. “I was more than qualified for the position I was in but I struggled with the physical realities of my chronic illness.” I continue to persevere and learn while my husband and I decided to try for another child. Just after our embryo transfer, I became ill with sepsis. This was not supposed to happen. We thought my port-a-cath was a safer option, I had the line for

almost 3 years with no struggles. We were pregnant and I was septic. “This was my worst nightmare.” We continued to hope for the best but ultimately I miscarried. After enduring my ninth infection from sepsis, “I needed to find a better way.”

Fragmentation of inner dialogue. My narrative is fraught with fragmentation. Moments when my unconscious was at a juxtaposition with what is occurring in my life at that time. My inner dialogue was feverishly trying to make sense of what is happening at that moment, and trying to understand those difficult instances. Upon my initial symptoms my internal dialogue included “Why me?” I believed that there had to be a valid reason for me to be experiencing pain. Over time, as a consequence of hearing skepticism from many health professionals, my internal dialogue changed to “How could I make this pain up? How could I be in this much pain and there be no reason for it?” My inner voice is present all throughout my narrative and is burdened with tensions between my unconscious and my reality. I wondered, “if only I didn’t get sick.” I initially feared, “How would I share with our children the realities of my chronic illness ... and how was I going to live day to day?” Even more so, there are moments in my life that remain to grieve, to revisit, to document, and to analyze. Experiences that remain raw and disjointed. Tender moments that I have been unable to refine. Examples of these times included my previous relationship, “What if I didn’t get better? Would he still love me?”; my fears of living “stuck in pain”; and the guilt I felt as a result of the pain my chronic illness has caused: “How could I let this happen?” The most prominent example of my raw emotions was when my husband and I experienced a miscarriage, “My inadequacies, my chronic illness. I am so sorry Baby. Please forgive me.”

My journey to acceptance has been long and complicated. I thought time and time again that I had accepted my life with a chronic illness but I had not. I continued to

jeopardize my health because of my own unrealistic ideals and the ideas I felt from others. It has only been in the last year that I finally had a firm understanding of my needs, of what my life is like with a chronic illness, and the understanding that I am human being who is competent and capable in my own way. Even with a positive mindset that focuses on my abilities it is important to consider that these moments remain to be fragmented in my life and filled with emotions that are challenging to feel.

Reconciling my identity. In the last year I have continued to pursue my career and advocacy aspirations, my dissertation, and most importantly, I have been the wife and mother I want to be. In this year, I have drastically changed. The changes have not been obvious but I have finally come to a time in my life where I have “just let myself be.” I learned that I am living in every moment “through the beauty of my family.” “Their love has taught me to love myself.” *So how would I learn to act in a way that would honour my way of being?* I began to wonder, “What if I stopped over extending myself and I learned to live well with my chronic illness? What if I slowed down and I practiced serenity, at all times not just when I was overwhelmed and hurting?” I started a new plan and was able to live in a different capacity. My days required less but the moments I was able to engage in were richer. I was able to go on vacation and take my daughter to swimming lessons. But these changes meant a reduction in my day-to-day life. I needed to ensure I was reducing my activities and that included work. At first I was nervous. “I worried about how I would be judged as less committed to the profession.” But I learned that, “I needed time to be well.”

I had reawakened to understanding my life with a chronic illness. “I had finally given myself permission to heal ... I had to let go of my fears of chronic illness and opened my heart to love and be loved.” I am now comfortable sharing about my chronic illness; it is a

part of my life and my chronic illness is my norm. “I have habilitated my life which has included taking the time I need for my body to be healthy ALL of the time. I never stop telling myself that I am healthy, that I am full of life.” I have learned to look at what my body’s abilities are but also am very mindful of what my needs are. The body I have, the person I am, “has made my life possible.” Lastly, I have grown and, “I am creating a life that values time, which I am present in, and includes me living well in my own capacity as an individual with a chronic illness. I continued learning ways to sustainably maintain my needs.” In reconciling my identity, I have finally given myself the opportunity to be.

The “issues of identity” theme captured my journey of living with a chronic illness and the impact on my perception of who I was as an individual. The “issue of identity” theme included the subthemes: fix me; identity crisis; searching for myself; in pursuit of acceptance; and reconciling my identity. These subthemes distinguish salient experiences and thoughts that resonated with me as I continued to learn to live with a chronic illness.

Extraordinary Gifts I Have Received

Throughout my journey of living with a chronic illness there were many turbulent times when, “I could not understand that my life had the potential to be full of gifts that included: meaning, love, and wonder.” Through those challenging experiences, I persevered with faith in the person I was and who I could become—I strived for wellness. I learned to be grateful for what I previously had taken for granted as a healthy person. Interconnected within this theme is the component of self-directed learning. Even during very complicated times, I wondered about how I could persevere, how would I be able to live day-to-day, and how I would continue my aspirations. There were many times when circumstances were grave, but I was committed to trying, to learning, and to growing. It is through my self-

directed learning from living with a chronic illness that I have received many extraordinary gifts. Subthemes of the extraordinary gifts I have received include: hope to persevere; learning to love; mindful of my time; and gratitude for the extraordinary gifts I have received.

Hope to persevere. Hope to persevere is weaved throughout my unraveling and search of my identity. I saw through these times by holding onto hope; hope that I would persist and further my education, and that “I would be able to pursue my new dreams whatever they might be.” I became fascinated with people’s ability to heal themselves within. I explored many holistic strategies, and “I read as many self-help and wellness books as I could. I craved inspirational stories and healing. I wanted to know how others were living and how they came to be.” I read and re-read because all of these stories revealed possibility and filled me with hope, that I too could be well. “Hope helped me to get through those early days of pain.”

I am immensely grateful to the many people in my life who have displayed hope at times when I needed it most—times when I could have given up and hope could have vanished. My urologist was one of the first doctors of many who truly believed there was an illness that had yet to be uncovered, “I am still moved by the kindness he displayed.” My mom always believed that we would uncover the cause of my illness, she never wavered. Even when doubt surrounded me, she continued to hold onto hope. One memory of her bringing Christmas to me in the hospital demonstrated her eternal optimism, “[My mom] refused to let me believe that being in the hospital would interfere with the magic of Christmas.” I will always be grateful for the medical support I received from Dr. T. He has saved my life on numerous occasions and even more than that, he believed I was worth

saving. “[Dr. T.] had listened, investigated my symptoms, and he saw me as human being with a complicated physical illness.” My sister has always had the ability to remind me: “when I have been stubborn and unwilling to accept who I am, she has been there to remind me of what I can do.” She has always filled me with honest hopefulness. These people and experiences emphasize the support I received from those around me and how integral they were in helping me continue to have hope.

My participation in fundraising efforts to support DIGITS helped me make sense of my life with a chronic illness and ultimately gave me much hope. Creating the website for DIGITS, speaking to patients, and organizing fundraising events helped me validate and believe that I could live with this illness and aid others. By aiding others, I do not mean people were in need of my assistance, but that by working together we could create a platform for individuals living with DIGITS and share what our lives are like. “Learning my role as a patient advocate has taken time for me to establish and realize that I need boundaries to maintain my own health and wellness.”

There were many times when “what I hoped for and envisioned was not part of our present life. I was determined to try anything in pursuit of our dreams.” I believed that I could find a position that would meet my needs and career aspirations, that we would have a family, and that I could live well. During challenging times and uncertainty because of my chronic illness “I continued to cling to hope.” Hope is what has helped me manifest the beauty and life that surrounds me.

Learning to love. First and foremost I had to learn to love myself and I have found myself to be the most difficult to love. For years I viewed my chronic illness as a battle between who I really am and my chronic illness being my evil counterpart.

When my husband came into my life he saw who I was in that moment; he was never influenced by the medical needs I had. “I didn’t feel like a person who was sick with him.” He has always had the ability to see who I truly am and is there to remind me when I forget. “To be quite honest I think he knows my needs better than I know my own and he is the first to ensure we keep our life balanced.” My husband’s pure acceptance of me and belief that I was competent has been integral to me learning about love. “We have both cried many tears and had many moments of frustration resulting from my illness but those moments have never influenced how he sees me.” My husband’s proposal also had a profound impact on my understanding of love.

Even now when I think back to Rob proposing, I am in awe of how it didn’t matter to him that I was still struggling with procedures to help my symptoms, it didn’t matter that my day had been spent in the hospital, and from celebrating with my family I was exhausted and sore. He saw past all of that. He believed we would create a life of love that was filled with meaning.

We continued to plan our wedding despite incredible adversity with regards to my health but that didn’t matter to us, “We wanted to live in the moment and were grateful for the love we shared.” Our “date nights” that occurred during my frequent and long hospital stays are cherished memories where I felt incredibly loved and fulfilled. My husband, “has shown me to love myself by sharing what he sees in me ... that I am not an illness.” He has continued to remind me “that I was enough and he loved me regardless of my health situation ... he has shown me how to love myself by sharing what he sees in me.” There were times when my husband was more responsive to my health needs than I was to my own: “he was seeing lots of red flags with how much work I had committed to and how my symptoms were acting up,

but I didn't listen." There were times in my life that I thought I had loved my body but I realised that I still was very much immersed in what I could do and judged myself based on my abilities to achieve my goals. I needed to "learn about love, being kinder to myself, and opening myself to healing." Eventually I had no choice but to listen and my life depended on me changing. In order for me to listen and attend to my bodily needs, I needed to appreciate and love who I was.

Having our daughter has "filled us with love for her." She has taught me about unconditional love in giving people the opportunity to be. Our second pregnancy also taught me a lot about love because even within our short pregnancy I remained grateful to have had the opportunity to love that baby. Learning to love has meant,

I had let go of my fears of my chronic illness and opened my heart to love and be loved. Through my personal wellness I was finally able to fully experience each moment of my life. Love has governed my healing. In every moment I now tried to come from a place of love. When I am not coming from a place of love, I ask myself, *why am I doing this?*

From opening myself up to love, I have been surrounded by love and "am in love with the beauty that surrounds my life." The love I have experienced has revealed to me, "how powerful love is."

Mindful of my time. At the onset of my symptoms I was consumed with how much time was being taken from me when I experienced being sick. I was only reassured when I was advised I just needed "time to recover." But my body needed more time to heal than I had originally thought and "I needed to withdraw more and more from the life I had known." During the initial period of my illness, how I spent my time drastically changed. It was less

time with everyone else and more time with myself. I realised, “I needed to be active in my healing, that there were ways in which I could help myself spiritually, emotionally, and physically.” And yet, there were moments when I was angry that I had all of this time that I was “in pain by myself.” There were many instances when I had new medications, treatments, and procedures and each one of these needed time to work. “More time ... it seemed that my pain and symptoms included taking away my time.” Not only did these interventions require time but I required time to learn about and accept the body I had. I needed time to learn how to function and be comfortable with the person I had become and even then I still had mislead myself about the severity of my chronic illness.

All this time I had been telling myself I knew what living with a chronic illness had entailed but I had successfully been ignoring all of the warning signs I needed. A person can die with one bout of sepsis. I had lived through eight. Each time, the infection became more severe and the bacteria more advanced.

My relationship with time began to change when,

I started to think about all the time I had been sick; all the time I had been so sick and had given myself no time to heal. I was exhausted. I reflected on how I would not only quickly return to commitments but I would overschedule and not adhere to my bodily needs.

It was upon this mindfulness of time, “I was finally learning how to live with a chronic illness and giving myself the much needed time to heal.” When our daughter was born, I was reminded of all of the time I had spent with my Oma and Opa. She reinforced how precious time is and what an extraordinary gift time is. During my most recent episode of sepsis, “my chronic illness had taken what is most valuable to me. Time.” But then I

thought about how I had never truly given myself the time I needed to be well. “What if I gave myself time to eat, sleep, walk, write, and be with my loved ones? ... I learned that I needed time to be well.” Being mindful of my time has had a profound impact on my life because, “I try my best to live one moment at a time ... I am creating a life that values time.” Despite all of the hostility I have felt towards my chronic illness taking my time, it has been time that has given me the opportunity to learn and be mindful of, “how precious time is.”

Gratitude for extraordinary gifts. “I am filled with gratitude” is written within the first paragraph of my narrative. I am thankful for my life in its entirety because each of those moments have contributed to the person I am today and the life I have. The medical interventions I have had have been gruelling and yet, all of these interventions have made my life possible. For instance, “my ostomy should be celebrated not hidden” and further, “I am grateful for the body I have.” I have fully immersed myself in being thankful for all of the extraordinary gifts that I have received. I am grateful because my chronic illness has made me real. “I know that I have become stronger, kinder, more compassionate, more appreciative, and more aware of the life I have. In a strange way my chronic illness has made my life better.” These are words that I never considered thinking because I viewed my chronic illness as something that took. Not only have I received many extraordinary gifts from having a chronic illness but I am filled with thankfulness for the life I am living.

The extraordinary gifts I have received theme illuminated the ways in which living with my chronic illness has contributed to enhancing my life. The subthemes hope to persevere, learning to love, mindful of my time, and gratitude for the extraordinary gifts I have received have demonstrated the nature of the gifts I have received.

Tensions in Understanding Chronic Illness

Tensions in understanding chronic illness is a theme that emerged while I was coding the data and introduced an additional research question, *how can chronic illness be reframed?* Throughout my narrative I am frequently at a juxtaposition between my experience of living with a chronic illness and the perceptions of others about how I should be living with a chronic illness. Ultimately, my narrative is an alternate view of what life with a chronic illness consists of. The subthemes within tensions in understanding chronic illness include: my fear of chronic illness, provisions for chronic illness in silence, and renewed understanding of chronic illness.

My fear of chronic illness. Initially when I experienced my symptoms I was extremely distressed with being limited to the role of a person who was sick. I had identified as someone who was healthy and I would not accept anyone suggesting otherwise. I was fearful of being a person who was sick, and even more so, someone with a disability. My fears were informed by misconceptions about what life with an illness and disability consisted of. I thought these concepts were subordinate to health and included being dependent, weak, and fragile. “I was supposed to be better and wasn’t, I didn’t understand why this was happening to me ... I was afraid that I would not return to my normal healthy life.” I believed that I could only return to the life I had known, “and a new normal was not an option.” As my symptoms continued, every element of my life had been effected, “everything I had known was disappearing” and further, I had become “an outsider” to the life I had been a part of.

It was not until I became aware of holistic wellness that I began to discover alternate ways to experience healing and to define wellness. At the same time, “I didn’t know what to

do with myself or how to help alleviate my pain.” It wasn’t until I realised, “that I needed to be active in my healing, that there were ways I could help myself spiritually, emotionally, and physically.” Even with my understanding of whole body healing, I remained to be “ashamed of who I had become and the struggles I was facing with pain and illness.”

Provisions for illness in silence. Provisions for illness included when I first began to realise that I needed to start making accommodations and changes to my life as a result of the symptoms I was experiencing. “I was relearning how to be a student with health needs and that was challenging for me to accept. I didn’t want to be defined as someone with needs. I struggled with self-identifying as someone with a disability.”

In the medical community I experienced many different opinions as to what was contributing to my pain and symptoms, and it took time before I received an accurate diagnosis. Although, I was starting to make many provisions in my life, “[medical professionals] didn’t see me.” It was not until I had met my urologist and Dr. T when understanding the implications of my symptoms being chronic began to resonate. In response to learning my illness was in fact chronic, “I was devastated.” This devastation stemmed from my misconceptions of what life with a chronic illness would include.

For many years, I remained quiet about my experiences. “I was still very shy and insecure about my health needs.” When the discussion about an ostomy became a reality, “I was petrified” about what my body would become and about the thoughts of others. My fears were also evident in my refusal to have visitors.

I never wanted anyone to see me at my worst and make small talk. I saw the way they looked at me their eyes filled with gloom. I felt their tense and worried energy. I sensed the discomfort of being in a hospital setting. All I wanted was them to see me,

the Taunya they knew and who was still alive inside me. What they saw was the physical changes I couldn't control.

Provisions for illness in silence includes times when I suffered quietly with the effects of my illness and believed I needed to endure my chronic illness silently. Although I was making changes and accommodations in my life, I was afraid to admit to others the realities of my chronic illness.

Confronting chronic illness. Confronting chronic illness is a subtheme that supports times when I persevered and did not succumb to my initial preconceptions about living with a chronic illness. Despite my chronic illness, my husband and I were married and we continued to create the life we wanted despite the medical adversities I faced. I was confronting my chronic illness. When I shared my story for the first time as a keynote, "this was the beginning of me becoming an advocate and realising that people really don't know what life with a chronic illness is like."

When I was challenged at my placement in the Faculty of Education about my eating habits, again, I was reminded of the lack of knowledge of chronic illness. "Not once did this person consider the potential dietary restrictions as the reason I looked the way I did." I addressed this issue but I continued to vary in how often I shared my true reality since there were times when, "I remained afraid to say 'no I am not well enough.'" Confronting my chronic illness also included my misunderstandings because I knew I had a chronic illness, but I thought that I could control my chronic illness. I pushed myself. I was determined to prove that I was more than an illness. I could do it all. "I put on a façade that I was not affected by my chronic illness." My ambitions were a coping strategy, "it was a way of

sustaining the life I knew ... I didn't ever stop." When my husband and I decided to sell the house we built,

I realized that for years Rob and I had been living in homes with stairs, when I regularly needed an IV pole. I would keep all of my medical supplies (IV and ostomy supplies) hidden and located in inconvenient locations in our home. It didn't make sense; I used these supplies daily. I had been making my day-to-day living so much harder by pretending my needs were not the reality of my life. All this time I had been telling myself I knew what living with a chronic illness had entailed but I had successfully been ignoring all of the warning signs I needed to be paying attention to. I needed to create space for my chronic illness in my life. Finally I had begun to understand the severity of my chronic illness, but I still worried about the implications on my professional aspirations. I felt uncomfortable and unworthy when people would ask me questions about why I had stopped working or going to school. "I didn't want to feel their judgement or pity." Even more so, I did not want to hear their misguided representations of what life with a chronic illness consisted of. My response became, "I am focusing on getting healthy." Misunderstandings of chronic illness are evident throughout my narrative and influenced how I understood my chronic illness. After experiencing repeated tensions and difference, I needed to alter how chronic illness was posed.

Renewed understanding of chronic illness. The renewed understanding of chronic illness theme is not only reflective of my personal growth, but also, of when I started to openly communicate my needs. After many years of living with a chronic illness, I needed to give myself permission to heal. I had to stop resenting my body and how my life had been affected. From there I was able to learn to become more comfortable with

my needs and communicating my needs to others without feeling guilty or that I was less of a person. I struggled with always apologizing for the need to accommodate my health.

I started a blog to reveal how I was manifesting wellness in my life with a chronic illness. When I became pregnant, “I wanted to share that being a parent is not only possible with a chronic illness, but is an incredible gift.” My renewed understanding revealed that “my chronic illness does not change who I am.” Furthermore, “my body is my shell and at times my body has difficulty expressing the essence of who I am but I am bigger than my body.” My transformed view of chronic illness has instilled in me an immense determination to reframe chronic illness. “I never want Cecelia to feel the negativity and burdens that life with a chronic illness can consist of. I hope she sees through the negativity and sees the extraordinary gifts that our lives are full of.”

Tensions in understanding chronic illness included the subthemes: my fear of chronic illness; provisions for chronic illness in silence; and renewed understanding of chronic illness. This theme has uncovered my journey of understanding what a chronic illness was and how my views of chronic illness differ from my initial thoughts and perceptions.

Chapter 9: Discussion

This dissertation investigated the research question, what are the extraordinary gifts I have received from living with a chronic illness? The sub-questions included the following:

1. What are my experiences from living with a chronic illness?
2. What has contributed to me positively viewing my life with a chronic illness?
3. How can chronic illness be reframed?

Implications of Investigating Extraordinary Gifts From Living With Chronic Illness

Armstrong's (2010) model of extraordinary gifts for individuals who are neurodiverse served as this dissertation's strength-based framework by providing an alternate perspective of how chronic illness could be perceived. By composing my story through narrative inquiry, I shared my experiences of living with a chronic illness. The findings of this dissertation included the overarching themes issues of identity, extraordinary gifts I have received, and tensions in understanding chronic illness. A discussion of the implications of the findings from this research study follows.

The experiences I endured as an individual with a chronic illness pertained to the issues of identity theme. The experiences I had were complex since I needed time to process and learn about who I was as a person with a chronic illness. The subthemes—fix me; identity crisis; searching for myself; in pursuit of acceptance; and reconciling my identity—encapsulated the progression of how I questioned my identity and how I would pursue the life I desired while living with a chronic illness. Similar to Taylor (2009), I needed to be willing to give up what I was so I could redefine myself. I realised that my

present self was not determined by who I was in the past, and I needed to learn to love who I had become.

The theme “the extraordinary gifts I have received” included the subthemes hope to persevere; learning to love; mindful of my time; and gratitude for extraordinary gifts. Even during times of adversity, I tried to remain focused on the positives in my life. I continued to hope and aspire by focusing on what I wanted rather than what I did not want. Taylor (2009) writes, “I had to define my priorities for what I wanted to get back the most and not waste energy on other things” (p. 120). Comparable to Taylor, I found that the people who surrounded me taught me about love: “I needed people to love—not for the person I had been, but for who I might I become. ... I needed to have dreams to work toward” (2009, pp. 118-119).

Tensions in understanding chronic illness included the subthemes my fear of chronic illness; provisions for chronic illness in silence; and renewed understanding of chronic illness. The tension in understanding chronic illness theme and corresponding subthemes fostered the emergent research question, how can chronic illness be reframed? This theme illuminated how incongruent my experiences were from the initial perceptions I had about living with an illness and disability, and the perceptions of others about the reality of living with a chronic illness and disability. Once I confronted the misunderstandings and mistaken perceptions of chronic illness that I had been exposed to, I was able to foster a transformed understanding of chronic illness that encompassed the extraordinary life I have come to know.

I used to resent the time I was sick. I felt all of the moments I was sick had been a waste of my life and of my time. I believed my life was passing by without meaning, and

then over time, I realised that it was up to me to create a life full of meaning. Woven throughout my narrative is the quest to create a meaningful life. What I had yet to understand is that every day in each moment, I was creating a life full of meaning and purpose. During these times of despair, I was unaware that I was transforming into the person I have become. Heilbrun (1988) refers to Erik Erickson's moratorium stage in adolescence, which is defined by confusion and aimlessness in youth that is unconscious preparation for later development of skills and strategies, and applies this concept to woman who are experiencing transformations (although they do not know this at the time). My confusion in learning to deal with an illness, and the time I was sick was my moratorium. These experiences have fostered the funds of knowledge I needed to go forth in my life and have contributed to who I have become today, a person who deeply values the gifts I have received (Moll et al., 1992; Solorzano & Yosso, 2002).

Narrative Inquiry Considerations

The narrative in this dissertation was informed by the field texts of my life, memories, and the participants active in this research study, each of which has incurred considerations. A discussion about the autobiographical and member checking considerations follows.

Autobiographical considerations. The composition of the narrative was an interpretive process between my field texts and participants. As a researcher interested in chronic illness,

[I had a] special interest in the situation ... repeated and continually stated and negotiated with participants. Therefore, the way we enter the inquiry field

influences what we attend to. We deliberately select some aspects that turn up in field texts. (Clandinin & Connelly, 2000, p. 93)

Furthermore, this research study was focused on the gifts I have received while living with a chronic illness. At the time of composing my journals, I did not anticipate that, in time and when amalgamated with my other journal entries, they would become field texts that “take on a pattern as they are interwoven with other field texts in the construction of research texts” (Clandinin & Connelly, 2000, p. 104).

Writing the narrative included revisiting memories that I had long forgotten—memories that I couldn’t bring myself to acknowledge or cope with because I did not appreciate the experiences I had, nor did I fathom how my experiences contributed to understanding how chronic illness is framed. Since the focus of the data gathering phase is the exploration of the personal experience, I was reminded of how much time I spent trying to survive my chronic illness, and how often I was solely focused on the day at hand. The findings and discussion sections focused on my analysis of my narrative and attended to the theoretical implications meaning found throughout my narrative (Josselson, 2007). As the writer of the narrative, I fully comprehended that the purpose of my dissertation was to further the understanding of life with a chronic illness and that I am sharing my truth in a world that contains multiple truths. As Clandinin and Connelly (2000) state,

Writers may decide that they own a memory and still conclude that they ought not tell a story based on it because of a feeling that the other person would not want it told or would be hurt in the telling. (p. 177)

Member checking considerations. Composing the narrative has given me the opportunity to read, write, and reflect on the experiences I have had. I have returned to

moments when I was not the person I wanted to be and when I did not even recognize the person I was writing about. Josselson (2007) writes that although participants may know that it was *them* in the narrative, it can remain difficult to recognize the person they were that was reflected in the narrative. I did not anticipate the emotional journey I experienced while in the data gathering stage of my dissertation.

As the researcher I needed to develop trust with the participants in this study regarding their representation in the narrative. Participants were given the opportunity to review how they were represented in my narrative with the option to add to, omit, or change their representation in my narrative. Since I was the researcher and writer of the narrative, I was not prepared for how member checking would have an impact on the personal contact between myself as a researcher, and the other participants. I did not foresee any difficulties in member checking because in narrative inquiry it can be challenging to articulate all the benefits and harms since the researcher does not have any indication of how participants will respond (Josselson, 2007). Additionally, it was impossible to predict how participants will respond to how they were represented in the story, “Every aspect of our report may have unforeseen idiosyncratic meaning to the individual we are writing about, no matter how careful we are” (Josselson, 2007, p. 550). Often, if a participant has a problem with what is written, it is because they have an issue with the interpretation that is being projected, not the objective facts (Josselson, 2007). As the researcher in the study, I composed the narrative in a linear progression that would make sense to the reader. I created a specific reconstruction of my narrative but “there could be other reconstructions” (Clandinin & Connelly, 2000, p. 101).

Member checking was a challenging experience because I was the individual with the chronic illness; I have unveiled my vulnerabilities. At times, the observations and judgments about who I was were difficult to hear because I had written my individual “story to the larger, theoretically significant categories in social science,” not to someone’s personal interest in their own story (Josselson, 2007, p. 549). I faced situations where others, including participants in this study, did not value my perspective and experiences, and I was reminded about how my illness had an impact on them. It was as if no time had passed and I was viewed as the same person I was years ago, a sick person who made mistakes, who didn’t deal the chronic illness the *right* way. My perspective was not valued or valid and did not want to be heard. Yet again, I was in a position of being Othered. The healthy participant in a position of power reprimanded me for my past actions. I, the person with a chronic illness was powerless, the healthy participant had the power, and consequently believed their power meant knowing how I should be as a person with a chronic illness. I was the subordinate person with an illness who needed to be told how I should have experienced my illness and how I should have responded. Furthermore, Josselson (2007) states the purpose of the narrative is, “the researcher’s understanding or interpretation of the text ... the report is not ‘about’ the participants but ‘about’ the researcher’s meaning making” (p. 547). As the researcher, I was reminded of Clandinin and Connelly’s (2000) awareness of having a “wakefulness” premise in narrative research, that I “need to be awake to criticism but not necessarily accepting of it” (pp. 182-183). Additionally, it is imperative that narrative research includes a skillfully crafted analysis and reflection centered in furthering our understanding of what being human means with the hope that this will lead to a better world (Czarniawska, 2004; Josselson, 2007).

Recommendations

The recommendations derived from this dissertation include:

- To continue to hear the stories of people living with a chronic illness from a strengths based perspective;
- To investigate the influence of chronic illness on families who have a member with a chronic illness; and
- To continue to reframe the understanding of what living with a chronic illness consists of by deconstructing the assumptions and misunderstandings that surround individuals and families affected by chronic illness.

Hearing the voices of people with chronic illness. Chronic illness continues to be a term that includes many meanings and diagnoses (Martin, 2007; Walker, 2010). With such an array of interpretations, the needs of individuals with chronic illness are quite different (Kimpson, 2005; Shaw & McCabe, 2008; Shiu, 2004; Thies & McAllister, 2008; Wideman-Johnston, 2010, 2014b). Since there is no one way to live with a chronic illness, there remains a need for stories to be shared about what life with a chronic illness consists of (Davison et al., 2000). Individuals with a chronic illness perceives their reality and the implications of their illness in their own way. When people with a chronic illness decide to pursue help, they continue to face difficulties and lack support because limited understandings of illness persist (Carel, 2008). When individuals share the realities of their life with a chronic illness, it can include feelings of shame, discrimination, and misunderstanding, which is often due to the misrepresentations of life with a chronic illness (Charmaz, 1983; Davison et al., 2000). While individuals with chronic illness continue to

harness feelings of inadequacy and guilt for having a chronic illness, they strive to live their life in pursuit of a standard set by those from a well-perspective (Whitsitt, 2010).

The need to make sense of my chronic illness in a strength-based framework was informed by my transition and desire to be a parent and eventually a mother. Research exploring the positive growth of mothers with chronic illness also remains to be limited. Vallido et al. (2010) discussed the burdens and guilt mothers felt as a result of the implications of their illness, and further stated the need for the positive aspects of being a mother with an illness to be studied. This dissertation attempts to contribute to that gap by sharing my story which included an authentic experience of chronic illness. Furthermore this research study supports hearing voices of those with chronic illness.

Research investigating the experiences of those with chronic illness and their families. There is a need for individuals with chronic illness to share their stories because of the varying experience of each individual (Clay et al., 2004; Thies & McAllister, 2008). In order for people with chronic illness to openly communicate their experiences, further support and resources for individuals and their families is required (Charmaz, 1983, 1991; Schuster et al., 2011). With regards to additional support for individuals with chronic illness and their families, the lack of positive interventions has been identified (Shiu, 2004). There is limited research available that includes the perceptions of spouses and children of people with illness (Friedemann, 1999; Rosland et al., 2012). Studies that have investigated the effects of illness on the family focused on negative implications such as emotional suffering and challenging behaviour (Earley & Cushway, 2002; Schrag et al., 2004; Wong et al., 2009). The need to continue to investigate the experiences and perspectives of spouses and children of those with chronic illness remains imminent (Kean,

2009; Kurz, 2012), especially from a strength-based perspective. My husband, daughter, and I continue to grow, love, and adapt in positive ways as a result from my chronic illness, and this concept is largely neglected in research.

Continue to reframe the understanding of chronic illness. Illich (2013) states how individuals who are sick are thought to be subordinate and in need of fixing. Edwards (2013) discusses how people do not want to converse about illness, especially when the conversation focuses on the individuals' disabilities or impairments (Wendell, 2001). According to Illich, in order to restore health and reframe illness, individuals need to act in a way that is harmonious and authentic to their life. This dissertation has reframed chronic illness by my documented journey to create a sustainable and meaningful life filled with extraordinary gifts while living with a chronic illness.

Much of the research inclusive to those with chronic illness and their families included adverse implications such as emotional trauma, isolation, grief and shame, and lack of support (Blackford, 1999; Charmaz, 1983, 1991; Kean, 2009; Mukherjee et al., 2002; Rosenfeld et al., 1983; Rosland et al., 2012; Schrag et al., 2004; Smith & Friedemann, 1999; White et al., 2011). The actual experiences of families as a whole remains to be absent (Smith & Friedemann, 1999). Despite the accounts and findings related to the destructive aspects of living with a chronic illness, improved family relationships and bonds provided the foundation for this dissertation to illuminate the positive aspects to living with a chronic illness (Blackford, 1999; Kean, 2009; Mukherjee et al., 2002). Although there were hardships as a result of my chronic illness that affected my family and me, we needed to focus on more than the negatives. Ware (2006) discussed the silence that surrounds disability and the absence of authentic dialogue. Together with my

family, I had to change the conversation. I had to focus on what “healthy” meant to me. If I continued to remain silent, stereotypes and misinterpretations about my life persisted. Further, it became essential to my survival that I change my understanding of what it meant to be normal because I struggled with trying to become the idyllic normal person (Wendell, 2013). Through my journey of self-directed learning (Ricci, 2012), I became well by focusing on the positive aspects of my life and by learning to appreciate the life I had come to live. Through my changed perception of how I could live my life, my life finally encompassed wellness. I reframed my life with chronic illness. I am abundantly filled with love and gratitude; I have found peace.

Next Steps

A lack of research investigating chronic illness from a strength-based lens remains. It is hoped that this dissertation will contribute to the limited quantity of literature that has endeavoured to reframe chronic illness. This dissertation articulated my experiences of chronic illness, the extraordinary gifts that have been received, and shared a counter-story of life with a chronic illness (Solorzano & Yosso, 2002). This research study has not embodied all of the complexities of living with a chronic illness but illuminated the multifaceted nature of chronic illness, and ways in which chronic illness has affected all areas of my life. My experiences have been unique to my perception of reality and are not meant to suggest there is a universal way to living with a chronic illness. This dissertation has exposed the experiences I have had as a result of living with a chronic illness and contributes to the body of literature that seeks to investigate the experiences of individuals and families affected by chronic illness.

By providing a comprehensive narrative of my life, the purpose of this dissertation is to contribute to sharing stories of individuals with chronic illness, with the intention of advocating for the ability to create a meaningful life while living with a chronic illness. Next steps for this dissertation will include further analysis for additional themes throughout my narrative from different theoretical lenses. Examples of this could include a feminist approach, or engaging my narrative in a discourse analysis. Investigating the differences between how I view myself and how I have perceived others to view me is also a consideration for further study. Analyzing the differences between my own perceptions and the perceptions of others may reveal areas of my self that I am unaware of. Altering the theoretical lens to encompass other perspectives and theories will provide additional richness to inform understandings about living with a chronic illness. Furthermore, this dissertation speaks to the need for equitable access for those with chronic illness pursuing education, careers, and family aspirations.

References

- Allman, P. (2009). Paulo Freire's contributions to radical adult education. In A. Darder, M. P. Baltodano, & R. D. Torres (Eds.), *The critical pedagogy reader* (pp. 417–430). New York, NY: Taylor & Francis.
- Armstrong, T. (2010). *Neurodiversity: Discovering the extraordinary gifts of autism, ADHD, Dyslexia, and other brain differences*. Cambridge, MA: Da Capo Press.
- Asbring, P. (2001). Chronic illness: A disruption in life: identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing*, 34(3), 312-319.
- Ashton, J. (2004). Life after the shock! The impact on families of caring for young children with chronic illness. *Australian Journal of Early Childhood*, 29(1), 22-26.
- Asprey, A., & Nash, T. (2006). The importance of awareness and communication for the inclusion of young people with life limiting and life threatening conditions in mainstream schools and colleges. *British Journal of Special Education*, 33(1), 10-18.
doi:10.1111/j.1467-8578.2006.00406.x
- Barthes, R. (1974). *S/Z* (R. Miller, Trans.). Toronto, ON: Hill & Wang.
- Becker, H. S. (2007). *How to start and finish your thesis, book, or article* (2nd ed.). Chicago, IL: University of Chicago Press.
- Berger, W. (2014). *A more beautiful question: The power of inquiry to spark breakthrough ideas*. New York, NY: Bloomsbury.
- Blackford, K. A. (1999). A child's growing up with a parent who has Multiple Sclerosis: Theories and experiences. *Disability & Society*, 14(5), 673-685.
doi:10.1080/09687599926019

- Boyd, K. M. (2000). Disease, illness, sickness, health, healing and wholeness: Exploring some elusive concepts. *Medical Humanities*, 26, 9-17. doi:10.1136/mh.26.1.9
- Bruner, J. (2004). Life as narrative. *New School for Social Research*, 71(3), 691-710.
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2010, December). *Tri-council policy statement: Ethical conduct for research involving humans*. Ottawa, ON: Interagency Secretariat on Research Ethics. Retrieved from http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf
- Carel, H. (2008). *Illness*. Toronto, ON: Acumen.
- Carey, S. (1999). Sources of conceptual change. In E. K. Scholnick, K. Nelson, S. A. Gelman, & P. H. Miller (Eds.), *Conceptual development: Piaget's legacy* (pp. 293-326). Mahwah, NJ: Erlbaum.
- Chang, H. (2007). *Autoethnography as a method: Raising cultural consciousness about self and others*. Retrieved from http://www.academia.edu/1244871/Autoethnography_as_method
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness*, 5(2), 168-195.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco, CA: Jossey-Bass.

- Clandinin, D. J., & Huber, J. (2010). Narrative inquiry. In B. McGaw, E. Baker, & P. P. Peterson (Eds.), *International encyclopedia of education* (3rd ed., pp. 436-441). New York, NY: Elsevier. doi:10.1016/B978-0-08-044894-7.01387-7
- Clare, E. (2013). Gawking, gaping, staring. In M. Adams, W. J. Blumenfeld, C. Castaneda, H. W. Hackman, M. L. Peters, & X. Zuniga (Eds.), *Readings for diversity and social justice* (3rd ed., pp. 481-485). New York, NY: Routledge.
- Clay, D., Cortina, S., Harper, D. C., Cocco, K. M., & Drotar, D. (2004). Schoolteachers' experiences with childhood chronic illness. *Children's Health Care, 33*(3), 227-229. doi:10.1207/s15326888chc3303_5
- Connelly, M. F., & Clandinin, D. J. (1990). Stories of experience and narrative inquiry. *Educational Research, 19*(5), 2-14. doi:10.3102/0013189X019005002
- Crow, L. (1996). Including all of our lives: Renewing the social model of disability. In J. Morris (Ed.), *Encounters with strangers: Feminism and disability* (pp. 206-226). London, UK: Women's Press.
- Czarniawska, B. (2004). *Narratives in social science research*. Thousand Oaks, CA: Sage.
- Davison, K. P., Pennebaker, J. W., & Dickerson, S. S. (2000). Who talks? The social psychology of illness support groups. *American Psychologist Association, 55*(2), 205-217. doi:10.1037/0003-066X.55.2.205
- Denzin, N. K., & Lincoln, Y. S. (Eds.). (2002). *The qualitative inquiry reader*. Thousand Oaks, CA: Sage.
- Dolfman, M. (1973). The concept of health: A historic and analytical examination. *Journal of School Health, 43*(8), 491-497. doi:10.1111/j.1746-1561.1973.tb03740.x

- Donoghue, P. J., & Siegel, M. E. (2000). *Sick and tired of feeling sick and tired: Living with invisible chronic illness*. New York, NY: Norton.
- Earley, L., & Cushway, D. (2002). The parentified child. *Clinical Child Psychology and Psychiatry*, 7(2), 163-178. doi:10.1177/1359104502007002005
- Edwards, L. (2008). *Life disrupted: Getting real about chronic illness in your twenties and thirties*. New York, NY: Walker & Company.
- Edwards, L. (2013). *In the kingdom of the sick: The social history of chronic illness*. New York, NY: Walker & Company.
- Ellis, C. (2004). Analysis in storytelling. In *The ethnographic I: A methodological novel about autoethnography* (pp. 194-201). Walnut Creek, CA: Rowman & Littlefield.
- Ellis, C., Adams, T. E., & Bochner, A. P. (2011). Autoethnography an overview. *Qualitative Social Research*, 12(1), Art. 10. Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/1589/3095>
- Extraordinary. (2016). In *Oxford advanced learner's dictionary*. Retrieved from <http://www.oxfordlearnersdictionaries.com/us/definition/english/extraordinary?q=extraordinary>
- Fraze, C., Gilmour, J., & Mykitiuk, R. (2005). Now you see her, now you don't: How law shapes disabled women's experience of exposure, surveillance, and assessment in the clinical encounter. In D. Pothier and R. Devlin (Ed.), *Critical disability theory: Essays in philosophy, politics, policy, and law* (pp. 223-247). Vancouver, BC: UBC Press.
- Freire, P. (1970). *The pedagogy of the oppressed*. New York, NY: The Seabury Press.

- Freire, P. (1985). *The politics of education: Culture, power, and liberation*. South Hadley, MA: Bergin & Garvey.
- Freire, P. (2009). From pedagogy of the oppressed. In A. Darder, M. P. Baltodano, & R. D. Torres (Eds.), *The critical pedagogy reader* (pp. 52-60). New York, NY: Taylor & Francis.
- Gift. (2016). In *Oxford advanced learner's dictionary*. Retrieved from <http://www.oxforddictionaries.com/definition/learner/gift>
- Giroux, H. A. (2004). Critical pedagogy and the postmodern/divide: Towards a pedagogy of democratization. *Teacher Education Quarterly*, 31(1), 31-47.
- Goffman, E. (1959). *The presentation of self in everyday life*. New York, NY: Anchor Books.
- Golub, S. A., Gamarel, K. E., & Rendina, H. J. (2014). Loss and growth: Identity processes with distinct and complementary impacts on well-being among those living with chronic illness. *Psychology, Health & Medicine*, 19(5), 572-579.
doi:10.1080/13548506.2013.855318
- Gorad, S. (2014). The widespread abuse of statistics by researchers: What is the problem and what is the ethical way forward? *The Psychology of Education Review*, 38(1), 3-10.
- Greene, M. (2009). In search of a critical pedagogy. In A. Darder, M. P. Baltodano, & R. D. Torres (Eds.), *The critical pedagogy reader* (pp. 84-96). New York, NY: Taylor & Francis.
- Guba, E. G., & Lincoln, Y. S. (2005). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 191-216). Thousand Oaks, CA: Sage.
- Heilbrun, C. G. (1988). *Writing a women's life*. New York, NY: Norton.

- Hewitt, J. P. (2001). The social construction of social construction. *Qualitative Sociology*, 24(3), 417-423.
- Higgs, J., Horsfall, D., & Grace, S. (Eds.). (2009). *Writing qualitative research on practice*. Rotterdam, Netherlands: Sense.
- Hollister. (2004). *Managing your ileostomy*. Retrieved from https://www.hollister.com/anz/files/pdfs/ostomy_lit_il_managing.pdf
- Ill. (2016). In *Oxford advanced learner's dictionary*. Retrieved from http://www.oxfordlearnersdictionaries.com/us/definition/english/ill_1?q=ill
- Illich, I. (2013). *Limits to medicine: Medical nemesis: The expropriation of health*. New York, NY: Marion Boyars.
- Illness. (2016). In *Oxford advanced learner's dictionary*. Retrieved from <http://www.oxfordlearnersdictionaries.com/us/definition/english/illness?q=illness>
- International Foundation for Functional Gastrointestinal Disorders. (2015). *Motility disorders of the small intestine*. Retrieved from <http://www.aboutgimotility.org/site/about-gi-motility/disorders-of-the-small-intestine/>
- Josselson, R. (2007). The ethical attitude in narrative research. In D. J. Clandinin (Ed.), *Handbook of narrative inquiry* (pp. 537-566). Thousand Oaks, CA: Sage.
- Kant, I. (2010). *The critique of pure reason*. Haxelton, PA: Pennsylvania State University.
- Kean, S. (2009). Children and young people's strategies to access information during a family member's critical illness. *Journal of Clinical Nursing*, 19, 266-274. doi:10.1111/j.1365-2702.2009.02837.x
- Kimpson, S. A. (2005). Stepping off the road: A researcher's story of challenging method/changing methodology. *McGill Journal of Education*, 40(1), 157-178.

- Kizel, A. (2014). Life goes on even if there's a gravestone: Philosophy with children and adolescence on virtual memory sites. *Childhood & Philosophy*, 10(20), 421-433.
- Kurz, J. M. (2012). Older adolescents' experiences living with a parent who is a transplant patient. *Progress in Transplantation*, 22(3), 244-251. doi:10.7182/pit20122634
- Ladson-Billings, G., & Tate, W. F. (1995). Toward a critical race theory of education. *Teachers College Record*, 97(1), 47-68. doi:0161-4681-95/9701
- Lee, A. M., & Poole, G. (2005). An application to the transactional model to the analysis of chronic illness narratives. *Qualitative Health Research*, 15(3), 346-364. doi:10.1177/1049732304272914
- London Health Sciences Foundation. (2012). *DIGITS*. London, ON: London Health Sciences Centre.
- Martin, C. M. (2007). Chronic disease and illness care: Adding principles of family medicine to address ongoing health system redesign. *Canadian Family Physician*, 53(12), 2086-2091.
- Mayo Foundation for Medical Education and Research. (2016). *Diseases and conditions: Interstitial cystitis*. Retrieved from <http://www.mayoclinic.org/diseases-conditions/interstitial-cystitis/basics/definition/con-20022439>
- Merriam, S. B. (2009). *Qualitative research: A guide to design and implementation*. San Francisco, CA: Jossey-Bass.
- Miller, J. P. (2008). *The holistic curriculum*. Toronto, ON: OISE Press.
- Moll, L. C., Amanti, C., Neff, D., & Gonzolez, N. (1992). Funds of knowledge for teaching: Using a qualitative approach to connect homes and classrooms. *Theory Into Practice*, 31(2), 132-141. doi:10.1080/00405849209543534

- Morgan, D. J. (2007). Paradigms lost and pragmatism regained: Methodological implications of combining qualitative and quantitative methods, *Journal of Mixed Methods Research*, 1(1), 48-76. doi:10.1177/2345678906292462
- Mukherjee, S., Sloper, P., & Lewin, R. (2002). The meaning of parental illness to children: The case of inflammatory bowel disease. *Child: Care, Health, & Development*, 28(6), 479-485. doi:10.1046/j.1365-2214.2002.00302.x
- Murrow, E. J., & Oglesby, F. M. (1996). Acute and chronic illness: Similarities, differences and challenges. *Orthopedic Nursing*, 15(5), 47-51.
- Newacheck, P. W., & Taylor, W. R. (1992). Childhood chronic illness: Prevalence, severity, and impact. *American Journal of Public Health*, 82(3), 364-371.
doi:10.2105/AJPH.82.3.364
- Nipissing University. (2016). *Protocol forms*. Retrieved from <http://www.nipissingu.ca/academics/research-services/ethics/reb/Pages/Protocol-Forms.aspx>
- Nolte, D. L. (1972). *Children learn what they live*. Retrieved from http://www.empowermentresources.com/info2/childrenlearn-long_version.html
- Oliver, P. (2014). *Writing your thesis* (3rd ed.). Thousand Oaks, CA: Sage.
- Osteoporosis Canada. (2015). *What is osteoporosis?* Retrieved from <http://www.osteoporosis.ca/osteoporosis-and-you/what-is-osteoporosis/>
- Palmer, P. (2003). *A hidden wholeness: The journey toward an undivided life*. San Francisco, CA: Jossey-Bass.
- Patient. (2016). In *Oxford advanced learner's dictionary*. Retrieved from http://www.oxfordlearnersdictionaries.com/definition/english/patient_1?q=patient

- Polkinghorne, D. E. (1988). *Narrative knowing and the human sciences*. Albany, NY: State University of New York Press.
- Pothier, D., & Devlin, R. (2006). *Critical disability theory: Essays in Philosophy, politics, policy, and law*. Toronto, ON: UBC Press.
- Rehm, R. (2002). Creating a context of safety and achievement at school for children who are medically fragile/technology dependent. *Advances in Nursing Science*, 24(3), 71-84. doi:10.1097/00012272-200203000-00008
- Rehm, R., & Bradley, J. (2005a). Normalization in families raising a child who is medically fragile/technology dependent and developmentally delayed. *Qualitative Health Research*, 15(6), 807-820. doi:10.1177/1049732305276754
- Rehm, R., & Bradley, J. (2005b). The search for social safety and comfort in families raising children with complex chronic conditions. *Journal of Family Nursing*, 11(1), 59-78. doi:10.1177/1074840704272956
- Ricci, C. (2012). *The willed curriculum, unschooling, and self-direction: What do love, trust respect, care, and compassion have to do with learning?* Toronto, ON: Ricci Publishing.
- Ricci, C. (2015). *Self-determined learning and improvisation* Unpublished manuscript, Schulich School of Education. Nipissing University, North Bay, Ontario, Canada.
- Rosenbaum, P., & Gorter, J.W. (2012), The 'f-words' in childhood disability: I swear this is how we should think!. *Child Care Health Development*, 38(4), 457-463. doi: 0.1111/j.1365-2214.2011.01338

- Rosenfeld, A., Caplan, G., Yaroslavsky, A., Jacobowitz, J., Yuvel, Y., & LeBow, H. (1983). Adaptation of children of parents suffering from cancer: A preliminary study of a new field for primary prevention research. *Journal of Primary Prevention*, 3(4), 244-250. doi:10.1007/BF01325407
- Rosland, A. M., Heisler, M., & Piette, J. D. (2012). The impact of family behaviours and communication patterns on chronic illness outcomes: A systematic review. *Journal of Behavioural Medicine*, 35(2), 221-239. doi:10.1007/s10865-011-9354-4
- Ryan, T. G., (2006). The technologically-dependent/medically fragile at risk student. *International Journal of Special Education*, 21(3), 1-21.
- Schrag, A., Morley, D., Quinn, N., & Jahanshahi, M. (2004). Impact of Parkinson's disease on patients' adolescent and adult children. *Parkinsonism & Related Disorders*, 10(7), 391-397. doi:10.1016/j.parkreldis.2004.03.011
- Schuster, M. A., Chung, P. J., & Vestal, K. D. (2011). Children with health issues. *Future of Children*, 21(2), 91-116.
- Schwandt, T. A. (2007). *The Sage dictionary of qualitative inquiry* (3rd ed.). Thousand Oaks, CA: Sage.
- Selek, J. H., & Overman, S. S. (2013). *You don't look sick: Living well with invisible chronic illness* (2nd ed.). New York, NY: Demos Health.
- Sexson, S. B., & Madan-Swain, A. (2001). School re-entry for the child with chronic illness. *Journal of Learning Disabilities*, 26(2), 115-125. doi:10.1177/002221949302600204
- Shaw, S. R., & McCabe, P. C. (2008). Hospital-to-school transition for children with chronic illness: Meeting the new challenges of an evolving health care system. *Psychology in the Schools*, 45(1), 74-87. doi:10.1002/pits.20280

- Shiu, S. (2004). Positive interventions for children with chronic illness: Parents' and teachers' concerns and recommendations. *Australian Journal of Education*, 48(3), 239-252. doi:10.1177/000494410404800303
- Smith, A. A., & Friedemann, M. L. (1999). Perceived family dynamics of persons with chronic pain. *Journal of Advanced Nursing*, 30(3), 543-551. doi:10.1046/j.1365-2648.1999.01123.x
- Snow, K. (2016). *People first language and more*. Retrieved from <https://www.disabilityisnatural.com/people-first-language.html>
- Solorzano, D. G., & Yosso, T. J. (2002). Critical race methodology: Counter-storytelling as an analytical framework for educational research. *Qualitative Inquiry*, 8(1), 23-44. doi:10.1177/107780040200800103
- Sontag, S. (2001). *Illness as metaphor and AIDS and its metaphors*. New York, NY: Picador.
- Taylor, J. B. (2009). *My stroke of insight*. London, UK: First Plume.
- Teunissen, G. J., Visse, M. A., & Abma, T. A. (2013). Struggling between strength and vulnerability, a patients counter story. *Health Care Analysis*, 23, 288-305. doi:10.1007/s/10728-013-0254-3
- Thies, K. M., & McAllister, J. W. (2008). The health and education leadership project: A school initiative for children and adolescents with chronic health conditions. *Journal of School Health*, 71(5), 167-179.
- Thorne, S., Paterson, B., Acorn, S., Canam, C., Joachim, G., & Jillings, C. (2002). Chronic illness experience: Insights from a meta-study. *Qualitative Health Research*, 12(4), 437-452. doi:10.1177/104973202129120007

- Tolich, M. (2010). A critique of current practice: Ten foundational guidelines for autoethnographers. *Qualitative Health Research, 20*(12), 1599-1610.
doi:10.1177/1049732310376076
- Vallido, T., Wilkes, L. Carter, B., & Jackson, D. (2010). Mothering disrupted by illness: A narrative synthesis of qualitative research. *Journal of Advanced Nursing, 66*(7), 1435-1445. doi:10.11/j.1365-2648.2010.05350.x
- Walker, C. (2001). Recognising the changing boundaries of illness in defining terms of chronic illness: A prelude to understanding the changing needs of people with chronic illness. *Australian Health Review, 24*(2), 207-215.
- Wall, S. (2006). An autoethnography on learning about autoethnography. *International Journal of Qualitative Methods, 5*(2), 1-12. Retrieved from https://www.ualberta.ca/~iiqm/backissues/5_2/PDF/wall.pdf
- Ware, L. P. (2002). A moral conversation on disability: Risking the personal in educational contexts. *Hypatia, 17*(3), 143-172. doi:10.1111/j.1527-2001.2002.tb00945.x
- Ware, L. P. (2009). Writing, identity, and the other: Dare we do disability studies? In A. Darder, M. P. Baltodano, & R. D. Torres (Eds.), *Critical pedagogy reader* (pp. 397-416). New York, NY: Taylor & Francis.
- Wells, G. (2009). *The meaning makers: Learning to talk and talking to learn* (2nd ed.). Tonawanda, NY: Multilingual Matters.
- Wendell, S. (1996). *The rejected body*. New York, NY: Routledge.
- Wendell, S. (2001). Unhealthy disabled: Treating chronic illnesses as disabilities. *Hypatia, 16*(4), 17-33. doi:10.1353/hyp.2001.0062

- Wendell, S. (2013). The social construction of disability. In M. Adams, W. J. Blumenfeld, C. Castaneda, H. W. Hackman, M. L. Peters, & X. Zuniga (Eds.), *Readings for diversity and social justice* (3rd ed., pp. 481-485). New York, NY: Routledge.
- White, C., Bellamy, R., Powell, M., & Wittenauer, A. (2011). Talking about illness: Mothers' and toddlers' conversations during a joint book-reading task. *Early Child Development and Care, 181*(10), 1409-1419. doi:10.1080/03004430.2010.533268
- Whitsitt, D. R. (2010). Illness and meaning: A review of select writings. *Journal of Humanistic Psychology, 50*(1), 108-131. doi:10.1177/0022167809342549
- Wiebe, N. G. (2009). What is narrative inquiry? In C. Hoogland & N. Wiebe (Eds.), *Narrative inquiry in education: Inquiry through writing*. University of Western, London, Ontario, Canada
- Wideman-Johnston, T. (2010). *The academic journey of students with chronic gastrointestinal illness: Narratives from daughters and their mothers* (Unpublished master's thesis). Nipissing University, North Bay, ON.
- Wideman-Johnston, T. (2011a). A narrative: Meditation in the lives of children with chronic illness. *The Journal of Unschooling and Alternative Learning, 6*(11), 4-19. Retrieved from <http://jual.nipissingu.ca/wp-content/uploads/sites/25/2014/06/v61112.pdf>
- Wideman-Johnston, T. (2011b). Resilience and students with chronic illness: A literature review of fostering resilience into the lives of students with chronic illness. *Journal of Educational and Developmental Psychology, 1*(1), 127-132. doi:10.5539/jedp.v1n1p127

- Wideman-Johnston, T. (2014a). A self-study of my life with a chronic illness. *Journal of Unschooling and Alternative Learning*, 9(17), 42-58. Retrieved from <http://jual.nipissingu.ca/wp-content/uploads/sites/25/2014/06/v91174.pdf>
- Wideman-Johnston, T. (2014b). The academic journeys of students with chronic gastrointestinal illness: Narratives from daughters and their mothers. *Canadian Journal of New Scholars in Education*, 5(1), 1-10. Retrieved from <http://www.cjnse-rcjce.ca/ojs2/index.php/cjnse/article/view/194/182>
- Wideman-Johnston, T. (2015). *Comprehensive examination 1: Theoretical traditions*. Unpublished manuscript, Schulich School of Education, Nipissing University, North Bay, ON.
- Wolanin, T. R. (2013). Students with disabilities: Financial aid and policy issues. In M. Adams, W. J. Blumenfeld, C. Castaneda, H. W. Hackman, M. L. Peters, & X. Zuniga (Eds.), *Readings for diversity and social justice* (3rd ed., pp. 180-182). New York, NY: Routledge.
- Wolff, M. R. (2009). Auto/ethnography and the question of ethics. *Forum: Qualitative Social Research*, 10(1). Retrieved from <http://www.qualitative-research.net/index.php/fqs/article/view/1213/2645>
- Wong, M. L., Cavanaugh, C. E., MacLeamy, J. B., Sojourner-Nelson, A., & Koopman, C. (2009). Posttraumatic growth and adverse long-term effects of parental cancer in children. *Families, Systems, & Health*, 27(1), 53-63. doi:10.1037/a0014771
- World Health Organization (2016). *Health*. Retrieved from <http://www.who.int/trade/glossary/story046/en/>

Appendix A: Participant Consent



Participant Information Letter and Consent for Identified Participants

Dear Participant

You are invited to participate in a research study entitled “The Extraordinary Gifts Received from Living with a Chronic Illness” conducted by Carlo Ricci and Taunya Wideman-Johnston and from The Schulich School of Education at Nipissing University. The results of this study will contribute to dissertation research.

The objectives of this research study are to reframe the understanding of chronic illness by revealing the strengths and gifts of living with a chronic illness. Taunya will share her story that poses chronic illness in a positive light by sharing the gifts she has received since living with a chronic illness.

If you volunteer to participate in this study:

You will review prepared sections of Taunya’s narrative. You will have the opportunity to review how you are being represented in Taunya’s story, offer input, and/or omit certain information that pertains to you. You will be able to openly share their thoughts and Taunya will have care and compassion for the experiences you have endured. Taunya will provide you with the opportunity to openly share your thoughts and experiences without any judgement.

This research study involves addressing personal stories of Taunya’s experiences with a chronic illness. This may evoke different emotions pertaining to difficult experiences and responses by the medical, educational, and/or social communities. Risks will be minimized by posing chronic illness in a positive light. Should you evoke more serious emotional responses, names and contact for psychological support will be provided.

Since Taunya is sharing her personal story about living with a chronic illness, in the instance you are directly involved in the story you will be described with a pseudonym but it is possible a reader may be able to identify you as a participant.

Benefits of the research study:

The benefits of this study include advocacy and awareness about living with a chronic illness within my family context. The intention for this dissertation is to inform families understanding of chronic illness and potentially for other children with parents with chronic illness to experience a similar result. If you decide to participate, you will be able to reminisce and reflect on past experiences potentially providing opportunities for self-awareness and growth.

Any information obtained in connection with you in this study will remain confidential and will be disclosed only with your permission. Participation in this study is voluntary and you are free to withdraw at any time. You may withdraw your consent at any time and discontinue participation without penalty. Should you choose to withdraw, please let me know by phone call, email or in person. Any data collected at that point will be destroyed. Paper records will be shredded and recycled. Electronic data will be stored on a USB and that device will be destroyed.

If you have any questions or concerns about the research, please feel free to contact Carlo Ricci @ carlor@nipissingu.ca and/or Taunya Wideman-Johnston by phone 519-588-3084 or email @ taunyaw@nipissingu.ca.

INFORMED CONSENT TO PARTICIPATE IN RESEARCH

As a participant in this research project, I understand what I am agreeing to do, and that I am free to decline involvement or withdraw from this project at any time, and there are steps being taken to protect me. I have read this Participant Information Letter and Consent Form and have had any questions, concerns, or complains answered to my satisfaction. I have been provided with a copy of this letter.

Name

Date

Signature

This study has been reviewed and received ethics clearance through Nipissing University's Research Ethics Board. If you have any questions regarding your rights as a research participant, contact:
Research Services
Nipissing University
North Bay, ON P1B 8L7
ethics@nipissingu.ca
705-476-8037

Appendix B : Parent Participant Consent



Participant Information Letter and Consent for Identified Participants

Dear Parent

You are invited to participate in a research study entitled “The Extraordinary Gifts Received from Living with a Chronic Illness” conducted by Carlo Ricci and Taunya Wideman-Johnston and from The Schulich School of Education at Nipissing University. The results of this study will contribute to dissertation research.

Taunya is writing a memoir of her life with a chronic illness and may mention individuals in her life who may appear in my recollections. Taunya is seeking consent to include such memories in her dissertation.

The objectives of this research study are to reframe the understanding of chronic illness by revealing the strengths and gifts of living with a chronic illness. Taunya will share her story that poses chronic illness in a positive light by sharing the gifts she has received since living with a chronic illness.

If you agree to have your child volunteer to participate in this study:

You will review prepared sections of Taunya’s narrative that pertain to your child. You will have the opportunity to review how your child is being represented in Taunya’s story, offer input, and/or omit certain information that pertains to him/her. You will be provided with aspects of Taunya’s transcript that pertain to your child. You will be able to openly share their thoughts and Taunya will have care and compassion for the experiences your child has endured. Taunya will provide you with the opportunity to openly share your thoughts and experiences without any judgement. Taunya will receive verbal consent from your child prior to meeting with them.

This research study involves addressing personal stories of Taunya’s experiences with a chronic illness. In the future, your child reading this dissertation may evoke different emotions pertaining to difficult experiences and responses by the medical, educational, and/or social communities. Risks will be minimized by posing chronic illness in a positive light.

Since Taunya is sharing her personal story about living with a chronic illness, in the instance your child is directly involved in the story it is possible a reader may be able to identify your child as a participant.

Benefits of the research study:

The benefits of this study include advocacy and awareness about living with a chronic illness within my family context. The intention for this dissertation is to inform families understanding of chronic illness and potentially for other children with parents with chronic illness to experience a similar result. If you decide for your child to participate, you will be able to reminisce and reflect on past experiences potentially providing opportunities for self-awareness and growth.

Any information obtained in connection with this study and your child will remain confidential and will be disclosed only with your permission. Participation in this study is voluntary and you are free to withdraw your child at any time. You may withdraw your consent at any time and discontinue participation without penalty. Should you choose to withdraw, please let me know by phone call, email or in person. Any data collected at that point will be destroyed. Paper records will be shredded and recycled. Electronic data will be stored on a USB and that device will be destroyed.

If you have any questions or concerns about the research, please feel free to contact Carlo Ricci @ carlor@nipissingu.ca and/or Taunya Wideman-Johnston by phone 519-588-3084 or email @ taunyaw@nipissingu.ca.

INFORMED CONSENT TO PARTICIPATE IN RESEARCH

As a parent of a child participant in this research project, I understand what I am agreeing to do, and that I am free to decline involvement or withdraw from this project at any time, and there are steps being taken to protect me. I have read this Participant Information Letter and Consent Form and have had any questions, concerns, or complains answered to my satisfaction. I have been provided with a copy of this letter.

Name **Date**

Signature

This study has been reviewed and received ethics clearance through Nipissing University’s Research Ethics Board. If you have any questions regarding your rights as a research participant, contact:

Research Services
Nipissing University
North Bay, ON P1B 8L7
ethics@nipissingu.ca
705-476-8037