“I Had to be Brave”: Exploring Children’s Perspectives of Paediatric Medical Trauma and Resilience

by

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A thesis submitted in conformity with the requirements for the degree of Master of Social Work
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2016

Abstract

Using a phenomenological design, eight (8) children from a paediatric rehabilitation hospital, between the ages of 6 and 12, were interviewed to understand their medical experiences and issues of resilience. All children were exposed to what has been defined in the literature as paediatric medical trauma, or the overwhelming experiences that can occur in medical settings. Through an iterative hermeneutic based analysis, themes emerged about their medical trauma, understanding of resilience, and ways in which they viewed themselves and their environment. Children reported their most challenging symptoms in acute care, and experiences in rehabilitation that maintained difficulties. Though children did not understand the formal term resilience, they understood the concept in simpler terms. All children identified themselves as resilient, describing and giving examples of their resilience, which are discussed throughout the thesis. This study importantly amplifies children’s voices within their own care. Implications for future practice and research are discussed.
Acknowledgments

I would first like to thank my thesis committee, without whom, this project would remain a ‘what if…’ To Ramona, who took me on initially to complete an independent reading course, thank you for your dedication to my growth over the past two years. Despite a very full schedule, you continued your support as my thesis supervisor, guiding me and pushing me to stay on task. Thank you for your steadfast encouragement. Similarly, Keith, despite your busy schedule, dedicated time each week to helping me navigate the research process. Thanks for teaching me the importance of focus. And to Eunjung, who saw my potential from our first class together, thank you for your sharp insight, and challenging me to consider the process of learning over the final product. I understand that mentoring Master’s thesis students can be a thankless task. I not only want to acknowledge your time and effort, but also say that the best thanks that I can give to you is to continue to support emerging social workers and researchers as I move forward in my career.

There are many people at Holland Bloorview to thank for their support. To the SODR social workers, Val and Brittany, who supported me through this study from inception to implementation, thank you for your time, expertise, and encouragement. Thanks also to Dagmara and Melissa for their support, even outside of the SODR unit. I must also extend my sincerest gratitude to Sonia, a fellow student and researcher at Holland Bloorview. Your support, guidance, interest, and friendship sustained me through the challenges of this process.

To my partner, Tanner, my family, and friends, who stuck with me through the highs and the lows of the process. Thanks for your constant encouragement, interest, and for reminding me that playing hard is just as important as working hard. Tan, thank you for reminding me how important this work is when it got tough, bringing me caffeinated encouragement, reminding me that sleep is important, offering to help even when you knew it was not possible, withstanding my endless comparisons to anything happening around us to trauma and resilience, and not minding that my laptop suddenly became my plus one everywhere we went.

Finally, my sincerest appreciation goes out to the participants in this study, who shared their good and bad times with the honesty that can only be delivered by a child. Thank you for trusting me to tell your stories. We have so much to learn from you.
Table of Contents

Acknowledgments ................................................................................................................... iii

Table of Contents .................................................................................................................. iv

List of Figures ........................................................................................................................ viii

List of Appendices ................................................................................................................ ix

Chapter 1 Introduction .......................................................................................................... 1

1 Introduction ......................................................................................................................... 1

1.1 Study Overview ................................................................................................................ 1

1.2 The Problem of Paediatric Medical Trauma in Canada .................................................. 2

1.2.1 Intentional and unintentional causes ......................................................................... 2

1.3 Paediatric Medical Trauma Defined .............................................................................. 3

1.4 The Etiology and Risks of Paediatric Medical Trauma .................................................. 4

1.4.1 PMT as a childhood trauma ....................................................................................... 4

1.4.2 Post-traumatic stress symptoms .............................................................................. 5

1.4.3 Traumatic stress as a model for medical trauma ..................................................... 7

1.4.4 Traumatic stress as a disorder .................................................................................. 7

1.4.5 Acute versus chronic exposure to medical trauma .................................................. 8

1.5 Resiliency ......................................................................................................................... 9

1.5.1 The Social-Ecological Model of Resilience ............................................................... 10

1.5.2 The importance of exploring resilience ...................................................................... 12

1.6 Children’s Voices in Health Care ................................................................................. 13

1.6.1 Children’s rights ........................................................................................................ 14

1.6.2 Reconceptualization of children ............................................................................. 15

1.6.3 Including children as research participants ............................................................. 16

1.7 Study Rationale ............................................................................................................... 17

Chapter 2 Review of Background Literature ....................................................................... 19

2 Review of Background Literature ................................................................................... 19

2.1 Research Literature Reviewed – Paediatric Medical Trauma and Resilience ................. 19
2.2 Literature Review Results ........................................................................................................ 21
   2.2.1 Defining resilience in paediatric medical trauma .......................................................... 21
   2.2.2 Trajectories of resilience in paediatric medical trauma ............................................... 23
   2.2.3 The importance of child-centred perspectives .............................................................. 24
   2.2.4 Risk and protective factors ........................................................................................... 25
   2.2.5 Interventions .................................................................................................................. 29
2.3 Implications ............................................................................................................................. 31

Chapter 3 Design and Methods .................................................................................................. 35
3 Design and Methods ................................................................................................................ 35
   3.1 Hermeneutic Phenomenology ............................................................................................ 36
   3.2 Study Context .................................................................................................................... 39
   3.3 Sampling ............................................................................................................................ 40
       3.3.1 Sample Size ................................................................................................................ 42
   3.4 Recruitment ....................................................................................................................... 43
   3.5 Data Collection .................................................................................................................. 45
       3.5.1 Interview guide .......................................................................................................... 45
       3.5.2 Interview dialogue ..................................................................................................... 45
   3.6 Data Analysis ..................................................................................................................... 46
   3.7 Ensuring Trustworthiness ................................................................................................. 51
       3.7.1 Positioning statement ................................................................................................. 54

Chapter 4 Findings ...................................................................................................................... 57
4 Findings ..................................................................................................................................... 57
   4.1 Children’s Perceptions of Medical Experiences as Traumatic ......................................... 58
       4.1.1 Overwhelmed ............................................................................................................ 61
       4.1.2 Unexpected trauma and feeling unprepared ............................................................. 62
   4.2 Children’s Understanding of Resilience .......................................................................... 68
   4.3 Children’s Perceptions of Themselves as Resilient ......................................................... 68
       4.3.1 Theme: Perseverance ............................................................................................... 69
       4.3.2 Theme: Resilience as a process .............................................................................. 71
   4.4 Factors That Promote and Inhibit Resilience ................................................................. 71
       4.4.1 Theme: Control ......................................................................................................... 72
Appendix D – Recruitment Flyer ................................................................. 135
Appendix E – Assent Form ....................................................................... 136
Appendix F – Informed Consent Form ...................................................... 139
Appendix G- Interview Guide .................................................................. 143
List of Figures

**Figure 1.1** – Model of Bonfrenbrenner's (1979) Ecological Systems Theory

**Figure 1.2** – Social-Ecological Resilience Model
List of Appendices

Appendix A – List of Selected Abbreviations

Appendix B – Literature Review Table

Appendix C – Recruitment Script

Appendix D – Recruitment Flyer

Appendix E – Assent Form

Appendix F – Informed Consent Form

Appendix G – Interview Guide
Chapter 1
Introduction

1 Introduction

1.1 Study Overview

A significant number of children have had adverse experiences related to medical care that can be considered traumatic, which fall under the umbrella term of paediatric medical trauma (PMT). (See Appendix A for a list of selected abbreviations used throughout this thesis). PMT can be defined as the physical and psychological effects of injuries, pain, and illness, as well as the experience of hospitalization, medical treatments, and other procedures (National Child Traumatic Stress Network [NCTSN], 2004; Webb, 2009). Over time, PMT can cause a range of reactions in affected children, from post-traumatic stress symptoms including hyper-arousal, re-experiencing, and avoidance to clinical labels of post-traumatic stress disorder, depression, anxiety, and other mental health concerns (Klinic, 2013). Despite the challenges that children face within and beyond the hospital, most are resilient to this adversity (Furtado, 2015). The intersection of literature covering PMT and resilience is currently understudied and sporadic, focusing mainly on parent and professional perspectives, failing to understand the experience from children’s perspectives. Given that trauma is not based on the objective severity of the event, but subjective perceptions, it is important to understand children’s perspectives (NCTSN, 2004). Despite patients’ rights to be involved in their own care, paediatric clients are dually marginalized by their age and also by their health status (Taub, 2003). Thus, it is even more important to provide space for their voices to be heard, valued, and shared in the context of their own care. The goal of this thesis is to examine children’s perspectives of their experiences of PMT and resilience. This study proposed a phenomenological design using a social-ecological theoretical framework to explore resilience through the lived experience of children who have been exposed to PMT. Eight in-depth interviews were conducted with Specialized Orthopaedic and Developmental Rehabilitation (SODR) inpatients from Holland Bloorview Kids Rehabilitation Hospital aged 6-12 years old. Kvale’s (1996) interview methodology was used to elicit rich narrative data for a phenomenological analysis. The overall study aim was to provide a more holistic picture of children’s experiences of PMT and resilience and to use these findings to inform health care practitioners on how to better care for children in the hospital.
1.2 The Problem of Paediatric Medical Trauma in Canada

Murray and Lopez (1996) stated in a World Health Organization report that medically traumatic events are one of the most potentially traumatizing events in childhood worldwide. In Canada, unintentional injuries are the leading cause of mortality, morbidity, and disability among children, and have been for a number of years (Oliver & Kohen, 2015; Public Health Agency of Canada, 2009). Approximately one-third of children have experienced traumatic injuries and illnesses (Copeland, Keeler, Angold, & Costello, 2007). Children make up less than one percent of new cancer diagnoses per year, though this is significant given the treatment and effects of cancer can last beyond childhood and even life long (Ellison, De, Mery, & Grundy, 2009).

Medically ill and injured children are exposed to circumstances before, during, and after hospitalization that can be considered traumatic. These events can include shocking accidents, scary rescues, painful and invasive procedures, separation from parents, intensive rehabilitation, life-threatening illnesses or injuries, or lasting physical scars, impairments, or disabilities. Additionally, hospitalization itself can be distressing (NCTSN, 2004; Webb, 2009). PMT also includes the physical and psychological effects of injuries, pain, and illness, as well as the experience of hospitalization, medical treatments, and other procedures (NCTSN, 2004; Webb, 2009). This type of trauma has recently been distinguished as a type of childhood trauma, and is formally referred to as paediatric medical trauma (PMT). The following section will further highlight the scope of this issue in Canada.

1.2.1 Intentional and unintentional causes.

Within this topic, it is important to distinguish between unintentional and intentional injuries, or to differentiate between the perceived causation of injuries. Unintentional injuries are those that are accidental and can include motor vehicle accidents (MVAs), poisoning, falls, fires, burns, or drowning (World Health Organization [WHO], 2008). It is notable that the use of the term ‘accident’ is discouraged, based on the concept that both intentional and unintentional injuries are not random and can be prevented (WHO, 2008). Intentional injuries are inflicted based on a purposeful motive, and can include exposure to interpersonal abuse, neglect, community violence, or war (WHO, 2008). Intentional injuries can also be self-inflicted, as in self-harm or suicide attempts.
In Canada, approximately 418 out of every 1,000 children were hospitalized in 2008 (Public Health Agency of Canada, 2012). The majority of these hospitalizations were related to unintentional injuries (i.e. 333 out of 1,000 children), with falls making up nearly half of this figure (Public Health Agency of Canada, 2012). Intentional injuries occurred less often, but remain a significant proportion of Canada’s children and youth. Approximately 78 out of 1,000 children sustained intentional injuries; of these 78 injuries, 44 were self-harming, and 34 were assaults from others (Public Health Agency of Canada, 2012). In the same year, the rate of substantiated child maltreatment was approximately 16 children of 1,000 children in Canada (Public Health Agency of Canada, 2010). Children who have been maltreated and require medical intervention are at greater risk for adverse outcomes, within and beyond hospitalization, given their accumulation of traumatic exposure (Klinic Community Health Centre, 2013). The complexities of maltreatment-based injuries necessitate distinction in traumatology literature, and though this is a critically important topic, it remains beyond the scope of the current study. This thesis will focus on children who have experienced PMT from unintentional causes, which make up the majority of hospitalizations. Despite the high prevalence of unintentional injury and illness in Canada, the effects have been documented in traumatology literature to a far lesser degree than maltreatment (Schwartz et al., 2011), yet the risks of these types of trauma are significant to developing children.

1.3 Paediatric Medical Trauma Defined

Medical trauma is broadly defined by behavioural paediatrician Joan Lovett (2009) as “any overwhelming experience that is related to illness, injury, or medical treatment” (p. 60). Within the scope of this paper, the term medical challenge will be used synonymously with PMT. Webb (2009) noted that this terminology acknowledges difficulty, but also suggests that as a challenge, it can be overcome. Though there is a distinction between medicine and surgery in paediatrics, medical trauma can be used to describe both experiences (Kassam-Adams, 2009; Levett, 2009; Webb, 2009). This broad description is justified given that definitions of medical trauma place greater emphasis upon the child’s assessment of the event rather than the specific event itself (Levett, 2009; Webb, 2009).

Kazak and colleagues (2006) created The Integrative Model of Medical Traumatic Stress (The Integrative Model) following medical challenges (to be discussed later in this chapter), justifying
its use across illnesses and injuries. The authors noted that the single commonality among survivors of PMT is the challenge it presents to children (and their parents, siblings, peers, and others) about the world as a safe place and invulnerability (Kazak et al., 2006). Other common factors between medical challenges that distinguish them as traumatic may include (perceived or real) life-threat, uncertainty about the course and outcome of the event, a frightening hospital environment, including high-tech and invasive equipment for treatment, and potentially, severe pain (NTCSN, 2004). In contrast, within a specific type of medical issue there can be a great deal of heterogeneity (e.g. “degree of acuity, onset, length of exposure, intensity, threat of reoccurrence, follow-up complications, obviousness, and the number of family members directly involved” [Kazak et al., 2006, pp. 347]), which may affect whether it is perceived as traumatic or not. Thus, it is appropriate to have a broad perspective of PMT.

1.4 The Etiology and Risks of Paediatric Medical Trauma

1.4.1 PMT as a childhood trauma.

PMT is a type of childhood trauma, which is defined as an event (or series of events) in which a minor experiences or perceives a threat to their own, or a loved one’s “sense of self, safety, or survival” (Schwartz et al., 2011, p. 3). Traumatic childhood events have three defining features: the event was unexpected, the child was unprepared, and there is nothing that could have been done to stop it (Klinic Community Health Centre [KCHC], 2013). The classification of an event as traumatic is based on the child’s assessment of their experience, and not necessarily the presence or absence of the event itself (Levett, 2009). Importantly, trauma is perceived and therefore, experienced differently based on a child’s context and culture (Ungar, 2013).

Similarly, and as with any type of trauma, the responses a child has to medical trauma are subjective to their experience and perceptions of it, not the objective severity of the event (NCTSN, 2004). The reactions that children experience can vary in intensity and range from adaptive to dysfunctional. For this reason, best practices necessitate the use of screening tools in acute or emergency settings, to screen children who may be more at risk of developing clinical symptoms of traumatic stress (NCTSN, 2004). The reactions that children have to medical challenges will be discussed in the following section.
1.4.2 Post-traumatic stress symptoms.

The difficulties children face following medical trauma are generally referred to as post-traumatic stress symptoms (PTSS). Up to 80% of children experience some form of PTSS (NTCSN, 2004). For most children, these stressful reactions are normative and adaptive in the face of trauma, and will become weaker over time until they subside (Children’s Hospital of Philadelphia, 2014). Yet one in six children still experience bothersome, or significant, PTSS six months past the initial event (Children’s Hospital of Philadelphia, 2014). A meta-analysis conducted by Kahana, Feeny, Youngstrom and Drotar (2006) found that across 26 studies, the average prevalence rates for significant PTSS was 20% in injured children and 12% in ill children. It is important to note that significant PTSS are associated with adverse outcomes, regardless of whether PTSD is eventually diagnosed or not (Holbrook, et al., 2005).

PTSS includes hyper-arousal, re-experiencing the traumatic event, and/or avoidance of reminders or triggers to the accident (NCTSN, 2004; Smyth, 2008). Hyper-arousal can include feelings of anxiousness, jumpiness, or being ‘on edge’, with symptoms such as excessive worrying, startling easily, having outbursts, difficulty maintaining focus, and/or difficulty sleeping (Children’s Hospital of Philadelphia, 2014). Re-experiencing can include thinking a lot about what happened, having nightmares, or physical symptoms associated with reminders of the event (e.g. stomachache, headache, increased heart rate) (Children’s Hospital of Philadelphia, 2014). Children may demonstrate avoidance as a stress reaction by not talking about the event, staying away from any reminders of the event, developing fear(s), and/or a general disinterest in previously enjoyable activities or company (Children’s Hospital of Philadelphia, 2014).

It is important to consider the relative utility of each of these symptoms in the context of survival. Trauma overwhelms a child’s ability to cope, and often produces a physiological ‘fight, flight, or freeze’ response (van der Kolk & Courtois, 2005). Hyper-arousal is the manifestation of this response state for a prolonged period of time, which is adaptive in the face of stressors, but the resulting cascade of physiological reactions in the body can lead to physical and mental health issues if unresolved (van der Kolk & Courtois, 2005). Re-experiencing the event is adaptive in the sense that it allows an individual to remember and work through what happened to them, however, this is concerning when children experience uncontrollable and invasive flashbacks, which can be just as distressing as the event itself (Shalev & Ursano, 2003). Finally,
avoidance may include children becoming more cautious than before, or preventing themselves from encountering triggers that may be too difficult to deal with, but if unresolved, can interfere with daily life (Children’s Hospital of Philadelphia, 2014). Together, these responses are adaptive in that they communicate to those in a child’s social environment that they are distressed and require support (Kassam-Adams, 2006).

It is important to distinguish between stress and traumatic stress. Medical challenges are stressful in the sense that they are difficult to manage and strain a child and their family’s resources to cope (NTCSN, 2004). However, some aspects are considered traumatic in the sense that they are extremely frightening, are sudden, overwhelming, involve pain, and may be life threatening (NTCSN, 2004). These reactions do not just strain the child and family, but also seriously impair overall functioning (NTCSN, 2004). This is particularly relevant for parents, who are important models for children during this time, and who may also face difficult decisions under traumatically stressful situations (NTCSN, 2004).

There are a number of known risk factors that increase the likelihood of children developing more significant PTSS, including a history of traumatic experiences or behavioural and emotional issues, displaying severe stress reactions early on, experiencing more intense pain, exposure to frightening stimuli (i.e. sights and sounds) in the hospital, separation from parent or caregiver, lack of peer support, perception of life threat or severity of issue (Children’s Hospital of Philadelphia, 2014; NCTSN, 2004). Alternatively, protective factors include parental presence and support, and positive peer supports (Children’s Hospital of Philadelphia, 2014).

By definition, when PTSS persist over time, this causes impairments to day-to-day functioning (Kassam-Adams, 2005). Considering the range of stressful reactions and avoidance that medical trauma can cause, PTSS can affect patients’ adherence to medical treatment (Children’s Hospital of Philadelphia, 2014) and impede optimal recovery (NCTSN, 2004). Consequently (and similarly to other traumas), PMT can result in negative and distorted thoughts about oneself (i.e. “It’s my fault this happened to me”) (Lovett, 2009). In all, these reactions cause disruptions to typical development and can form the basis of clinical diagnoses, discussed next.
1.4.3 Traumatic stress as a model for medical trauma.

As mentioned previously in this chapter, Kazak and colleagues (2006) created The Integrative Model to describe the commonalities in medical traumatic stress across injury and illness, which included three identified general stages across time, phase I, II, and III. Phase I is the peri-trauma period occurring during and immediately after the potentially traumatic event (Kazak et al., 2006). Phase II is the acute stage that unfolds during treatment; PMT is assumed to be ongoing and dynamic. Finally, phase III is the long-term effects, after treatment is complete. It is notable that this model is family-centered, and that there is no one expected trajectory through the model. Survivors of PMT may experience recurring or cycles of trauma; it is possible that trauma can re-occur. The participants included in this study will likely be in the phase II stage, as they are still in treatment, rehabilitating following orthopedic injuries or procedures.

1.4.4 Traumatic stress as a disorder.

Clinically, PMT is most closely associated with acute stress disorder (ASD) and post-traumatic stress disorder (PTSD). Notably, clinical diagnoses are not the preferred measure of difficulties, as many children suffer from sub-clinical symptoms and/or the profile of their symptomology may not fit classification requirements (Kazak et al., 2006). ASD is defined by dysfunctional and disruptive symptoms of hyper-arousal, re-experiencing, and avoidance behaviours, enduring for more than two days and up to four weeks following the incident (American Psychiatric Association, 2013). If these symptoms persist beyond four weeks and continue to impair daily functioning, a diagnosis of post-traumatic stress disorder (PTSD) may be appropriate, according to the Diagnostic and Statistical Manual, 5th edition (American Psychiatric Association, 2013). The main difference between ASD and PTSD, other than the length of time from the initial event, is the presence of dissociative symptoms in ASD (i.e. numbing, reduced awareness, depersonalization, derealization, or amnesia) (American Psychiatric Association, 2013). Dissociative symptoms are included as a ‘specifier’ in PTSD diagnoses (American Psychiatric Association, 2013). PTSD can affect children in all or any of the bio-psycho-social domains of life (Fairbank & Fairbank, 2009) and there is evidence to suggest that there is an interplay between these domains that determines whether and how stress reactions will manifest in children (Marsac, Kassam-Adams, Delahanty, Widaman, & Barakat, 2014). Other mental health issues that may arise following exposure to trauma include anxiety, depression, conduct disorder,
borderline personality disorder, phobic disorder, panic disorder, and others (Klinic, 2013). Terr (1991) notes that the symptoms exhibited by these disorders may be better explained by responses to trauma than by psychopathology. Given the vulnerability of children at this stage, and the potential long-term challenges they may face, it is important to thoroughly address instances of childhood trauma, as it is thought to be the root cause of many mental health issues (Terr, 1991).

### 1.4.5 Acute versus chronic exposure to medical trauma.

Trauma can occur as a single event, series of events, or as a chronic condition, which can produce varied responses and risks as exposure to trauma accumulates. Bronfman, Campis, and Koocher (1998) differentiate between two types of PMT: event-related trauma, referring to the actual event and potential rescue process (i.e. car accidents), and iatrogenic trauma, which is derived from medical procedures following an injury or illness (i.e. emergency surgery). Bronfman and colleagues (1998) further elaborated on event-related trauma and iatrogenic trauma – conceptualizations that can be compared to Terr’s (1991) seminal work on childhood trauma, which roughly distinguished two types - Type I and Type II. Type I is defined as occurring suddenly, is acute and unforeseen, while Type II is repetitive in nature, occurs over time, and is chronic (Terr, 1991). Single events causing physical injury or illness may be reflective of Type I trauma, while permanent physical changes, such as disability or disfigurement, may reflect the lasting symptoms of Type II trauma (Terr, 1991). Terr (1991) also discussed ‘complex trauma’ in which children demonstrate a combination of the two types, often seen in accidents or sudden-onset illnesses or viruses that cause lasting damage or chronic pain. It is important to remember that irrespective of the ‘type’ or ‘category’ of trauma that children experience, trauma creates the potential to adversely impact children’s functioning and development in various domains.

Despite the high risk that PMT presents children at this vulnerable stage of development, whether chronic or acute, meta-analyses have demonstrated that children are remarkably resilient overall (Webb, 2009), even without professional intervention (Kassam-Adams & Winston, 2004; Kazak et al., 2006). Current research focuses on screening tools to identify children who present with greater risks for chronic traumatic stress reactions, as well as preventative intervention and treatment programs (Children’s Hospital of Philadelphia, 2014). Though these studies are
important, most fail to address the strengths that children possess. By better understanding what makes children resilient, we can promote these factors in all children, as opposed to targeting children that will (ideally) be addressed through screening and early intervention. Resilience involves navigating adversity using an individual’s resources (Ungar, 2008, 2011). By understanding what resilience means to children, and taking inventory of a child’s current inventory of resources, we can more effectively provide support to help children overcome their medical challenges.

1.5 Resiliency

Resilience represents a shift in how researchers and practitioners approach issues related to trauma and other adversities, drawing upon influences from positive psychology and prevention science (Greene, 2008). Resilience was first conceptualized by Rutter (1987) as uniquely successful adaptations to adversity that moved beyond mere surviving to thriving. Later, Borden (1992) introduced the personal narrative to resilience, where resilient individuals were those who were able to maintain their personal narrative over their life course. Masten (1994) classically defined resilience as ‘ordinary magic’, where children and adolescents have an almost supernatural ability to cope with stressors. Traditional theorists viewed resilience as an individual-level trait that manifests in a variety of ways (Greene, 2007).

The more contemporary view of resilience shifts the scope of resilience from a sole micro perspective to also exploring the role of the mezzo and macro systems. Michael Ungar (2008, 2011, 2013) has further drawn upon the seminal work of Urie Bronfenbrenner’s (1979) Ecological Systems Theory to investigate how systems like families, schools, teams, cultures, and communities can help or hinder adaptive responses. Ungar (2013) stated that “this resistance to the effects of exposure, also termed resilience, is less a reflection of the individual’s capacity to overcome life challenges as the child’s informal and formal social networks to facilitate positive development under stress” (p. 255). Therefore, supportive and connected environments are more requisite to successful adaptation to challenges than the presence of a specific inborn genetic trait or characteristic (Ungar, 2011). The social ecological perspective posits a person-in-environment stance, which aligns with the social work basis of this thesis. Further, as health professionals and organizations shift to more client-centred models of patients (Ungar, 2011;
2013) this model is especially appropriate. Therefore, social ecology will be used as the guiding framework for critically analyzing the intersection of resilience and PMT.

1.5.1 The Social-Ecological Model of Resilience.

Ecological Systems Theory (Bronfenbrenner, 1979) has become a seminal application of recognizing the influences of an individual’s environment, particularly in children. This model is a foundational element of social work practice. A traditional image depicting the systems surrounding each individual can be found as Figure 1. At the center of the model is the individual, who possesses his or her own intrapersonal skills, values, and perspectives, as well as their biological predispositions. Surrounding the individual are systems that affect them, notably,
less directly as you move further from the individual. First, the microsystem represents the direct effects of relationships with others, such as parents, siblings, and friends. Relationships within this level form the mesosystem, which is most often seen in parental relationship with teachers, or parent relationship with health care providers. Exosystem influences exert influence indirectly through policies that affect an individual, such as hospital or departmental policies and funding systems. All greater cultural influences fall under the macrosystem; one example is perceptions of hospitalized children through media. Finally, the chronosystem represents historical changes over time, such as the shift from solely recognizing the physical aspect of health to incorporating psychological and social well-being as well.

Similarly to Bronfenbrenner’s (1979) theory, social-ecological models of resilience place the individual child at the center of the model, and their pervasive influence through all systems is apparent. Consider the adapted model in Figure 2. Each of the systems not only wraparound each

![Figure 2 – Social-Ecological Resilience Model](Untitled image of resilience model). Retrieved from www.open.edu

child, but work together to raise the child to the top of the model. It is known that there are many aspects of a child’s social environment that affect trauma and subsequent coping (e.g. whether parents were present, involvement in religious groups), and this needs to be recognized so we can continue to build on a child’s strengths (Kahuna et al., 2006; Kazak et al., 2006). Luthar and Cicchetti (2000) advised that when considering resilience as a model, it is important to acknowledge that any positive individual adaptations are steeped in the social norms in their environment.

For the purpose of the following thesis, resilience was conceptualized using Ungar’s all-encompassing, social-ecological definition of resilience:

In the context of exposure to significant adversity, resilience is both the capacity of individuals to navigate their way to the psychological, social, cultural, and physical resources that sustain their well being, and their capacity individually and collectively to negotiate for these resources to be provided and experienced in culturally meaningful ways (Ungar, 2008; 2011).

Thus, resilience is perceived to be a process that occurs over time in response to hardship, where the responsibility for the resilience-sustaining resources is shared between the individual and their environment. This process includes positive adaptations by the individual to their environment to achieve and sustain well being.

1.5.2 The importance of exploring resilience.

Resilience is not about making individuals immune to trauma, or in this case, preventing children from experiencing post-traumatic stress symptoms. The ideal of a child who can get through difficult experiences in the hospital unaffected is an unrealistic and unhelpful expectation. Instead, this study sought to identify the challenges that children face within the hospital and how they built strength through these experiences. The stimulus for this research project was based on my experiences at Holland Bloorview Kids Rehabilitation Hospital (HBKRH). During my first social work placement, I provided psychosocial support to children in the on-site school, Bloorview School Authority, as well as co-facilitated a social support group for children on the Specialized Orthopaedic and Developmental Rehabilitation (SODR) unit. It was from this experience that I came to hear of children’s medical circumstances, from health care providers,
but most often from clients themselves. In speaking to these young clients, I was amazed at each child’s capacity for resilience facing this adversity and I wanted to know more about how children seemed to adjust so well in a very difficult time, especially during an important stage of development.

Exploring resilience is beneficial for a number of reasons. This lens focuses on strengths and competencies, transforming what could be viewed as ‘deficits’ as either adaptive or maladaptive in the context of the individual (Luthar & Cicchetti, 2000). Trauma and resilience, as discussed, are highly unique to a child and their perceptions, thus what professionals may believe to be maladaptive could be considered protective to a child. This is apparent in the previous discussion of the survival-based benefits of trauma. In our multicultural society, it is increasingly important to recognize the variation in adaptation, and provide culturally sensitive supports (García-Coll et al., 1996). Resilience naturally promotes early intervention as opposed to treatment, as is the case when practitioners are looking for issues to resolve (Luthar & Cicchetti, 2000). Thus, promoting resilience is not just targeting those who are displaying problematic symptoms, which may fail to identify children who are struggling. Instead, it is continuing to build on the strengths and resources each child possesses and can access within their environment. When applied to research, resilience attempts to explain how certain characteristics lead individuals to resilient or vulnerable pathways (Luthar & Cicchetti, 2000).

A potential issue with resilience is the possibility for it to be perceived as a personal trait (i.e. resiliency), and as such, an individual’s responsibility for obtaining the skills necessary to succeed (Luthar & Cicchetti, 2000). This is especially problematic with at-risk children and youth, who face environmental adversity that reaches far beyond ‘trying harder’ (Luthar & Cicchetti, 2000). In defining resilience within a social- ecological context, the onus is on the community to promote resilience (Ungar, 2013). This is logical given that either the benefits of positive adaptation, or the downfalls of maladjustment will be experienced in the community.

1.6 Children’s Voices in Health Care

A significant contribution of this research is the recognition of children’s presence in the context of their own care. The children involved in this study are in middle childhood, a period typically thought to extend from age 6-12 years old. During this time, children begin to spend more time away from their families, and develop their own identity as they independently discover the
world around them (Berger & Chuang, 2014). During middle childhood, young people become more reasonable as they develop greater flexibility in their thinking, increased self-awareness, and the ability to recognize and understand others’ feelings (Berger & Chuang, 2014). Current literature mostly evaluates adults’ reactions to trauma and insufficiently recognizes the differences that children bring as a result of their developmental level (Alisic et al., 2011; Salmon & Bryant, 2002). For example, children’s language and knowledge will affect how potentially traumatic events are encoded, perceived, and committed to memory (Salmon & Bryant, 2002). For example, in a study of paediatric cancer survivors, Kazak and colleagues (1997) suggested that children may not have understood the real risk of their diagnosis and been protected from the risk of developing clinically traumatic symptoms. As children work through trauma, developmental factors such as emotional regulation, emotional intelligence, awareness of mental processes, and inhibition of specific cognitions affect the impact of the event (Salmon & Bryant, 2002). Taken together, children experience trauma differently than adults, but it is undesirable to expect or wish for children to be passive in their care. As will be discussed, children have the right to be involved in decisions that affect them, as they possess agency, and - despite concerns about including children in research - their perspectives are important in changing the current landscape of paediatric care.

1.6.1 Children’s rights.

The rights of children in the context of their own health care are receiving increased attention, especially as health care systems move to more client-centered and family-centered care models. The United Nations (1989) Convention on the Rights of the Child asserts that every child has the right to self-determination, dignity, respect, non-interference, and the right to make informed decisions. This aligns with rights granted to patients, but paediatric patients represent a special case in that decisions are ‘triadic’, involving a complex relationship between the child, their parent or guardian, and the health care practitioner (Taub, 2003). However, current frameworks are more reflective of legal entitlements, which deem children incompetent in decision-making, than on the imperatives of medical ethics and children’s rights (Canadian Paediatric Society, 2004). This is concerning because children are a vulnerable population due to their position of power relative to their parent’s influence and health care providers’ position of power relative to parents. Hospitalized children may be further marginalized by their health status as well, and deemed incapable of involvement based on external factors. Certainly, professionals and
guardians are expected to consider the best interests of their children when making medical decisions. Despite the shift toward client and family centered care, more attention needs to be focused on how to involve children in their own care, as many children still have no voice in their care. Involving children in their care is not about giving children final say about important decisions, or disregarding parental or professional advice, but instead, including children as appropriate, based on their developmental level (Taub, 2003). To this end, a spectrum can exist that is respectful of children’s direct experiences and responsive to children’s agency, which may involve providing accurate information at a basic level, and providing choices to children when possible (Canadian Paediatric Society, 2004; Taub, 2003). For example, an injection may be non-negotiable, but perhaps a choice of location could be offered to the child. As discussed, it is important to recognize the developmental level of children, be understanding that they may not grasp the long-term necessity of their care, and be empathic to the fact that though their care may be routine to practitioners, it is extraordinary for children, and often quite frightening and overwhelming.

1.6.2 Reconceptualization of children.

In the context of resilience literature, age has been described as being a cultural characteristic, or as reflection of social norms within a particular group (Ungar, 2013). This is a shift from previous developmental and structural perspectives which viewed children as “vulnerable, incomplete… ‘adults-to-be’” (Överlien, 2016, p. 2). More recent conceptualizations recognize the agency, or ability to independently behave, that children possess (James & James, 2012). This is particularly important in the context of a social ecological perspective, because the relationships between children and the systems surrounding them are not passive or unidirectional, but dynamic and bidirectional (Överlien, 2016). Children possess information and knowledge that is different from adults, but are nonetheless capable social actors (James & Prout, 1997). For this reason, it is inappropriate to use adults as sole proxies for children’s opinions, and imperative that children are included on matters that concern their own experiences (Kirk, 2007). Childhood itself is socially constructed, and is reflective of the social, cultural, and historical norms of the time (James & Prout, 1997). Importantly, age does not chronologically follow the same trajectory of development and is a relative concept (James & James, 2012). Children who have been hospitalized may have experienced interruptions in what would be
considered ‘typical childhood’ as compared to their peers, and chronological ages may be more or less relevant to their current development.

1.6.3 Including children as research participants.

Including children in research has been discouraged in the past based on the assumptions that data obtained from children was unreliable and their vulnerability places them at risk of exploitation (Kirk, 2007). Children’s accounts may not be a perfectly accurate recount of the event, but instead, reflect their subjective perspectives (Punch, 2002). Other issues include that the content of the interview may reflect the methodology used, particularly with children (Kirk, 2007). It is important to note that these issues also exist in research completed with adults and current literature suggests that when this is taken into account, it is possible to include children in research and accurately represent their worldview (Creswell, 2013). This issue also calls into question the assumptions that are made by the researcher. As will be discussed further in the Methodology section (Chapter 3), this study took a postmodern approach (Kvale, 1996), which posits that there is no one, singular ‘truth’ and that all accounts of reality are valid and will be respected as such. In fact, it is important to consider what children perceive to be their reality so we can better understand and address their unique needs following trauma from this perspective. For this reason, it was not only sufficient, but imperative to include children in this study to explore their experiences of PMT and resilience.

Taken together, valuable information from children themselves is scant in this area. Exploring children’s perspectives fits within the values of social work, which seeks to acknowledge and bring forward the voices of those who are marginalized. Children who have been hospitalized are dually marginalized because of their young age and because of their health status. Both are important considerations when involving children in their care, but the bottom line is that children have the right to be involved in their own care. Given consent laws, health care professionals are expected to offer their expertise and advise in the best interest of their clients, and parents are expected to make decisions that will benefit their child. The findings of this research will do more than inform clinical practice, they will contribute to the growing literature on including children “in their own” voice, which may have a direct impact on the importance of asking children about their own childcare experiences, and approaches to research with children in healthcare.
1.7 Study Rationale

It is clear that much remains to be discovered in the area of PMT and resilience, particularly from children’s perspectives. The proposed study aims were to begin to address this gap in literature by exploring the often-overlooked child perspective of PMT and resiliency. Children aged from 6 to 12 years old who were receiving care in the Specialized Orthopaedic and Developmental Rehabilitation (SODR) unit at Holland Bloorview Kids Rehabilitation Hospital (HBKRH) participated in in-depth interviews guided by Kvale’s (1996) interview methodology to elicit rich narrative data for a phenomenological analysis.

Choosing hermeneutic phenomenology was an important personal choice, as it best reflected the values and epistemological stance that I hold as a social worker best, in comparison to other methodologies. I have learned that hermeneutics is about discovering the lived experiences of individuals, which was ultimately what I wanted to capture with this research. Unlike transcendental phenomenology, the data is not only a rich description of the participant’s experiences, but also reflects what it means to children to be a child in the hospital experiencing PMT. In other words, it goes beyond the descriptive to capture the meaning made by the child participants. Current literature fails to consider this perspective, instead relying on interpretations of children’s experiences through the lens of a parent, or health care professional. Hermeneutics also recognizes participants as the experts in their own lives who are capable of giving meaning to their experiences. Ultimately, this fits with the mandate of social work practice, which places great value on the life view of the client, and respects this by allowing clients autonomy. Social work also seeks to break down power imbalances, which is relevant to the current study given the participant’s age and health status vulnerabilities. Children have the right to be involved in their own care and current clinical models devalue this right, placing ultimate power to experts – health care professionals. My experiences with paediatric patients has taught me that children have many things right about their experiences, and we have much to learn from them if they are given a platform to share their voice. It has been my goal for this study to be their platform.

Thus, this study posed the broad question of ‘How do children experience potentially traumatic medical events, and how (if at all) are they resilient in these circumstances? More specifically, the research questions were:
1. In what ways do children consider their medical experiences traumatic, or not?
2. How do children describe and understand resilience?
3. In what ways do children perceive themselves as resilient, or not?
4. What factors do children perceive in promoting or inhibiting resilience? And how do they make meaning from these factors?

The findings of the study will be used to inform future clinical practice and research. Children’s ability to be resilient is partially dependent on professionals’ understanding and application of traumatic stress (Kazak et al., 2006; NTCSN, 2004). Before we as professionals can help children, we must first understand the issue, identify strengths and weaknesses, then create appropriate interventions. Given the assessment of an event as traumatic (or not) is determined by an individual, it is imperative that medical challenges are explored through the lens of the children who have direct experience. Similarly, resilience is not a static concept, but a dynamic adaptation unique to each child and their individual social ecology. Trauma-informed care has the capacity to adapt children’s emotional reactions and coping strategies, which can improve both physical and psychological outcomes (Alisic et al., 2011). Smyth (2008) notes that trauma work intersects with a variety of health disciplines and social workers are well-positioned to organize, build connections, and lead interprofessional teams that would benefit from a trauma-informed and resilience-based model. Therefore, using a strengths-based resiliency framework has the potential for direct positive effects for affected children, as well as for their families and other systems that are affected by medical challenges.
Chapter 2
Review of Background Literature

2 Review of Background Literature

The purpose of the following chapter is to review the current literature describing resiliency in children who have experienced PMT. From a social-ecological framework, the literature review examines and critically reviews resilience models in PMT, finding common ground between approaches. The review justifies a child-centered model, and will explore individual and environmental levels of risk and protective factors. This scoping review was completed in preparation for the current study and published in the International Journal for Child and Youth Resilience (see Furtado, 2015). The content has been revised for applicability to this thesis.

2.1 Research Literature Reviewed – Paediatric Medical Trauma and Resilience

Given that the intersection between PMT and resilience is relatively new, it was anticipated that limited literature would exist in this area. As a result, a scoping review was determined to be more appropriate than a systematic review. The purpose of a scoping review is to create a map of the existing literature (Arksey & O’Malley, 2005; Pham et al., 2014). In undertaking the objectives of a scoping review, the specific, iterative method of searching described by Arksey and O’Malley (2005) was followed in order to ensure sufficient saturation and unbiased investigation of the topic. This approach necessitates five stages: (1) creating a research question, (2) identifying appropriate studies, (3) selecting studies, (4) charting data, and (5) organizing and reporting the results (Arksey & O’Malley, 2005). The research question that guided this investigation was: What is known from the existing literature about the resilience of children ages 0-18 who have experienced medical trauma? From this research question, limitations were placed on the search in order to locate and select appropriate studies.

In the second stage of scoping reviews, a methodical approach to inclusion and exclusion criteria for identifying appropriate studies is required (Arksey & O’Malley, 2005; Pham et al., 2014). The limitations placed upon the methods of scoping in this review included the keywords, date range, and databases selected, which will be described in further detail. The keywords used in this literature review were important in capturing the right type of trauma, population, and
framework. These three domains were reflected in the search strategy. The first refers to the type of trauma – paediatric medical trauma. This term was inconsistent across databases and therefore derivatives of the following terms were used to correctly capture PMT: paediatric trauma, paediatric trauma, physical trauma, medical trauma, medical traumatic stress, accident, injury, and illness. Note alternative spellings were included to ensure comprehensiveness. The second group of keywords focused on the population, which were children aged 0-12 years old. The keyword used was child*, the asterisk allowing multiple endings (i.e. child, children, childhood, etc.). Using this strategy was found to be effective throughout the search and was therefore maintained across databases. Finally, resilien* (i.e. resilience, resiliency, resilient) or emotional adjustment was found to be effective when searching databases. The date range was capped as far back as 2008, unless the work was seminal or critical to the understanding of the topic. Similarly, the search strategy sought to collect only peer-reviewed journal articles, however, book chapters that examined empirical studies and incorporated practice wisdom were also included, if relevant and critical to understanding of topic.

Ultimately, four types of searches were conducted to ensure a comprehensive database search. The first was a catalogue search to obtain an overall picture of the journals, books, and other publications that existed on the topic. This was followed by database searches. Given the social work intent of this paper, top social work databases were searched (Social Services Abstracts, Social Work Abstracts, ASSIA, Social Sciences Abstracts, The Campbell Collaboration, The Cochrane Library, HealthStar/ OVID HealthStar, PsychINFO, Social Sciences Citation Index, Sociological Abstracts, Encyclopaedia of Social Work). The third strategy involved entering the search terms into the institutional library’s articles tab to ensure a thorough search. Finally, Google Scholar was used to cross-reference with the institution’s materials and other online sources.

The third stage of scoping reviews requires the author to select appropriate studies (Arksey & O’Malley, 2005; Pham et al., 2014). Many of the articles examined specific types of medical trauma as opposed to PMT as a whole. Therefore, the author methodically selected those that fit within the definition of PMT as including a significant element of trauma as defined by Lovett (2009) as an “overwhelming experience” for a child (e.g. eczema was excluded, but cancer was included). Furthermore, children must have been the focus of the model, study, or intervention,
in maintaining consistency with the social-ecological perspective of resilience. Finally, resilience theory must have been used in a way that was determined by the author to be significant. Resilience is an increasingly popular area of study, with varying approaches and applications. Thus, the presence of the keyword resilience within the article or abstract was insufficient to qualify; resilience must have been used as a model from which to frame the study. The following section discusses the final selections that are explored in detail, after all of the scoping limitations were applied.

2.2 Literature Review Results

Together, the search yielded nine studies and several chapters within one book, which collectively informed the remainder of this report. Generally speaking, four of the articles focused on building theories and models within PMT, three examined intervention strategies, and two examined risk and protective factors, though there is overlap between the topics. This literature review confirms that this study will be the first of its kind to directly explore children’s perspectives of PMT and resilience and will therefore become an important explorative addition to the literature to this area. As part of the fourth stage described by Arksey and O’Malley (2005), the selected studies were summarized into a chart. The chart, which can be found as Appendix B, includes more detailed information about the purpose, methodology, main findings, and application of each journal article. The final stage of a scoping review requires organizing and reporting the results of the review (Arksey & O’Malley; Pham et al., 2014). The following section seeks to provide an overview of the results and generate some coherence among the wide breadth of articles collected.

2.2.1 Defining resilience in paediatric medical trauma.

This literature review examined resilience within the context of paediatric medical trauma. The articles located in the systematic search yielded a limited number of academic publications covering a wide scope of types of trauma, approaches to resilience, methodologies, and findings. Resilience was determined to be relatively high overall in the populations examined in the studies, with rates ranging from 57%-84% (DeYoung, Kenardy, Cobham, & Kimble, 2012; Fee & Hinton, 2011; Kim & Yoo, 2010; Le Brocque, Hendrikz, & Kenardy, 2010; Phipps et al., 2012). However, it is important to note that the variance in conception, operationalization, and application of resilience differed widely; therefore it is not possible to draw accurate conclusions
about PMT as a whole. Many authors noted a lack of coherence in the field of resilience in general - especially in the context of the relatively new field of PMT - but support continued use of the model under further investigation (Beer & Bronner, 2010; Boles, 2013; Castellano-Tejedor, Blasco-Blasco, Perez-Campdepadros, & Capdevilla, 2014; DeYoung et al., 2012; Fee & Hinton, 2011; Kim & Yoo, 2010; Le Brocque et al., 2010; Tonks et al., 2011). Similarly, each of the studies noted a significant area of novelty in their research, thus highlighting the gaps that exist within this field (Beer & Bronner, 2010; Boles, 2013; Castellano-Tejedor et al., 2014; DeYoung et al., 2012; Fee & Hinton, 2011; Kim & Yoo, 2010; Le Brocque et al., 2010; Phipps et al., 2012; Tonks et al., 2011). Thus, it was important to create a clear definition of resilience and PMT in moving forward with this study.

Castellano-Tejedor and colleagues (2014) discussed the many differences in approaches to resilience in their literature review of children with cancer (and application to PMT in general) and determined that unifying elements exist across approaches. Resilience is not only the absence of negative adaptations but also the presence of positive adaptations, personally and environmentally, with the goal of restoring balance in the lives of children, or returning to a state of homeostasis (Castellano-Tejedor et al., 2014). Across studies included in this scoping review, a restoration of balance or ‘return to baseline’ appeared to be the general measure of resilience. Specifically, post-traumatic stress symptoms measured distress over time to determine trajectories of resilience (DeYoung et al., 2012; Le Brocque et al., 2010) and to evaluate resilience-based interventions (Fee & Hinton, 2011; Phipps et al., 2012). Other studies used healthy controls to compare children experiencing PMT to an average or baseline (Tonks et al., 2011). Thus, despite differences in approaches, a unifying theme of restoration of balance among conceptualizations of resilience as well as application to various populations of children experiencing PMT.

In contrast to this attention to balance, Castellano-Tejedor and colleagues (2014) defined two other related, but independent constructs: post-traumatic growth and benefit finding. Though both terms are often used interchangeably with resilience, they move beyond the central concept of restoring balance to suggest that a child ends up better than before the adversity, as in post-traumatic growth (Castellano-Tejedor et al., 2014). An example of post-traumatic growth could be a deeper appreciation for life after cancer. Similarly, benefit finding is an adaptive strategy
identifying positive aspects associated with negative events (e.g. a child may point out that they made a new friend in the hospital that they otherwise would not have met) (Castellano-Tejedor et al., 2014). The difference between post-traumatic growth and benefit finding was discovered during the systematic search of articles and intentionally not used as a search term or as synonymous with resilience. It is important to recognize the difference between these concepts, and as independent of resilience, as a clear concept of resilience will be required for interviewing. Often these traits can be assumed to be indicators of resilience, as they provide evidence of positive thinking. Yet, positive thinking (as in benefit finding) can be maladaptive, if it causes a person to become detached from their situation. Similarly, it is possible for individuals to adaptively move on from medical challenges without developing significant insight about their experience.

2.2.2 Trajectories of resilience in paediatric medical trauma.
In keeping with a broad definition of resilience, the next section examines the general trajectories noted in groups of children who have experienced medical trauma. Le Brocque, Hendrikz, and Kenardy (2010) used a model derived from Bonnano, Layne, and their respective colleagues to examine resilience trajectories in children who had unintentional traumatic injuries. It is based on measuring four patterns of posttraumatic stress symptoms (PTSS) over time: resilient, recovery, chronic, and delayed (Le Brocque et al., 2010). The resilient pathway, which was demonstrated in 57% of children, began with slightly elevated PTSS but returned to low or no distress within four to six weeks and was maintained at six months. 33% of children were in the recovery trajectory, where PTSS began as high but slowly declined to normal within six months. Chronically high levels of PTSS were demonstrated in 10% of children and remained stable over two years post-injury. There was no evidence for delayed symptomology in this group, as proposed by the original theorists to show low starting PTSS with increasing symptoms over time (Le Brocque et al., 2010).

DeYoung et al. (2012) used the same methodology as the previous researchers, applying it instead to resilience pathways for young children who sustained unintentional burns. Similar to previous results, the majority of children were resilient (72%), many recovered (18%) only a small proportion of children’s distress levels remained chronic (8%) over six months and none followed the delayed pattern (DeYoung et al., 2012). This not only provided evidence of the
efficacy of the resilience model in this population, but also demonstrated that acute stress symptoms are normative and not an accurate predictor of children at risk for PTSD (DeYoung et al., 2012; Le Brocque et al., 2010).

2.2.3 The importance of child-centred perspectives.

A major distinction that was found between articles was the measurement of resilience from either the child or parent’s perspective. Kim and Yoo (2010) critique the major limitation of previous studies examining resilience in PMT as the use of parent perspectives, when a social-ecological resilience framework requires the child to be the focus of intervention. Parent and child self-reports have not demonstrated consistency (Rende & Plomin, 1991, as cited in Kim & Yoo, 2010). Phipps et al. (2012) found differences in reporting between children and parents on measures of posttraumatic stress, where more children than parents rated the child themself as above threshold for PTSD diagnosis at baseline and after treatment (21.0% to 7.1% in patient reports and 14.5% to 6.2% in parent reports). This suggests that children are capable of self-identifying concerns, perhaps better than their parents (Phipps et al., 2012). It is important therefore, to include the child perspective to ensure health care professionals are adequately monitoring the psychological health of children.

In contrast, children also considered themselves more resilient than perceived by parents. Fee and Hinton (2011) found that despite the chronic and pervasive difficulties caused by Douchenne Muscular Dystrophy, the boys in their sample were highly resilient, with individual qualities of disease progression and severity being statistically unrelated to resilience. The authors suggested “the quantifiable nature of the adversity may be less important to the child than the positive adaptation to it” (Fee & Hinton, 2011, p. 649). In other words, though parents, teachers, or researchers may be able to provide estimates of a child’s perceived issues and efficacy in overcoming them, they impose their own values and beliefs in this process that may not be similar to the child’s. Again, this highlights the individual nature of both trauma and resilience and the differences between parent and child perspectives. In the case of the 1-6 year old children sampled in DeYoung and colleagues (2012) study, it is not always possible or developmentally appropriate for children to directly articulate their concerns about medical trauma in research, but every effort should be made to keep the child’s perspective the focus of the methodology and medical intervention. The following section will use a child-centered focus...
within the social-ecological model to examine the risk and protective factors of paediatric medical trauma.

2.2.4 Risk and protective factors.
Resilience literature often refers to risk factors and protective factors (Greene, 2008). Trauma, and more specifically, PMT, would be considered a risk factor, as it increases the likelihood of event-related stress and adverse outcomes (Webb, 2009). Cumulative risk is another key phrase used to quantify the relative number of contributing risks to one case (Greene, 2008). Ungar (2013) has asserted that uniquely intersecting marginalities, such as culture, family dynamics, and poverty will affect a child’s capacity for resilience and also negates a one-size-fits-all approach to responding to trauma. Protective factors also exist to mitigate the effects of cumulative risk and promote the balanced state that characterizes resilience (Greene, 2008). The following sections will use the social-ecological model to frame risk and protective factors that exist at the individual as well as key aspects of a child’s social environment: parents, peers and teachers.

2.2.4.1 Individual factors.
According to Kim & Yoo (2010), resilience models seek to build upon the strengths of children and use their existing resources to solve problems as they see them, which increases the intrapersonal protective factors of self-esteem and self-worth. In contrast, a problem-based model views the sick child as the problem, which then requires external resources and interventions to fix (Castellano-Tejedor et al., 2014; Kim & Yoo, 2010; Webb, 2009). Webb (2009) notes that in a problem-centred model, a child’s identity can be in a state of crisis, potentially shifting their self-image from a ‘child with a sickness’ to a ‘sick child’. This negative self-image can become pervasive and children increasingly doubt themselves, their abilities, and begin to pull away from who they once were (Webb, 2009).

Meta-analyses have demonstrated that specific sociodemographic variables are not predictive of PTSS as studies have shown contradictory findings (Camisasca, 2011). Similarly inconclusive findings were described in a literature review of resilience in paediatric oncology patients (Castellano-Tejedor et al., 2014). A child-centered study conducted by Kim and Yoo (2010) found no significant differences associated with age, gender, religion, existence of siblings, mother’s age, academic performance, duration of illness or type of cancer and resilience
outcomes. Similarly, Phipps et al. (2012) found very high overall resilience in children with cancer undergoing stem cell transplantation regardless of gender, socioeconomic status, resident parent, site, type of transplant, or diagnostic group.

Outside of paediatric oncology, Fee and Hinton’s (2011) study of boys with Deuchenne muscular dystrophy found no significant correlation between resilience and the individual factors of intellectual functioning and physical ability. In children with unintentional injuries, severity of injuries had an impact: those with fractures, dislocations, and lacerations in comparison to burns, internal and multiple injuries, were more resilient (Le Brocque et al., 2010). Younger children were more resilient than older children with unintentional injuries (Le Brocque et al., 2010), though De Young and colleagues (2012) dispelled the myth that young children are always resilient (8% of the burn victims studied had chronic PTSD symptoms after six months). Finally, behavioural concerns were shown to have an impact, where children with fewer internalizing and externalizing issues were more resilient overall (Fee & Hinton, 2011; Le Brocque et al., 2010).

Tonks and colleagues (2012) note that children with acquired brain injuries present a special case in PMT where primary and secondary traumas may impact a child’s ability to access intrapersonal as well as interpersonal skills. Damage to the brain responsible for executive functioning may impair a child’s ability to access the personal resources or protective factors that are characteristic of resilience (Tonks et al., 2012). The authors found that children with ABIs were less resilient, demonstrating lower levels of mastery and resourcefulness, as well as higher levels of emotional reactivity and vulnerability, and consequently were more depressed and anxious than matched peers. Resilience risk factors (i.e. lack of resourcefulness and increased vulnerability) were correlated with depression and anxiety for both ABI and control groups. The authors suggested that children experiencing medical challenges in general may be less resilient because (a) they are less able to mentally access personal resources in the context of greater vulnerability both socially and emotionally, or (b) children experiencing PMT may have greater emotional distress overall which impacts their strategies for resilience. Thus, it appears that children who have suffered from brain injuries present a special case in PMT and should be distinguished when making generalizations about PMT as a whole.

Taken together, there are many individual factors that can influence the experience of PMT and resilience. Given the complex etiology, it may not be possible to make generalizations about
individuals’ capacity for resilience based on their individual characteristics. Further, in the social-ecological model of resilience, which seeks to recognize an individual’s experience within their unique social location (Ungar, 2013), social and environmental factors have a great deal of influence upon children. This topic will be explored further in the next section.

2.2.4.2 Social environment.

According to Webb (2009), an ecological perspective is not only an important consideration but is foundational to working with medically challenged children. In the context of this literature review, environmental level risk and protective factors demonstrated stronger relationships to adversity and resilience, respectively, than individual level factors (Fee & Hinton, 2011; Kim & Yoo, 2012; Tonks et al., 2011). According to Fee and Hinton (2011), a child’s perceived quality of support, degree of social embeddedness, and enacted support are aspects of overall social support. The authors define social embeddedness as “the relationships children have with others including family, friends, and the community” (Fee & Hinton, 2011, p. 649). Enacted support is defined as “positive feedback, guidance, and the emotional support received” (Fee & Hinton, 2011, p. 649). Children have less access to their social support network in hospital settings, in comparison to their parents, siblings, or typically developing peers (Boles, 2013). Within this model, diminished opportunities to recruit sources of support may logically inhibit resilient pathways, but this may be mitigated by the presence of other children in the hospital experiencing similar challenges, as well as a variety of options available to connect with loved ones from a distance. Parents, peers, and teachers form three important aspects of children’s social environments and will be considered in the following sections. Though many other aspects of social environments could be included, and should be addressed in future research, the scope of the current literature review only covered these sources of social support as significant contributors to PMT and resilience.

2.2.4.2.1 Including parents.

Including parents when considering social support is critical because parents are the primary attachment to children and generally form the most important relationship in early development (Webb, 2009). These early relations have been shown to have effects on development over time, particularly in the growing area of neuroscience. Starting with the ontogenic view of the child at the center of their ecology, a child’s secure attachment with caregivers has the capacity to
mitigate effects of trauma, especially when parents regulate their emotions effectively and can model this regulatory behaviour appropriately for their children (Schore & Schore, 2008). Given this newly expanding realm of knowledge, it is important for parents (as well as teachers, and other important figures in a child’s life), to model resilient behaviours and build supportive environments (Smyth, 2008; Ungar, 2013), especially for younger children who have fewer independent skills and strengths to draw from (De Young et al., 2012). Fee and Hinton (2011) found that social support was the greatest contributor to resilience in boys with a chronic neuromuscular disorder and that parents with less stress were found to have sons with more positive behaviours. These inter-personal factors have demonstrated influence on the process of resilience that is as important as the environmental and contextual factors impeding or promoting resilience.

Nancy Boyd Webb (2009), an American clinical social worker and scholar in the field of paediatric medical trauma, notes that in her extensive experience, parents are an impossibly linked component of children’s resilience. Though children are the locus of the environmental model, it is often parents who must adjust the other systems around the child to ensure they will accommodate the many ways in which medical illnesses affect children (Webb, 2009). Kim and Yoo (2010) note that children are increasingly receiving care within the home, necessitating a whole-family approach, as there is more demand and stress on caregivers. For this reason, parents are often the focus of PMT resilience interventions (Boles, 2013). Parent attitudes, therefore, have a significant effect on the child and must be a focus for health care professionals, but not to the exclusion of children themselves (Castellano-Tejedor, et al., 2014; Kim & Yoo, 2012).

2.2.4.2.2 Including peers.
School-age children require development of cognitive skills, co-operative social interactions with peers, and building self-esteem through such interactions and friendships (Ball, Bindler, & Cowan, 2008). Siblings and classmates are two particularly important sources of social support for young children (Webb, 2009). Social support in the form of social embeddedness is a strong protective factor for children with medical challenges (Fee & Hinton, 2011; Kim & Yoo, 2012). Chronic illnesses can present a variety of stress factors for children, including changes in appearance, differential treatment, or disruption to typical development (Kim & Yoo, 2012).
Even while away from their friends and in a hospital or other medical setting, providing times for
social interaction through age-appropriate play can provide an outlet for connecting to others,
making sense of one’s diagnosis, relieving stress and anxiety, easing pain, and building on skills
to achieve mastery, self-esteem, and provide children with a sense of control over an otherwise
overwhelming situation (Boles, 2013; Webb, 2009).

Boles (2013) suggests that children stand to benefit from returning to an environment (i.e.,
classroom) where peers have been educated and prepared for changes, needs, and desires of the
returning student. Children are naturally curious and should be given the opportunity to ask
questions in a safe environment, in order to avoid excessive questioning directed to the child
upon return, who may already be anxious about the process (Kim & Yoo, 2012). Thus, it is
important to educate peers and friends on the illness of the child, as they may be misinformed
and could be a source of teasing and bullying, which - an additional risk factor.

2.2.4.2.3 Including teachers.
In studies of resilience factors in children with paediatric cancer, relationship with teachers was
statistically significant in bivariate analyses but no longer in multivariate analyses (Kim & Yoo,
2012). The researchers suggested that within the context of their study, this finding could mean
that teacher’s attitudes toward sick children had an indirect effect on the ways in which peers and
friends view the child, which was shown to be more statistically significant at multivariate level
(Kim & Yoo, 2012). Given the previously stated importance of peers for children with medical
challenges, teachers can be a very effective ally for preparing classmates and creating an
inclusive environment. Resilience research that has focused on social and environmental
relationships has demonstrated that one attentive adult has the protective capacity to mitigate
many cumulative risk factors as a mentor (Ungar, 2011). Thus, though often forgotten in
literature, it is important to include teachers and other significant role models in a child’s
environment to promote resilience.

2.2.5 Interventions.
Interventions that directly address the needs of children experiencing medical challenges were
included in this literature review, thus three studies will be described, as well as chapters from a
handbook on the topic. Firstly, Beer and Bronner (2010) have suggested that Eye Movement
Desensitization and Reprocessing (EMDR) has gathered a sufficient evidence-base in adult
trauma literature to be applied to children experiencing PMT. EMDR with children (as well as parents) and requires the client to recall and focus on such disturbing events while completing external tasks simultaneously (i.e. following therapist’s finger with a pen or listening to specific sounds on headphones) until the stress level decreases to normal (Beer & Bronner, 2010). Further investigation is required to explore the effectiveness of this intervention in child samples.

Phipps and colleagues (2012) found that despite assignment to interventions (weekly massages and humour therapy) given to children, children and parents, or neither, no significant differences were found in resilience outcomes. Overall, researchers in top teaching hospitals across Canada and the United States found very high rates of resilience in patients, which they partly attributed to benefit finding across groups (Phipps et al., 2012). At admission, overall, children’s self-reported depression was only one standard deviation below average for matched healthy children, thus it would be difficult to improve on this finding (Phipps et al., 2012). The remarkable outcomes of children across interventions in the Phipps and colleagues (2012) study was further hypothesized to be the result of attention to psychosocial outcomes by professionals such as social workers and child life specialists within the hospital. Further, though post-traumatic stress was significantly higher than in matched healthy children at intake, by the end of the intervention, post-traumatic stress returned to normative levels, suggesting that a resilience model is a better fit than a trauma model for children with cancer undergoing stem cell transplantations (Phipps et al., 2012).

Similarly to the previous study, DeYoung and colleagues (2012) found that young children with unintentional burn injuries had relatively minor injuries, yet surprisingly high rates of psychological disorders (35%). In contrast to literature that had demonstrated children with severe burns as more resilient, the authors suggested the cause of this difference could have been their designation as outpatients and therefore, more limited access to psychosocial interventions by health care staff, including clinical social workers (De Young et al., 2012).

Boles (2013) as well as Phipps and colleagues (2012) have noted a lack of specific strategies to foster resilience in children experiencing PMT. Boles (2013) described the importance of educational opportunities about a child’s diagnosis, preparation for medical procedures, play-based therapies, and discharge and transition support (Boles, 2013). As a therapeutic intervention, the benefits of play with paediatric patients can be summarized as a familiar, child-
centred method of working through issues, as well as potentially alleviating pain and distress, offering peer-support, and providing children with mastery and control in an overwhelming environment (Boles, 2013). Just as parents wish to be informed of the details of an upcoming procedure, it is important to provide the same education to children, appropriate to their developmental level, to ease anxiety (Boles, 2013). Medical play using multisensorial techniques can educate children on procedures that they will personally experience in a developmentally appropriate way (Boles, 2013).

In recognizing the importance of parents in fostering resilience of children experiencing PMT, clinical social workers can help support parents and families in a variety of ways. Social workers can help parents to navigate the health care system in general, as a variety of factors may prevent parents from fully accessing resources for their children including language barriers, financial strain, or unfamiliarity with systems as a newcomer, immigrant, refugee, or individual with precarious status. Stress and anxiety can prevent parents from retaining and understanding information, thus a social worker could attend meetings with parents to take notes for parents, and review them at a more appropriate time (Webb, 2009). Webb (2009) noted that parents can also feel intimidated by medical professionals, and that social workers can help families determine which questions to ask physicians or other healthcare professionals, or facilitate conversations between families and other staff (Webb, 2009). Social workers (and other supports, such as psychologists and child life specialists) can provide resource counselling and make referrals, or offer psychoeducation and support groups (Webb, 2009). Given appropriate consent, social workers can advocate for clients and families in school meetings, mentor teachers on how to support children with PMT in the classroom, and educate a child’s peers (Webb, 2009). It is important that interventions are interdisciplinary and social workers are well positioned, especially in health care settings, to fill the role of case management between various professions.

2.3 Implications

Taken together, the social-ecological model of resilience fits well within the context of PMT. This child-centered approach also aligns with social work’s practice principles of starting where the client is, perceiving problems from the client’s perspective, and working at the client’s pace. These foundational social work approaches are increasingly borrowed in other medical and allied
health professions and organizations. In the medical sciences, problem-focused models are understandable to some degree given the realities of health and disease. However, it is the responsibility of health care workers to look at the whole client – to see past them as a patient and see instead a child seeking well-being and possessing skills, talents, and positivity. As health care workers who facilitate change, there is real value in drawing out strengths and empowering clients to make changes within their own lives, no matter how young or old (Botta, 2009). In a society that often silences the voice of children, especially those who are at risk, this critically informed perspective is of even greater importance.

Biopsychosocial assessments are common in health care professions including doctors, nurses, psychologists, social workers, child life specialists, and so on. Therefore, using the social-ecological lens to view children with medical challenges is both appropriate and intuitive. A variety of methods can be employed to provide information to children, support their healthy development, and use therapeutic intervention to build on their current skills and promote resilience. Thus, though the child always maintains focus as the client, social workers should recognize the need to include other elements of a child’s system, such as parents, peers, and teachers, intervening as necessary with these stakeholders.

The scope of the current literature review was not intended to address the potential effects of cumulative risk in PMT. However, this approach is warranted for future reviews. Most studies did not adequately account for such risk factors, though those that did suggested that the characteristics explored (i.e. age, gender, religion, previous traumatic experiences) are not as strongly related as perceived social support (Fee & Hinton, 2011; Kim & Yoo, 2012; Le Brocque et al., 2010). Ungar (2013) has demonstrated how intersecting marginalities based on the social location of an individual (such as culture, family dynamics, and poverty) may present cumulative risk factors and may affect a child’s capacity for resilience. In accordance with the interventions presented, recognition of cumulative risk factors negates a one-size-fits-all approach to PMT. Social workers can recognize cumulative effects of risk and help clients recruit personal strengths, as well as use external resources (if required) to mitigate such risks and build resilience.
These strategies form the basis of a trauma-informed approach. Trauma-informed approaches suggest a change in the culture of an organization, which recognizes the prevalence, importance, and impact of trauma (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014). In contrast, trauma-specific strategies are used to address the effects of trauma (SAMHSA, 2014). Current models promote trauma-specific strategies in hospitals, which are important. Some of these supports include social workers, child life specialists, psychologists, and psychiatrists, who understand the effects of trauma, can recognize the ways in which PMT affect clients, and use evidence-based strategies to provide biopsychosocial support (Boles, 2013). The findings of this scoping review demonstrate that these strategies are critical, but that given the pervasiveness and potential effects of PMT, improvements can be made by adopting a trauma-informed culture within hospitals, where all professionals can support children’s resilience. For a more detailed description of the core principles of trauma-informed spaces, see the textbox, ‘The Core Principles of Trauma-Informed Spaces’.

### The Core Principles of Trauma-Informed Spaces

The principles of trauma-informed services may vary based on the population being served, but best practices necessitate the following:

- Understanding the effects of trauma (Elliott, Bjelajac, Fallot, Markoff, & Reed, 2005; Harris & Fallot, 2001; Klinic Community Health Centre, 2013)
- Safety: Avoiding re-triggers (Elliott et al., 2005; Klinic Community Health Centre, 2013; SAMHSA, 2014; van der Kolk & Courtois, 2005)
- Collaborative, trusting, and healing relationship with provider (Elliott et al., 2005; Klinic Community Health Centre, 2013; SAMSHA, 2014; van der Kolk & Courtois, 2005)
- Promoting client autonomy and empowerment (Elliott et al., 2005; Klinic Community Health Centre, 2013; SAMSHA, 2014; van der Kolk & Courtois, 2005)
- Recognizing the influence of systems (Elliott et al., 2005; SAMHSA, 2014) strengths-based (Elliott et al., 2005; Klinic Community Health Centre, 2013)

Given the consistently resilient nature of children demonstrated in the studies examined within this literature review, further study is required to investigate the factors that contribute to
resilience from a child’s perspective, using developmentally appropriate measures. Collecting qualitative data will be particularly useful in determining factors that may be lost using limited quantitative methods (Phipps et al., 2012). Many of the studies included proxies from parents and professionals, and this has been determined to be ineffective in discovering children’s experiences. The current study will use a hermeneutic approach to explore children’s perspectives of PMT and resilience. A detailed discussion of the methods used in this study will follow in the next chapter.
3 Design and Methods

The previous chapters described the absence of literature exploring PMT and resilience from a children’s perspective, justifying the necessity of this lens. The exploratory qualitative design and methodology has been tailored to achieve this goal. According to Kvale (1996), phenomenology “studies the subjects’ perspectives on their world; attempts to describe in detail the content and structure of the subjects’ consciousness, to grasp the qualitative diversity of their experiences and to explicate their essential meanings” (p. 53). Specifically, a hermeneutic phenomenological approach as described by Kvale (1996) was selected. Central to this methodology is in-depth interviewing to describe the lived experiences and identify the relevant conceptual material related to PMT and resilience. The branch of hermeneutic phenomenology was selected to move beyond describing an individual’s lived experience, by also uncovering the meaning of that experience to the individual. Kvale (1996) notes that there has been a shift from positivism to more postmodern social constructions of reality, recognizing that individuals, and in this case, children, create innately subjective representations of reality. Such subjective experiences cannot be adequately captured through quantifiable data, but highlight a further subjectivity that exists between the interviewer and the participant in co-creating understanding of a topic through questions and answers. For this reason, Kvale (1996) uses a hermeneutic approach, recognizing that the interview is co-constructed between the interviewer and interviewee, taking the postmodern approach to meaning making as inseparable from the context in which the phenomena exists. In order to carry out a study employing hermeneutic phenomenology, the researcher must first have some understanding of the philosophy of the approach, which grounds all other aspects of the methodology (Wilcke, 2002; Pascal, Johnson, Dore, & Trainor, 2010).

According to Kvale (1996), seven steps form the basis of interview investigations: thematizing, designing, interviewing, transcribing, analyzing, verifying, and reporting. Thematizing is central to qualitative interviews; it involves developing a conceptual and theoretical understanding of the topic before designing the methodology, which is a direct reflection of the thematizing. In the given study, previous research has demonstrated that though children are at the centre of
resilience theories, little is known about their perspectives. This study is designed to better understand their direct experiences. The interviews were transcribed verbatim for analysis. In this study, verifying was completed by conducting referent checks with the two social workers on the unit, as well as reviewing and revising emerging themes with a subset of participants. All seven stages will be recruited using Kvale’s (1996) methodology.

3.1 Hermeneutic Phenomenology

Phenomenology as a whole stems from German philosophy with the purpose of capturing an individual’s life world, or lived experience (Laverty, 2003). There are two distinct approaches: transcendental and hermeneutic, both of which began out of a rejection of the dominating empirical approach to human experience (Laverty, 2003). The transcendental approach, coined by Husserl, is based on the concept that lived experiences occur within one’s consciousness and must be captured in a way that is free of explanations of causes and origins – deemed the ‘core essence’ of the experience (Wilcke, 2002). It is possible to study this core essence by making one’s assumptions as the interviewer explicit, and then suspending or ‘bracketing’ these personal beliefs in order to enter the world of the interviewee (Laverty, 2003; Wilcke, 2002). The task of transcendental approaches, or descriptive phenomenology, is to objectively use participants’ knowledge and experiences to reveal consciousness; findings are then reported in explicit descriptions (Wilcke, 2002).

One of Husserl’s students was Heidegger, who had a similar rejection of positivism, but felt that descriptions fell short of providing meaning (Osborne, 1994). Heidegger (1962) disagreed with Husserl’s conception of capturing and describing consciousness as separate from the world (Laverty, 2003). Heidegger posited that life was understood through experiences, not consciousness or knowledge (Thompson, 1990). Instead, he believed there is an unbreakable unity between an individual and the world, which is informed by a person’s history or background (Koch, 1995). Each person’s experience is unique but making generalizations are still possible when understanding the utility of the individual within the world (Wilcke, 2002).

Dasien, or being-in-the-world, is the notion that human existence occurs in a world that is taken for granted; and as such, the task becomes to reveal these hidden meanings (Speigelberg, 1960). Similarly, Mitsein, or being-with-the-world is the idea that human relationships are interconnected and one uses themselves to understand and relate to others (Pascal et al., 2010).
This unity and interconnectedness extended to his rejection of bracketing, as Heidegger disagreed that lived experience could be explored in a value-free relationship between researcher and participant (Wilcke, 2002). Instead, Heidegger stressed that instead of attempting to bracket out presuppositions, researchers need to become more aware of their values and biases and bring these to the forefront, outlining how they influence the process of co-creation (Wilcke, 2002). Together, these aspects create the philosophical foundation of the hermeneutic phenomenological approach.

The term ‘hermeneutic’ comes from the Greek word *hermeneuein*, which means ‘to interpret’ (Hoad, 1996). The term is also derived from the Greek god Hermes, who was the messenger between the gods, and invented language and writing, transforming what cannot be known to something that can be understood (Thompson, 1990). Similarly, hermeneutics today relies on interpretation and language (Lavery, 2003; Wilcke, 2002). Language is the medium for communicating or reproducing identity, which is recognized as a social construction in hermeneutics (White, 1997). Gadamer (1997) added three metaphors to the interpretation used in hermeneutic phenomenological approaches:

1) Fusion of Horizons: A ‘horizon’ is “a range of vision that includes everything that can be seen from a particular vantage point” (Gadamer, 1997, p. 302). The perspective that I bring to this research is made transparent throughout the thesis, but in particular within the positioning statement that concludes this chapter. The ‘fusion of horizons’ is an aspect of the process of understanding where the researcher’s horizon blends with the topic of inquiry (Thompson, 1990). In the context of the interview, this fusion involves a process in which the researcher’s perspective is broadened by the participants’ standpoints and then examined and reexamined by continually offering new perspectives (Wilcke, 2002). Horizons therefore are dynamic, with the viewpoint expanding with greater understanding (Wilcke, 2002). The fusion of horizons was explored in the context of the interview (discussed below) and also was used as an aspect of interpretation during the data analysis strategy.

2) The Act of Dialogue: This concept is related to the fusion of horizons, in that this occurs through dialectic, genuine conversation, including questions and answers (Gadamer, 1997). It is through discussion and relating to others that we can appreciate their lived experience, making new understanding, horizons, and interpretation possible (Gadamer, 1997). The purpose of
questioning is not to understand the individuals themselves, but to understand what they are discussing (Wilcke, 2002). The context of the interviews completed in this research is further discussed in the Data Collection section of this chapter, as well as mentioned throughout the thesis, where relevant.

3) The Hermeneutic Circle: This is an interpretive process of understanding that moves back and forth between parts of an experience, to the whole experience and back again (Gadamer, 1997). The end of the hermeneutic circle occurs when one reaches an inner unity within the text, without contradictions (Kvale, 1996). In this research, the hermeneutic circle was used to inform the data analysis strategy, taking this perspective by exploring phenomena within a case, extrapolating it within the other cases and using this to reevaluate individual descriptions and meanings. This can be seen in the fourth chapter, where poignant quotes from one participant are used to inform the experience of all participants, and also placed within the context of the individual; as was completed in the hermeneutic phenomenological social work research by Wilcke (2002).

See textbox ‘Hermeneutical Canons of Interpretation’ for a description of the cannons that were used to analyze data.
3.2 Study Context

When engaging in hermeneutic phenomenology, the researcher must first orient themselves to the phenomena (Van Manen, 1994). Doing so allows the researcher to take on a deeper meaning of the interpretations that can be made about the topics discussed by participants. It is important to first consider the environment that the participants reside in as inpatients at HBKRH. As an organization, HBKRH sees its vision as ‘a world of possibilities’ and values caring, client and
family-centred care, excellence, innovation, partnership, and respect (HBKRH, 2013). Thus, the care that children receive is inter-professional in nature and often strengths-based, involving both children as well as their families. The building itself is fairly new, just ten years old, and every element of its design considers accessibility. Hallways are wide enough to allow those operating wheelchairs, walkers, and other mobility devices with ample space to walk next to others. Each door can be automatically opened with a gentle push and desks, buttons, and taps are all within reach. The facility itself is bright, colourful, well maintained, and reflective of the young clients within its walls. It could certainly be the case that the physical environment of the hospital is conducive to resilience, in that the accessible design facilitates independence. HBKRH provides a team of professionals and a range of services to each client (i.e. physicians, nurses, psychologists, social workers, child life specialists, therapeutic recreation specialists, etc.). Most health care professionals work typical business hours Monday to Friday, but on the units, including the SODR unit, there are several nursing stations that employ staff around the clock. Each room has two beds and depending on the capacity of the unit, will be shared with a roommate. There is one television to share in the rooms, and an accessible bathroom. There is a chair that converts to a bed for parents to stay at the bedside, but some are allocated space on the on-site family accommodations floor. Typically, clients in the SODR unit attend school on site at the Bloorview School Authority, a section 23 school (i.e., a school affiliated with a school board but operated in an atypical classroom environment and generally serving high-risk children and/or youth), and are pulled out for therapy appointments. Teachers liaise with clients’ home schools to keep children from falling behind in schoolwork. Evenings and weekends on the unit tend to be fairly quiet. There are shared spaces and optional programming for clients after hours. There is a library on-site and one restaurant open; the cafeteria is open limited hours. The hospital itself is in a relatively isolated location, near Sunnybrook hospital, in a residential area, but lacking easy access to shops nearby. These features of the physical location have impacts on the children within the hospital, and thus, their exposure to PMT and capacity for resilience.

3.3 Sampling

Eligible participants in the study included children who were English speaking, between the ages of 6-12 years old (inclusive), and were inpatients on the SODR unit. Given practical issues, only English-speaking children could be included to ensure that their experiences were accurately represented in the interviews. The ages of 6-12 years old represents middle childhood; children
at this age have effective communication skills and insight into their experiences, as described in Chapter 2. All children assented during a joint consent meeting with their parents, and signed a consent/assent agreement.

In terms of the age of the participants, studies have shown inconsistent findings across age groups. In a review of post-traumatic stress of children who have suffered injuries and illnesses, Camisasca (2011) found that of twelve studies that explored age as a factor, ten found no significant difference in age groups. The two studies that did reveal differences had results that suggested younger children have lower rates of PTSS and clinical disorders (Camisasca, 2011). However, these studies have failed to capture the unique perspectives of children, instead focusing on quantitative methods and adult opinion. In maintaining an ecological perspective of resilience, Ungar (2011) notes that differences in culture will create differences in perspectives of trauma and subsequent resilience. Age is a type of culture that can create such differences (i.e. friends take on a greater role as children build autonomy, and thus affect strategies for support and resilience). Webb (2009) notes that children’s comprehension of their medical health will vary based on their age. Given the wide breadth of PMT, isolating the middle childhood age group provided some necessary structure in this topic.

Children in the SODR unit at HBKRH have experienced a wide variety of physical traumas that may constitute PMT. Some examples include: spinal cord injuries, limb deficiencies, neuromuscular disorders, post-operative orthopaedic care, complex wound management, burns, chronic pain, complex epilepsy, cerebral palsy, complications of prematurity, and congenital abnormalities (Holland Bloorview, 2013). Children who have sustained brain injuries or have cognitive delays were excluded, as evidence suggests that their experiences significantly differ from other types of PMT (Tonks et al., 2011). The inclusion and exclusion of participants based on cognitive abilities was determined by the absence of diagnosed cognitive delays. Similarly, children with communication disorders or who require communication devices were excluded if they were unable to articulate their experiences, at the discretion of recruiters. Social workers on the SODR unit were engaged in this study as recruiters. They form strong working relationships with their clients and are aware of each child’s capacity to engage in an interview on this topic. Beyond these criteria, unit social workers/recruiters were consulted to determine the appropriateness of each eligible child for participation. They were tactful in their timing of approaching children, acknowledging that the first few weeks while children are adjusting would
not be a good time to add an additional task. They were also considerate of significant traumatic events in which the interview, though strengths-based and participant-driven, may trigger and further traumatize some patients.

Recruitment, which will be described further below, extended from February to April 2016. During this time, there were twelve children that met eligibility criteria. One inpatient was determined to be too traumatized to participate in an interview probing this topic for research purposes. Three clients declined to participate when approached by recruiters. Due to ethical issues, it is unknown exactly why these children (and/or parents) declined to participate. In total, eight interviews were completed. The children ranged from 6-12 years old; the average age was 9.75 years old. The sample was exactly half male and half female. The reason for admission varied, with the majority of children rehabilitating following orthopedic surgery, and others who were recovering after motor vehicle accidents, cancer treatments, and sudden illnesses.

3.3.1 Sample Size

The use of qualitative methods generally calls for sample size to be determined based on the concept of data saturation, as opposed to a discrete number of participants that will ensure representative sampling methods (Mason, 2010). Saturation can be described as reaching a point where collecting further data would not add new information to the understanding of the topic (Mason, 2010). In phenomenological research guidelines, authors have suggested “at least six” (Morse, 1994, p. 225) and “five to 25” (Creswell, 2013, p. 364) interviews can be sufficient to achieve data saturation. Strauss and Corbin (2008) support data saturation but point out that there are practical issues, including time, energy, money, and availability of participants that prevent researchers from completing this type of open-ended data collection. Other influencing factors suggested by Ritchie, Lewis, and Elam (2003) include "the heterogeneity of the population; the number of selection criteria; the extent to which 'nesting' of criteria is needed; groups of special interest that require intensive study; multiple samples within one study; types of data collection methods use; and the budget and resources available" (p. 84). It was expected that a sample of ten to twelve participants would be recruited for this study. As stated, a total of twelve children were eligible for recruitment, and eight participated in the study. The availability of participants as well as timeline for a one-year Master’s thesis were practical considerations. Importantly, the
themes that emerged through these eight interviews were determined to be sufficient in terms of saturation of conceptual materials to report findings.

A number of cannons of hermeneutic phenomenology guided the interpretation of data and three cannons are specifically relevant to data saturation. First, a coherent ‘inner unity’ of the text needs to exist (Kvale & Brinkmann, 2009). As will unfold in the final two chapters of this thesis, there were common experiences and meanings attributed to them that were uncovered through these interviews to achieve unity. Second, the text itself must contribute new knowledge to the field (Kvale & Brinkmann, 2009), which as an exploratory study, this thesis seeks to do. Finally, the text must be autonomous or be able to stand alone (Kvale & Brinkmann, 2009). This study has been informed by many previous works, but the findings from the interviews are novel, important, and stand alone, particularly as ‘local knowledge’.

3.4 Recruitment

Before recruitment commenced, ethics approval was sought from both HBKRH’s Bloorview Research Institute (BRI) as well as the University of Toronto’s respective Research Ethics Boards. The BRI examined the documents provided and identified concerns with the eligibility criteria, particularly clarifying how exclusion criteria would be more discretely identified, as well as concerns with achieving the sample size target of 10-12 participants with the ages limited to 6-12 years old. These concerns were addressed by detailing the ways in which personal health information would be used, as well as accepting the risk that the age limitation may have. It was considered more important for the study to remain developmentally appropriate by limiting participants to middle childhood than to introduce the complexities that adolescence may have provided. Other improvements included providing greater transparency to participants in the role of social workers as recruiters and the potential risks this may present, adjusting the informed assent/consent process to include both the child and family at the same time, as well as developing a secure long-term storage plan for the computerized data. An administrative REB review was also required from the University of Toronto given that a graduate student conducted this research. Following approval from BRI, the administrative review was approved from the University of Toronto REB without issue.

Purposive sampling was used to recruit participants for this study. Social workers on the SODR unit served as the primary recruiters. Note social workers were also used as referent checks and
to maintain ethical research practices, potential participants were informed of this. Further, all information remained confidential (e.g. transcripts were removed of identifying information). One other social worker became a recruiter because one participant’s room was located in another unit due to overflow. Both SODR social workers were provided a list of inclusion and exclusion criteria in an initial research meeting. The social workers were briefed on the definition of PMT, and identified SODR clients that fit the eligibility criteria (discussed previously, under Sampling). A bed summary (i.e., spreadsheet listing basic demographic and health information of current clients in a department) was used to ensure each client is considered using accurate information. Initial contact was made by one of the two social workers who were familiar with and part of the circle of care for these children on the SODR unit. The recruiter approached the family (i.e. parents and child) in-person with a script (see Appendix C) and provided a recruitment flyer (see Appendix D) to the family. If a family was interested, they were contacted by the researcher to provide additional details of the study, complete the informed consent and assent process and forms, and to schedule a time and location for the interview.

During this assent/consent (see Appendix E and F for informed assent and consent forms, respectively) process, I used professional judgement to develop a sense of children’s understanding during consent process. I addressed the information to them, and used language and comparisons that were appropriate to their developmental level. I assessed levels of understanding, modified my language, asked questions to clarify understanding, and created space for both parents and children to ask questions. This process helped to develop rapport and decrease anxiety or shyness that some children may have with strangers. In line with BRI requirements, this study required written documented consent (or assent) from both parents and children who were involved in the investigation. All parties were made aware that participation is voluntary, that information collected will remain confidential, the limits of confidentiality, and that they may withdraw from the study at any time without penalty. Declining to participate in the study in no way affected the client’s treatment received at Holland Bloorview.
3.5 Data Collection

3.5.1 Interview guide.

The interview guide can be found as Appendix G. Note that the interview guide is based on the research questions, and has an open structure to allow more space for children to express their experiences without leading or prompting. This also allows children more freedom to avoid topics that may be distressing, as the topic deals with a form of trauma, and maintain a strengths-based approach. The interviews were completed individually to prevent groupthink, or the tendency for participants to agree with one another (Sim, 1998), which was thought to have a potentially greater influence for children than adults. Further, in keeping with a hermeneutic tradition, completing the interviews with one child allows space for that child to share their own personal experiences, which may be compromised within a group setting (Kvale, 1996). This is particularly important given the breath of experiences that can cause PMT. Parents have a strong influence on their children’s experience in the hospital (Webb, 2009), thus, it was important that children felt comfortable and free to discuss their perceptions of parents as potential sources of strength or stress. There is evidence to demonstrate that parents’ presence affects child behaviour and responses (Gardner & Randall, 2012). Finally, one of the main objectives for this research was to fill the gap that currently fails to recognize or value children’s views and perceptions. For this reason, parents were not present in interviews.

3.5.2 Interview dialogue.

Dialogue is an important aspect of the interviews and contributes to the co-creation of knowledge in an interview. On the way to the interview, I would continue to build rapport with the child, following up on topics discussed in the informed assent/consent meeting, or showing them around the research floor. The interview began with an open-ended question inquiring about the context of the child’s hospitalization (i.e. ‘What brought you to Holland Bloorview?’). In maintaining the hermeneutic interview approach, questions centered on inquiring about both the description of the thing (i.e. event, situation, challenge, etc.) as well as the meaning the participant attributed to it (Kvale & Brinkmann, 2009). Probing questions were asked to obtain a detailed description of significant events. Examples included: “What did it sound like?” “What did the room look like?” “What did it feel like for your body to be ‘laying flat’?” Once this had been explored, open-ended questions were asked to determine the meaning of the event. For
example, “What’s it like to be the only kid at your school in a wheelchair?” “What does it mean to you to have your best friend call you to check in everyday?” “What’s important to you about having your own room?” Again, this intentionally completed to be reflective of hermeneutic methodology, which places emphasis on not only the description of an event, but also the meaning this had to the participant. It was also considered more developmentally appropriate to have children first describe their memories and verbalize the experience, mentally bringing them back to that time, before asking them to consider the meaning it held.

3.6 Data Analysis

In keeping with a hermeneutic phenomenological approach, analyses were dynamic and ongoing – beginning from study conception, continuing into the interview, and concluding once all data were collected (Kvale, 1996). Kvale (1996) and Kvale and Brinkmann’s (2009) six steps of analysis of the interview data were followed in this study.

1) The first stage of analysis occurred when the subjects described their experience spontaneously in the interview. During this stage, there is little interpretation between either party (Kvale & Brinkmann, 2009). For example, when asked about a challenge that they faced, participants spontaneously described their own account of this.

2) The second step occurs in some cases where the subject themselves uncovers new meanings through analysis of their own experience in the interview (Kvale, 1996). Direct interpretation from the researcher has not yet occurred. This occurred in some cases during interviews, as discussing PMT and resilience seemed to be a novel point of reflection for most participants.

3) In the third stage, the researcher used strategic skills within the interview (i.e. questions, prompts, and follow ups) to clarify and analyze content in real time with the subject (Kvale & Brinkmann, 2009). This was completed within each of the interviews. Importantly, children felt comfortable to disagree and further clarify when they felt I did not understand them, both spontaneously and when directly asked.

4) The fourth step is the analysis of the recorded interview, which involves the transcription and analytic approaches (Kvale, 1996). Transcriptions were entered into a well-reputed qualitative
software program, N*Vivo, to be coded and subjected to a clarification process for determining important information and recurring themes, as described by Kvale (1996).

The task of transcription is rarely described in qualitative research literature (Kvale & Brinkmann, 2009). Transcribing is part of analysis, given that discourse is translated from its original, oral form into the author's interpretation of it in written form (Kvale & Brinkmann, 2009). A systematic approach to transcription was developed and followed to maintain as much meaning as possible (Kvale, 1996). All transcripts included the following notations, which are maintained in the raw data reported in this thesis.

R: = researcher dialogue  
P: = participant dialogue  
(word) = inaudible or indistinguishable dialogue  
(word) = actions or other nonverbal cues  
[word] = R or P speaking at the same time as others’ dialogue  
- = interruption  
WORD = stressed sounds and/or spoken louder  
, = pause  
… = longer pause

Verbatim transcribing ensured that data analysis could occur using text that was as close to the child’s voice as possible, and by reporting data verbatim (with the omission of identifying details), audiences can make their own decisions about the validity of the text as it relates to the themes (Laverty, 2003). The transcript coding system was checked by an independent researcher to ensure accuracy, as discussed in the section below.

In order to maintain rich data that may not have been captured in the recordings, I kept detailed field notes, sometimes within the interview, and always following each interview. I completed these field notes within 48 hours so that the interviews were fresh in my mind. The field notes consisted of four questions:
1. What happened before and after the interview?  
2. What was the general emotional reaction?  
3. Which stories stand out?
4. Which particular moment(s) did the client present or behave differently?

As transcription was completed, I would continue to add to the field notes, keeping track of thoughts and ideas about how the text contributed to themes and related to research in the field. Again, leaving this type of ‘audit trail’ also contributes to trustworthiness (Creswell, 1998).

In keeping with Kvale and Brinkmann’s (2009) approach, which is based on the hermeneutic tradition, the interview data analysis focused on meaning. Importantly, the analysis included the assumptions and questions that the interpreter brings as a co-constructor of these meanings (i.e. their horizon) (Kvale & Brinkmann, 2009). This type of post-modern approach to analysis dispels the notion of ‘one truth’ to be discovered or uncovered by the researcher in an interview. Instead, this perspective embraces the assumption of the plurality of truth. The meanings, therefore, do not belong to either the interviewer or participant, but reflect a shared meaning. Shared meanings have been critiqued given potential issues of power imbalances in interviewing and validity in interpretation. The age difference and nature of researcher directing the interview presented a power dynamic between myself and the participants, which was attempted to be addressed by using open-ended questioning and member checking. The perspectives of this author are inextricably linked to the results and conclusions drawn, but the intent of this research was not to report the author’s intended meaning, but to allow readers to interpret the findings such that they can be used and tested in their own life and practice.

Coding was used as a method of structuring and condensing the rich data elicited from the interviews and corresponding transcription (Kvale & Brinkmann, 2009). The process of coding is to attach one or more keywords to textual data to organize it and make it available for identification at a later time (Kvale & Brinkmann, 2009). According to Gibbs (2007), anything can be coded, including “specific acts, events, activities, strategies, states, meanings, norms, symbols, levels of participation, relationships, conditions or constraints, consequences, settings, and also reflexive codings, recording the researcher’s role in the process” (p. 47-48). Effective coding is capable of capturing the fullness of the participants’ experiences. The N*Vivo for Mac program was used to help organize and retrieve codes.

Hermeneutics does not involve explicit, systematic steps for data analysis, but instead, requires the organic use of canons of interpretation to influence the analytic process (Kvale & Brinkmann, 2009). The methodology presented so far has appeared linear, but it is important to
note that data analysis in hermeneutics is more cyclical, referring back to the hermeneutic circle as well as the fusion of horizons, which influence the ways in which data are interpreted (Laverty, 2003; Wilcke, 2002). Nevertheless, a particular approach was adopted to balance the need for methodology with space for interpretation. Coding occurred within the interview first (i.e. individual transcripts were analyzed and coded) and then across interviews (i.e. comparing transcripts). The methodology used for coding followed that used by Wilcke (2002), who described how to use hermeneutic phenomenology as a research method in a social work. Wilke (2002) used the process of “horizontalization” as described by Creswell (1998) to cut and paste statements into common clusters of themes or meanings. In the same way, in this research, statements were highlighted and sorted into clusters that reflected similarities. Codes were not developed beforehand, thus, they were data-driven, but coding was heavily influenced by the current themes that existed in the literature. Children’s experiences and perspectives are the novel aspect of this research, however, there were key concepts that arose in the literature review that were expected to be addressed by children in the interviews. For example, risk and protective factors in past literature were determined to occur on an individual level, within children’s social environment, most notably including parents, peers, and teachers. As coding was completed within cases, themes emerged across cases, reflecting common experiences and meanings across participants. Using N*Vivo, codes were then condensed into common groupings until an inner unity was achieved across the data. The transcripts were revisited to ensure saturation of the data.

Recall Gadamer’s (1997) three metaphors of understanding. Both the fusion of horizons as well as the hermeneutic circle was utilized more explicitly at this stage (Gadamer, 1997). As I continued to go through the transcripts, moving between the participants reactions and my own responses and interpretations (described by Wilcke, 2002), it seemed that the clusters were sometimes in response to questions posed, and sometimes reflective of a deeper meanings within the responses. The responses tended to have more variation, as they were more context-specific to each child’s experience of PMT and resilience, but the meanings seemed to be more generalized to the majority of participants’ experiences. This was likely the product of the hermeneutic questioning strategies used, obtaining a rich description of the event before delving into meanings, and reflective of Gadamer’s (1997) act of dialogue. Both the descriptions and
meanings of the events will be maintained and made explicit in the fourth chapter describing the results.

As an exploratory study, the analysis was largely inductive, and triangulated with past research completed about PMT, Bronfenbrenner’s (1979) Ecological Systems Theory, and social-ecological models of resilience as guiding frameworks. After a first round of coding all of the raw data, the codes were then more focused and organized by recruiting the aforementioned theoretical frameworks. This was completed until saturation of the materials was achieved, or no new insights emerged and there was an inner unity of the codes included (Kvale & Brinkmann, 2009). The described analytic strategy was used with the research team, which included the student researcher, the University of Toronto thesis committee, as well as the social workers. Field notes were collected at these meetings. The student researcher as much as possible used a collaborative approach to generate and contextualize ideas from both hospital and university circles, and sought consultation from supervisors in the case that agreement could not be reached.

5) The fifth stage involves the members once again to check the interpretations - in this case, themes – that emerged from the study (Kvale, 1996). All of the participants that were included in this study had been discharged from the hospital, therefore, it was not possible to conduct a follow-up meeting at HBKRH. Instead, participants were called and a phone meeting was conducted to explore the participants’ perceptions of the emergent themes. Though almost all participants agreed to be contacted for follow-up and were telephoned, only two participants were reached for follow-up over the course of several days. The participants who completed the follow-up were considered to have significantly different challenges and insight to provide differing perspectives on the data. Both participants agreed on the themes, adding and clarifying based on their own lived experiences.

6) The sixth and final step described by Kvale (1996) is the analysis and interpretation involved in transforming new knowledge into action, which is not only contained in this study, but was presented in a published research article on the background research completed in Chapter 2, and shared with the SODR unit staff to direct their attention to the most relevant findings of the study to apply to practice. This study was also used to inform best practices that the SODR unit
currently uses in their pre-admission strategy. All participants were told that they will receive a summary of the research findings.

3.7 Ensuring Trustworthiness

In regards to ensuring trustworthiness, a number of strategies were used throughout the current study. As suggested by Drisko (1997), fidelity to the qualitative approach is critical to ensuring qualitative trustworthiness, and has been described in detail in the previous sections. Drisko (1997) describes four aspects of assessing the quality of qualitative data. First, qualitative work must ensure credibility or truthfulness (Reid, 1994), meaning that the conclusions drawn from the data must be reflective of the participants’ holistic experiences and merely complemented (not distorted) by the researcher’s interpretations (Drisko, 1997). This was achieved in a number of ways. Firstly, dependability of the data was achieved through verbatim transcription of the data, ensuring maintenance of the original description by the participant. A PhD student at HBKRH familiar with the study then additionally reviewed a transcript against the notations used to test the dependability of the raw data. There were 33 discrepancies, including words and grammar. When put into context, this represents 0.4% of the transcript (33 out of 7,622 words). More importantly, none of these discrepancies changed the meaning of the text. Most were omissions of ‘filler’ words (i.e. ‘umm’, ‘mhmm’, ‘okay’). Thus, the raw data itself remained true to the participants. Whenever possible, direct quotes – or raw data - were provided in the following chapter to support the analysis for confirmability and credibility (Drisko, 1997).

The second interpretive criterion is placing meanings of the data within the appropriate context (Leininger, 1994; Lincoln & Guba, 1985). One main strength of qualitative studies is the ability to provide a “local perspective”, or insight into the ways in which data was created in a given context (Drisko, 1997, p. 191). As a researcher, I spent a year and a half in this environment, allowing me to immerse myself in the same context as the participants and gain a better perspective of it. Including a description of the HBKRH context at the beginning of this chapter as well as contextualizing the findings later in the discussion and limitations are two additional concrete examples. I also attempted, wherever possible, to provide further transparency as to the ways in which the study was carried out, and how the selected methodology contributed to the overall trustworthiness of the study.
One important aspect of trustworthiness is a clear description of how I, as the researcher, influenced the co-construction of interviews. A hermeneutic approach was taken to these interviews, recognizing the importance of co-construction between the researcher and participant. This is especially important given that the research was conducted with children, where a power imbalance due to age is added to the power and control given to the interviewer. I attempted to make children as comfortable as possible and avoid topics that may have been distressing. This was highlighted in the informed consent/assent meetings and again discussed at the beginning of interviews. Participants were encouraged to ask questions, interrupt if necessary, and clarify whenever possible. In speaking to children, I provided some background about resilience and explained what it is in the context of providing information for informed consent. I began with an introduction of myself and asked if the children had ever heard of the word resilience or knew what it meant. Some had heard of the term before, but were unsure of the definition. The conversation went (generally) as follows:

As part of my placement at Holland Bloorview, I’ve met a lot of children who have been through very hard times in the hospital. They seem to have gotten through those challenges and I wanted to do this study to learn more about how they got through them. Resilience is a fancy word for getting through hard times or challenges. They may have happened here in the hospital, or in a different time or place. So far, we know things about what the hard times in hospitals are like from parents and from professionals. But we haven’t heard from kids what it’s really like. Because you’re the one who has been through everything, I think you are the expert in this. I’d like to know more about what you think about your time in the hospital, and how you got through it.

This introduction may be interpreted as priming children for resilience or suggesting that other children at HBKRH are resilient, but it was important to be transparent about where my interests and perspectives came from, as I believe that it is impossible to bracket these from influencing an interview. Further, this is also an aspect of co-constructing interviews with children. I felt this introduction was sufficient to prepare children for the interview as a background about PMT and resilience.

As discussed previously, building rapport was an ongoing process that began even before I met with children in the informed consent meeting. This was important to focus on, as co-
construction happens within a relationship, and even brief interactions can build rapport that can lead to rich data extraction in an interview (Polkinghorne, 1983). Importantly, I left space for children to share their own stories in the interview. I ensured questions remained open-ended, and clarified when possible. There were many instances when children corrected me – both spontaneously and when asking for clarification - demonstrating their comfort level and further highlighting the co-construction of the interviews. Again, reporting this information and remaining true to the approach selected – hermeneutic phenomenology – contributes to the trustworthiness of the data (Drisko, 1997).

The third aspect of interpretive criterion is confirmability (Drisko, 1997). Confirmability is the ability to use data as evidence that supports or contradicts interpretation and/or theory (Reid, 1994). The researcher sought to accurately capture the interviewee’s understanding of themselves and the meanings of their own words (e.g. clarifying within the interview). To this end, not only were participants’ direct accounts provided, but they were also confirmed against a number of other sources of evidence. Important contributions to validity outside the interview were completing referent checks with SODR unit social workers, and completing member checks with participants. Social workers provided professional accounts of their experiences of PMT and helped to organize descriptions and themes during data analysis. Preliminary findings were presented to the employees of the SODR unit, including nurses, child life specialists, social workers, psychologists, physicians, and management. There was much positive feedback about the findings and interest in using this information to improve pre-admission information provided to clients and families with the aim of better preparing them for PMT and on the path toward resilient recoveries. Finally, peer debriefing was used throughout the research process, through regular reviews of the analytic process and findings with committee members.

The fourth interpretive criterion refers to comprehensiveness of data collection and analysis, known as saturation (Drisko, 1997). This was originally found in the interviews, where a number of common experiences and perspectives appeared after the first three interviews and continued to be confirmed and further refined as children of different diagnoses and ages also discussed similar issues. Contradictions that occurred were included and explained given the context that may have influenced this difference. For example, one participant seemed to be an outlier in some ways due to both her multiple exposures to trauma and intersecting vulnerabilities. The impact this may have had on her answers and the ways in which they diverged and converged
with those of the other participants were discussed in detail. Such detailed descriptions are the benchmark required for comprehensive research reports that further affirm saturation (Strauss & Corbin, 2008). Finally, Koch (1995) states that the interpretive process is central to the rigor of hermeneutic phenomenological projects; for this reason, the process at arriving at descriptions as well as themes was made clear in the next chapter.

Positioning oneself as a researcher within a study is an important aspect of qualitative research (Creswell, 2013), assisting with addressing and reducing risks of bias (Drisko, 1997). This student researcher has included a reflexive positioning statement as part of maintaining transparency and in aligning with a hermeneutic approach to phenomenology, included next to conclude this chapter. Combined, all of the above contribute to the rigor of the study.

3.7.1 Positioning statement.

According to Creswell (2013), qualitative research requires those who carry it out to be reflexive, that is, explicitly connect the ways in which one’s own experiences, values, beliefs, and biases will influence the research process. This research project takes a hermeneutic approach, which is consistent with my personal belief that it is impossible to separate oneself enough from our own experience, beliefs, values, and biases to fully enter the world of another and truly understand what it is to be another person. I believe there is value in attempting to suspend your beliefs, as in transcendental approaches, but that essentially, the mind is relational in nature and is constantly seeking to find shared meaning and connection with others. Thus, the following is an attempt to create transparency in my role within the co-creation of knowledge through this research. Readers are free to then interpret the findings within this scope.

As a thesis, it is assumed to be clear that I, the writer, am a Master’s student and that this project is a part of my requirements for graduation. In contrast to other research-based programs where completing a thesis is mandatory, this is not the case for my program. Completing a thesis in the Master’s of Social Work (MSW) program at the University of Toronto is a voluntary and competitive process. It involves additional time (i.e. an extra semester) and effort on my behalf, as well as others involved, especially the thesis committee. Thus, it is important for readers to know my motivation for completing research on PMT and resilience.
Trauma has been a topic of increasing interest for me since beginning the MSW program. Specifically, childhood trauma as a whole presents in itself an issue that spans across sectors and is known to have lifelong effects. In working with Dr. Ramona Alaggia through an independent reading course, I was interested in exploring childhood trauma and resilience further, but the topic required refinement. As I was considering this, I had begun my placement at Holland Bloorview Kids Rehabilitation Hospital. As part of my placement, I began working in the attached school, Holland Bloorview School Authority, and working with clients on the Specialized Orthopedic Development and Rehabilitation (SODR) unit. I was in awe of the ways in which, overall, the children and the classrooms functioned ‘normally’ despite the challenges that each child faced in their rehabilitation process. As I learned more about the clients, they shared their stories with me: of chronic diseases, of sudden accidents and life-altering injuries, of months spent in the hospital, and other stories that I thought about even when I was not at placement.

The reason that these stories captured my attention was that it was so clear to me how each child had been resilient in the face of very challenging circumstances. Of course, I also noticed exceptions. I did not always see this resilience were with adults; parents and professionals who have had a lifetime of accumulated knowledge and experience to allow themselves to be completely hopeful.

It seemed to me that these experiences could be a form of trauma, thus I decided to explore this further in my independent reading course with Dr. Alaggia. I discovered that this phenomenon had a name – PMT. I wanted to know more about why I saw these trends in resilience following the trauma in the inpatients in the hospital.

I was first introduced to the concept of resilience in my undergraduate degree in Child, Youth, and Family studies. It has fascinated me how some children seem to ‘bounce back’ from adversity. I remain optimistic that all children have some capacity for resilience, given supportive and responsive environments. This optimism tends to manifest in my behavior: to draw out strengths, point out exceptions, and a general lean toward a strengths-based approach. It was important throughout this project (especially during interviews) to be curious about children’s experiences without inoculating them with my own beliefs.
Another important motivator for completing this research is to give children a voice. In my experiences, both in research and in practice, parents tend to dominate psychosocial support for important reasons. Still, I believe that children have very important insight to their own needs and care, but require a platform in which to share them. When considering impact, hearing children’s stories directly has had the greatest effects on me and my ability to understand, which is part of the reason that I would like to interview children, as opposed to focusing on parents’ or professionals’ perspectives. This research is not to downplay the importance of supporting parents, but instead discovering the insights that children have about their experience and their care that we can learn in order to better care for them.

As a researcher, I recognize the role that I played in co-creating an interview with a child. The nature of the interview, as well as social norms, dictated that I controlled the direction of questioning. Thus, I was mindful and critical of the questions I asked in attempting to capture each child’s voice, and not what I was hoping for a child to share in order to fit my ideas. As stated, it was important for me to be aware of my tendencies to explore and highlight strengths for kids and allow their own feelings, thoughts, and beliefs to emerge. It was also important for me to have a degree of objectivity when analyzing the data.
Chapter 4
Findings

4 Findings

The following section describes the results of the interviews conducted and will be presented in the same format as the research questions posed the study. First, children’s perceptions of their medical experiences as traumatic, and not traumatic, are explored. Next, children’s understandings of resilience are presented, followed by children’s perceptions of themselves as resilient or not. Finally, the factors that children interpreted as promoting and inhibiting resilience will be explored, along with how they made meaning of these experiences. The themes that emerged under this question are reflective of the social-ecological model of resilience and will be organized as such. In keeping with the hermeneutic approach to interviews, ‘the act of dialogue’ engaged with children was presented first as questions to elicit a rich description of the event, following by probing questions aimed at determining a deeper meaning. As mentioned previously, descriptions of the children’s experiences differed across participants and are offered in response to the research questions for context. However, greater consensus was found around meanings, which became themes emerging from each of the research questions. This process of interpretation is made clear in the following sections, as suggested by Creswell (2013), Drisko (1997), and Koch (1995).

Quotations are provided as evidence of the experiences of participants and examples of the meanings attached to these experiences. Quotes included follow the same verbatim rules for coding, as noted in Chapter 3 (p. 55). Notably, where there is back and forth from the researcher and participant, this is noted as R and P, respectively. The following symbol: [...] was additionally included in this section to represent when some of the speaker’s quote is skipped for brevity. Each quote will be followed by the participant’s age. Themes did not differ by gender and the decision was made to leave the participants’ gender out of the results to protect the identity of the participants. Given the small window of time that participants were recruited for this study, the fact that they were recruited by social workers on the unit, and the limited children that were eligible for the study, it is possible that identities could be confirmed by including gender. For this reason, personal pronouns used throughout the thesis will be gender neutral to protect the confidentiality of the participants.
4.1 Children’s Perceptions of Medical Experiences as Traumatic

Before delving into children’s experiences in the hospital as traumatic, or not, it is first important to understand the circumstances that brought participants to the hospital. The majority of children (i.e. five of eight) in this study were rehabilitating after an orthopedic surgery. Of these, two had cerebral palsy, a congenital disorder affecting muscle tone, movement, and motor skills (KidsHealth, 2016). One had surgery in their leg, and one other participant had surgery in their back, which was also related to a congenital condition. Of the remaining three participants, one participant sustained a spinal cord injury following a motor vehicle accident (MVA). One participant was rehabilitating following oncology treatment. The last participant was rehabilitating following Guillain-Barré syndrome (GBS), a rare and potentially life-threatening auto-immune disorder, attacking part of the peripheral nervous system. GBS limits use of muscles, and can cause paralysis, though the symptoms subside in most cases within weeks (National Institute of Neurological Disorders and Stroke, 2016). All children came to HBKRH following care in an acute hospital setting. The average length of stay for SODR clients is approximately two to three months, depending on recovery time, any complications that arise, and the coordination of discharge and transition home.

Within the interviews, trauma was discussed as having three critical elements: the event was unexpected, the child was unprepared, and the experience was overwhelming. These were aspects of trauma that were considered to be accessible ways of discussing children’s experiences and perceptions, versus discussing trauma in general, which is not only an advanced word, but has multiple (and loaded) meanings. Depending on the age of the participant, their capacity to discuss personal experiences, and the nature of the medical challenge, questions were explored differently. Once again, this highlights the co-construction of interviews, recognizing the differences that participants bring despite the same interviewer throughout the study.

Children were asked to identify and describe a challenge or challenges that they faced in the hospital. The purpose of this was to get children to think concretely about their experiences in the hospital, as opposed to discussing more abstract ideas of trauma and eventually, resilience. Most children listed their diagnosis or reason for stay at HBKRH as this challenge. The following are examples of challenges identified by participants: “My surgery. … I think I’ve had seven, when they were doing, um, when they were putting on different kinds of casts. And this
was, um, the real one.” (6); “Blood work. […] And because you can’t really see my veins. So it’s hard, to get it out.” (10); “At the start, I had a lot of pain. [R: Mhmm.] As I – I was just walking through all of that pain. Throbbing, and stabbing, and hot knife feelings.” (9) Surgery, invasive treatments such as needles, and pain have all been associated with medical trauma in literature (Children’s Hospital of Philadelphia, 2014; NCTSN, 2004; Webb, 2009). An older participant spoke directly about their experiences of trauma:

But, in the operation room - I was calm, only in the waiting room - I was having trauma. [R: Mhmm.] A bit. [R: Yeah.] But, some of my dad’s friends came, because some of my friends, were in school. Because it was on a Tuesday. So, [R: Mhmm.] not being beside my friends, not, my friends, um, comforting me, and um, like, I was just thinking about my friends and about like I’m not going to see them for such a long time, like, it’s going to be so bad and stuff, I don’t know. I was like, so scared and like, it’s just so bad, and I was just so scared and stuff. It was just- And the two years, just, I was happy, and uh, I was scared at the same time. And in the two years, I was like, ‘Yeah, I’m going to get better!’ but then, ‘Oh, it’s scary! And all the recovery’, and ‘Yay!’ and stuff. So, and I kept going back and forwards. But, yeah, so, the least amount of trauma, was the two years leading up, to the operation. But, um, starting a week before my operation, it started to feel more and more. And uh, yeah, it, um, and it was pretty scary in the waiting room. [R: Mhmm.] Because you know, in a few minutes, you have to go into the operation room. [R: Mhmm.] No turning back. They’re going to put tons of stuff on you. Tons of cold stuff. A really scary bed. Because you see all of the machines, and the, and the oxygen mask, and it’s getting all blurry and stuff. And they’re like, ‘You’re going to be okay.’ And they put a needle in you. (12)

Similarly, another participant described their experience of surgery, which can be interpreted as traumatic. During the interview, this participant described vivid details of the time before their surgery, and needed to stop at one point because they became visibly distraught. When I checked-in with the participant, they said they were sad, that this was hard to talk about, and did not wish to continue. Their fears and worries are evident in the following excerpts of the interview, before we moved on to a new topic:
When I went into the operating room, they took me in, and, they put me on the table. And they just put my eyes closed. And told me, ‘Just try to get a grip for a few minutes.’ But took me a while to get the mask on because I was crying.

They told me that, you know, your legs are going to be fine. So, don’t worry about it. Because you won’t, you won’t feel it. I was worried that I would feel it. But my mom and dad said, ‘You won’t feel it because you’re asleep.’ (9)

Though this participant did not use language specifically associated with trauma, their affect in the interview suggested that they were being triggered back to that event.

Similarly, another participant who sustained a spinal cord injury following a MVA did not refer to being traumatized but spoke in ways that gave evidence of trauma. They described their memories of the accident and being in acute care shortly after. The participant’s descriptions were expressed in snippets, which I understood as their fragmented memories of the accident. When asked what it felt like to wake up in the hospital, they answered that it was “weird.” After a long pause, they added, “Being in a bed. …And just laying there flat” (8). The participant’s description of what it felt like to wake up and realize that they were paralyzed – ‘just laying there flat’ - was a standout phrase of all the interviews. Further along, they described what made them feel sad in the hospital:

P: That I’m not at home, and that I’m not how I used to be.
R: Mhmm. Mhmm. So how did you used to be?
P: Walking. And not in a wheelchair. (Mouths ‘Forever’.)
P: Forever and ever and ever and ever! Forever and ever and ever andeverandevever andeverandevever oh, oh, oh oh oh! (Gesturing circle with finger.) (8)

The participant was drawing during the interview and after this exchange, then moved along to showing me some of their ‘scribbles’. They had drawn a number of happy and sad faces in pink marker, the same colour as their wheelchair, suggesting their mixed feelings toward it. It seemed to me that given the accident was relatively new, this participant was still adjusting to their new reality of life in a wheelchair. When discussing the events with the participant, they answered ‘I don’t know’ to many of the questions, despite efforts to modify questions and further probe. It
became apparent that this participant indeed, did not know, or did not recall many of the events shortly after hospitalization and was still coming to terms with the severity of her situation. For this reason, though this child did not explicitly state that their experiences were traumatic or provide direct evidence linking their experiences to PMT, it could be interpreted as traumatic.

Only one participant discussed their injuries as potentially life-threatening. They mentioned finding out after-the-fact, and appeared relatively unconcerned, seeming to appreciate their current state: “I only really found that out a month ago. That some people die. I wasn’t really like, ‘Oh my god, some people die!’ I just knew that it was horrible, and I survived. Until now. And that’s good.” (11) This type of perspective could be related to resilience, which will be discussed further in this chapter.

4.1.1 Overwhelmed.

Children were asked if they felt overwhelmed by their hospitalization, and the majority of children described ways in which their experiences felt this way. Some participants noted that they were overwhelmed with their medical challenge, or described strong emotions in relation to the events that were difficult to manage given their current state, or resources. Of the six children that discussed this topic, five said that they were overwhelmed, and one said they were not. The participant that was not overwhelmed also disagreed that their hospitalization was unexpected or they were unprepared for it. They did describe feelings of fear related to a medical event (i.e. blood work), but these quickly subsided once it was over.

The youngest participant, six years old, described the intense fear they had in the days following the surgery: “I didn’t like waking up in the morning in SickKids because I was afraid, every single day, something… Some kind of… Really… Doctor kind of thing would happen” (6). This quote brings to mind overwhelming fear coupled with lack of control, which is a theme described later in this chapter.

One participant noted that they were overwhelmed with the schedule, as well as being alone and being with unfamiliar people: “Probably the schedule. And, overwhelmed with the – my parents aren’t here a lot during the day, like I’m by myself most of the time. And sometimes I don’t know everyone.” (11). The intensity of scheduling was a topic discussed by other participants, as well,
It’s very tiring… Very tiring. ‘Cause whenever I have a break – Oh! – I have to go somewhere. Whenever I… I’m sleeping… I always… beep beep beep beep beep beep beep beep beep and during the middle of the night, that’s no good. But it’s always stuff… You know, I’m always rushed somewhere. (9)

Here, the participant describes the noises made by the equipment in their room, waking them up, invading their space, even when they are sleeping. One participant further pointed out the invasiveness of the equipment, “I had the heart rate monitor, and stuff, and as soon as I got nervous, it started beeping and I felt even worse.” (12) During the day, children in the hospital at HBKRH are whisked from school and multiple appointments with professionals, and at night, more social activities are planned. Another participant describes the entire experience of hospitalization as tiring, and evoking feelings of being overwhelmed by the process.

Because you get tired. And I’m getting sick and tired of this place because I already always came here for my appointments, and it was already like a second home. And now it’s literally like a home for me. Like, kind of weird for a hospital to be a home for you… But, yeah, just, like, being in Bloorview, honestly was tiring… Because I was like, crying in the middle of the night. Just, ‘Mom, I’m sick and tired of this place.’ I just want to get out of here and, ‘Mom, I’m tired!’ and stuff. And I was just moaning and groaning all the – at night, and it was just terrible. Those things were annoying that were on my feet. (12)

As part of their rehabilitation, this participant (and others) had immobilizers attached to their lower extremities, controlling their range of motion as they healed. These were described as frustrating to the participant, who could not take a break from them, in addition to the demands of their schedule and environment. Overall, participants provided evidence that their experiences are overwhelming, or exceed their resources at times, most notably toward the beginning of their time at HBKRH.

4.1.2 Unexpected trauma and feeling unprepared.

Children were also asked whether they felt their medical challenges were unexpected and whether they felt unprepared. For some participants, entry into the hospital came as a surprise, and even if they had some knowledge of what was to come, children described being unprepared or underprepared. In comparison to feeling overwhelmed, this topic was addressed less by
participants. And importantly, not all children felt that they were unprepared. For one participant who contracted a sudden illness and was physically unable to move, feeling both unprepared and unexpected was particularly concerning. In their own words:

It was sudden, I like, could barely move from there. [R: Mhmm.] I found out that it’s actually, like, serious. [R: Mhmm.] Because when I first went to the hospital, the only thing that wouldn’t work was one of my ankles. And, so, the doctor did a test, they said-he said ‘You should sleep in the hospital for tonight.’ And I’m like, ‘Okay, I’ll go back tomorrow.’ [R: Mhmm.] But it like, it took like, like three, three weeks. (11)

When asked about the meaning that had for them, they answered:

Um, sadness. Well, yeah. Kind of, confusion. [R: Mhmm.] Because like – Whaaaat?!
How did this happen and stuff?” How did I get from 24 hours before this I was at home. And now I’m here – how? (11)

Understandably, this child was unsure of what to make of their hospitalization when things took a turn for the worse. An interesting finding was that even among those with chronic conditions, where routine surgeries occur, finding out they needed surgery was still unexpected and significant. Consider the following two cases of participants who had to undergo hamstring release surgeries, common in children with CP, and the resulting reactions and feelings they had:

P: Um, the surgery was unexpected.
R: It was unexpected.
P: For my mom and dad, they said they knew that it was going to happen, but for me, I, I did not know. That it was going to happen.
R: Hunh. So how did it feel to know that your mum and dad knew but you didn’t know?
P: They didn’t want to scare me, but I understood that.
R: So you understood that. But how did it feel – What kind of feelings did you have about it?
P: Very angry. Angry because they never told me and then I was going to be prepared earlier.
R: So angry at…? Who?
P: My mom and my dad, a bit, but it’s a good thing they didn’t freak me out when I was
smaller [R: Oh, okay.] Because I was 8 when that hap- When they told me – So, that it was, I, I cried, not as much as I would have if I was 4. (9)

Later, the same participant is asked about whether they felt unprepared:

R: Did you feel unprepared?
P: Not really.
R: What helped you feel prepared?
P: Well my, well I went to visit tours of SickKids and Holland Bloorview.
R: Okay. So what difference did those tours make?
P: That I knew how I was gonna – my life, what my lifestyle was going to be, sort of. [R: Okay.] And, plus they changed the TVs to new, to new, OLG flat screen. [R: Oh, cool.] ‘Cause otherwise it was just a box. You know those old, computer-looking box thingys? (9)

This participant felt upset, but they eventually understood that waiting to find out was a good thing. Once they had more information, they felt prepared and had an idea in their mind of what life would be like during that time. They also mention looking forward to having new televisions. This comment reminds us that children in the hospital are still kids and get excited about things that kids would be excited about in their ‘normal life’. This concept will be discussed further in a later section. Similarly, another participant felt shocked by the news of their surgery at first:

Like, umm, two years ago [R: Mhmm.] They started talking about it. The first day, that they said I might need an operation, was the WORST day of my life. [R: Really.] I was crying and stuff because it was just scary thinking that I was going to have an operation. (12)

Later, the same participant discussed the difficulties their family had when signing the medical forms:

The last form that I had, that I had to sign before I had to go into the operation room, was the form that, ‘Are you sure you want to do the operation?’ …And, uh, that took a little bit long, for our family to do. Because […] it was pretty hard. Like, are you sure you
want to do this or not? We-We-we’ve been waiting two years, is this going to work properly? Is the operation going to work well? Or is it going to make things worse? Because honestly, operations sometimes, does make things worse. Sometimes, if it doesn’t go well, and, and it depends on the worse of the person. And thankfully, everything went well for me. Yeah. But, it was really hard. That part was, life changing. (12)

Even after two years of preparing themselves, this participant and their parents faced more difficulty as the potentially bad outcomes or worst case scenarios were once again presented, not only in passing, but in a way where the family needed to actively acknowledge them.

4.1.2.1 Theme: Missing out, hospitalization as abnormal.

A significant challenge that emerged as a theme as children described meanings of their medical challenge was missing out on their normal life, and the hospital being an abnormal childhood experience. Being in the hospital meant missing out on the things that they cared about: home, family, friends, school, hobbies, and pets. All participants described missing something or someone in the interviews. Consider the things children missed in the following examples:

I miss my cat! […] And my brothers. (8)

Whenever I go home on the weekends, I see my friends outside playing. Playing baseball and soccer and all of that stuff. And I’m like, ‘I should be outside there!’ and like, my parents are like, ‘It’s okay, like the amount you can do is still amazing.’ And I’m like, ‘Mom, you just don’t understand, like I can do way more’ and stuff. Like, ‘why are you guys like, making so many limitations for me?’ And they’re like, ‘No we’re not’ but honestly, I know they’re just trying to help, but still, I know I can do like, way, um better. But sometimes I feel sorry for my- My parents are like, ‘Don’t feel sorry for yourself.’ But honestly, I do sometimes. Because… I should be out there playing with my friends. But right now I can’t. Right now I can’t but four weeks from now I can. Still, that’s pretty long for me. [R: Mhmm.] Because, I want to, but I’m not allowed to. (12)

P: You have to get used to the fact that you have nothing to do, you’re just lying around all day.
R: So you mean in the hospital?
P: In the hospital and at home. You basically have nothing to do.
R: How come?
P: You don’t go to school, you can’t go outside, you can’t play, you can’t; do anything fun. (11)

As children explained the meanings they made out of hospitalization, not only did participants describe missing out, but relatedly, how hospitalization was an abnormal childhood event. Consider these descriptions and meanings in the following quotes:

R: And how do you feel about being in the hospital?
P: Well, I feel a bit sad, really, because I don’t get my life, really. Because I have another life. And then, yeah.
R: So you feel sad. What do you mean you have ‘another life’?
P: It’s sort of… Like I changed, like I changed my whole lifestyle. ‘Cause after that, I couldn’t see my friends a lot. I couldn’t, go outside a lot. (9)

Not normal. …Like, here’s the other kids, they barely go to the hospital. And you’re in the hospital for that whole entire time! It’s okay. I’m okay with it. Ahh, 50/50 on that ‘okay with it’. [R: Mhmm.] Like, I don’t feel upset about it, but it gets annoying over time. [R: Mhmm.] Because you have to go to these appointments, and they have to stretch you all the time, and they have to give you medications and stuff. But, but the medication part is pretty low for me because I don’t take a lot of medications. It’s mostly just the stretching and the, going for operations. Um, like, I, I know people that had operations at a younger age than what I had. But still. Twelve is still a very young age to get an operation. Like you don’t see my friends, like, getting operations this early. […] Like, how many times do my parents see the doctor? - Not, not not because of like, financial reasons, but how many times do you think my parents see the doctor? Maybe once or twice a year? Well I see them almost two, two or three, three or four times a month. [R: Mhmm.] Or maybe two times a week. [R: Mhmm.] So do you think that’s normal for a kid?! Well, honestly, I don’t think so. (12)

Completely felt it was not normal to be in that environment (9)
The implications of this perspective of abnormality are further elaborated later in this thesis.

4.1.2.2 Theme: Increased stress in acute care versus rehabilitation.

Many children discussed the differences between acute care environments and their current rehabilitation location. In general, their experiences in acute care seemed to be more traumatic than their stay in rehabilitation. The following participants’ comparisons of the environment in acute care versus rehabilitation is one such example:

But SickKids is um, louder. Because you could always hear the – you could always hear the helicopters going… and the, the car- the ambulances running off, or beep beep beep beep beep beep beep beep beep beep beep. Somebody’s… epidural or something is going off. [R: Ohh.] Or, somebody’s just calling in. So. Here, it’s much more quieter. (9)

Because at SickKids, it’s like you don’t have, like, as nice nurses. Like you have nurses, but you don’t have like, close nurses. One on one. And like, you have kids your own age closer. And like, you do rec, and like, more fun activities. [R: Ohh.] Like, at SickKids, they have activities, but not as much. And you stay in your room all day and you don’t get to go to school. (11)

Another participant described the difference of an acute setting in an intensive care unit, as opposed to a paediatric hospital:

Well, it was just a bad place. There was this person beside me – not beside me, like the bed was like, close, but he was I don’t know. He was on drugs or something. [R: Mhmm.] Because, he like, felt bad, but then the nurses brought up something, this, package thing in their hands, that they were kind of hiding it, and then he like ate it. And he became happy and stuff. [R: Oh!] So I would guess that it’s drugs. (11)

Overall, children described both the environment and circumstances in acute care to be more stressful than in rehabilitation. Notably, many of the challenges they described in the beginning of this chapter occurred in acute care settings. Still, many examples of the challenges children faced in rehabilitation were described in answering the first research question addressing children’s perceptions and meanings of PMT.
4.2 Children’s Understanding of Resilience

When children were probed regarding their current understanding of resilience, both in the informed consent meetings, as well as in the interviews, the majority of participants did not know what this term meant. Some had heard of it before, and a few made guesses of the definition of resilience, only one could articulate exactly what resilience is, or meant to them. One participant described resilience as “Like, that, you’re sort of, like… confident, and like, you were okay in the hospital, like, you got through it. You were patient and stuff like that.” (9) One parent of a young child in the study mentioned in the informed consent meeting the she often discussed resilience, in order to facilitate positive coping in her child. However, when this participant was asked about resilience, they could not remember what it was. It became clear that children do not understand the language of resilience. Terms were then simplified to reflect language that children understood, and where possible, their own words were used to replace more complex terms describing the same phenomena. Through this process of co-creating meaning, resilience was discussed as ‘getting through hard times’, risk factors became ‘hard times’ or ‘challenges’, and protective factors were then ‘things that helped you get through’. Children’s perceptions of themselves as resilient, as opposed to the concept in general, are described in the following section.

4.3 Children’s Perceptions of Themselves as Resilient

Importantly, each participant was asked if they thought they were resilient and all eight of them believed they were, and could describe a specific example of when they overcame a challenge within the hospital. Only one participant expressed some doubt in their ability to be resilient, answering, “Sometimes I get through it. But sometimes I don’t because it’s really hard. [R: Mhmm.] But usually, the most times, I get through it.” (8) Again, given the severe adversity and impact to quality of life this participant recently endured (i.e. MVA), they may be a special case. When considering the meaning that children attributed to their resilience, themes centered around perseverance. Finally, participants also discussed their resilience as a process over time, discussed under the theme of ‘Trajectories of Resilience’.
4.3.1 Theme: Perseverance.

When participants were asked to elaborate on in what ways they thought they were resilient, children described how they persevered and progressed through the difficult process of hospitalization. Three sub-themes also emerged: persevering toward independence, persevering to make progress/achieve goals, and persevering because of support.

Perseverance was described in a number of ways as being the driving force of resilience. The youngest participant, who endured seven surgeries by the age of six years old, stated, “I had to be brave.” (6) When asked to elaborate on the meaning of bravery, they replied, “It means that you have to – that you have to face your fears.” (6) Descriptor words were used that emanated perseverance, including toughness or hardiness, and inner strength. One participant offered this idea in the following quote: “Well, I tried to ignore them. You just have to fight through them. They just happen.” (11) Here, the participant describes both active and passive strategies to continue to get through hard times.

4.3.1.1 Subtheme: Perseverance toward independence.

Other participants believed they were resilient and had to persevere to be independent. An example of this appears in the following participant’s explanation:

Um, the thing that kept me going is because I like to be independent. [R: Mhmm.] So I had to work hard, so when anyone tried to help me, I was like, ‘No, I can do it myself.’ And that’s what made me stronger than most – um, I think, physically, than most-able-bodied kids that I know. [R: Mhmm.] Not, not, not to think that my friends are weak, or anything but it’s just basically I feel I’m a bit stronger than them because I have to work harder. (12)

In this context, the participant is describing the ways in which exposure to adversity makes them work harder than their peers to maintain independence. The topic of independence was brought up several times in this interview, highlighting its importance to this participant. This sense of perseverance and subsequent pride was also reflected by another participant, who explained that to get through hard times they maintained consistent effort, or was “trying my best.” (8) Later, the same participant stated “I want to know what I can do” (8), meaning to push their limits of what they currently think or feel is possible. Finally, connecting back to independence, this
participant said, “Sometimes when I do stuff on my own. I – That makes me proud of myself.” (8) It became clear that children found meaning in gaining independence, and believed that they were capable of being actors in their own experience to produce this result.

4.3.1.2 Subtheme: Perseverance toward progress or goals.

Some children noted that they overcame challenges, or were resilient by making progress or achieving goals. For example, one participant noted, “Because everything I wanted to do – accomplish – I accomplished.” (11) In another example, a participant explained that they ‘kept going’ and pushing through rehabilitation toward her goal because “I thought, um, if I do the stairs I could go home.” (11) One participant provided a very simple answer to why they thought they were resilient, “Just, doing it. Just doing everything.” (11) Overall, it seemed that the process of persevering through medical challenges experience in and of itself proved to children that they were capable of handling adversity.

4.3.1.3 Subtheme: Perseverance because of support.

Finally, children explained that the support that they got from the people around them was the reason why they were resilient. In contrast to the ways in which most children discussed their parents, friends, and peers as important supporters for resilience, some children noted they persevered because of the people around them. The following spontaneous answer from a participant highlights the importance of parents in resilience:

R: Yeah. Have you ever heard of the word resilience before? No? So that’s basically what the word means, so when there’s a challenge, that you, meet it and you get through it.

P: That’s what my mom helped me do. (10)

Parents were not the only people who were the reason provided for their resilience, but also peers and environment. “You just, you’re just in a place where everyone are doing the same thing that you are. And everyone is going through something bad. Maybe better or worse than yours. So you just- want to join them.” (11) It is an important distinction that children noted not just internal factors for their perceptions of themselves as resilient, but social and environmental factors, supporting this view of resilience.
4.3.2 Theme: Resilience as a process.

This theme starts to shift our understanding of resilience as a merely state or trait to a broader understanding of the processes involved. The opening section describing children’s descriptions and meanings of PMT alluded to the ways in which trauma was most severe closest to the original event or challenge and decreased over time. Children’s perceptions of themselves as resilient describe a process they went through, where over time, children outlined the ways in which they felt they returned to what they considered their ‘normal’ or, in some cases, the ways in which they grew. The participants recognized that life was not always perfect, in the sense that they did not need to be happy all of the time and that getting back to normal still meant that they had some not-so-good days. As one participant noted: “But as it started to move forward, negative started shrinking and positive started growing. Until I got to a 50/50. Which is, life is normally a 50/50.” (11) This participant’s reference to the ways in which the positive grew fits with the definition of resilience used in this thesis, which includes positive adaptations to adversity over time. Similarly, another participant explained:

I think it’s very unusual to be completely happy with your life. But, but it’s okay to be a little bit unhappy. And that’s what I am right now... And I think, um, uh, over the years, if the operation does work well, I think that percentage of being happy, will go higher and higher. (12)

Notably, these comments came from two of the older participants of the group, which may reflect their developmental stage and maturity. This theme was further checked for validation with two participants who strongly supported this concept as an accurate depiction of resilience over time. They provided further evidence that resilience is a process, stating, “you always need to start somewhere and continue on” (9) and “it happens over time” (11).

4.4 Factors That Promote and Inhibit Resilience

The final section of this chapter will address the last research question: What factors do the children interpret as promoting or inhibiting resilience? And how do they make meanings about these factors? In the interviews, questions were posed to children regarding what they felt was ‘helpful’ or ‘hard’ about their experiences in the hospital. The personal strategies they described varied, but the meanings they provided to children fell under three themes: control, coping, hope,
and positive thoughts. Unsurprisingly, support was found to be a theme with the sub-themes of parents, peers, health care practitioners, and feeling understood. Finally, one environmental theme emerged: school, with the sub-theme of teachers. Similarly to the social-ecological framework of resilience used in this study, children described factors that were individual, social or interpersonal, and environmental that affected them. The following section will be organized in a similar fashion.

4.4.1 Theme: Control.

One topic that was discussed often, directly or indirectly, by participants was control, or their lack thereof. Sub-themes included control over information and scheduling. One participant described their fears about getting more surgery: “When they – when they were talking in the room about surgery. And I got really scared, that it’s going to happen whenever. And anytime it has to happen.” And, “Um… Yes. …I didn’t like waking up in the morning in SickKids because I was afraid, every single day, something… Some kind of… Really… Doctor kind of thing would happen.” (6) The message that I perceived from this participant was the lack of control she felt – that at anytime, someone could walk into her room and take her into surgery.

4.4.1.1 Subtheme: Controlling information.

A critical aspect of control was related to information. Participants were articulate about what type of information they wanted, who they wanted it from, and when they wanted it. Participants described how nervousness and fear dissipated when they were provided with more information:

R: What kind of things made you feel nervous?  
P: That I – I didn’t know, what was going to happen. I didn’t know what I had to do. I didn’t know anyone. [R: Okay]. So.  
R: So lots of not knowing things. […] So I’m wondering a little bit more about feeling nervous. And feeling unsure. Was there anybody who told you? Or, when did you stop feeling like you weren’t so sure about things?  
P: After I met everyone. And I had an idea of what was going to happen. How it was going to happen. And all of that kinda stuff. (10)  

R: Do you ever feel scared in the hospital?  
P: Noooooo.
R: No? How are you never scared?
P: Because I know everybody.
R: Everybody as in, the people who work here?
P: Yeah.
R: Okay.
P: And every kid, and every kid, too. (8)

In general, participants wanted to know about the people around them, and what they were expected to do. When it came to the things that were going to happen to them, children had differing opinions, and communicated this to people who controlled information to them, notably parents and health care professionals (HCP).

R: And did you feel better when you knew everything was going to happen? Or did you feel better when you weren’t so sure?
P: A bit of both.
R: A bit of both? … Because…?
P: I didn’t really know, what was gonna happen. It’s kinda hard to explain.
R: It’s kinda hard to explain? So when would you want to know everything about what would happen to you?
P: After it’s all done.
[…]
R: But before?
P: Not, so much.
R: You don’t want to know everything. Okay … So, did you tell anybody that you didn’t want to know everything?
P: My parents.
R: You told your parents that. So what did your parents do with that information?
P: They didn’t tell me everything. (10)

R: Did you want to know?
P: No... Well, kind of yes. Well I didn’t want to know then because I was nervous about it.
R: Mhmm. Mhmm. So did you tell someone else ‘I don’t want to know too much’ or?
P: No.
R: No? They just knew?
P: Mom did. Um-
R: Do you think they knew that you were nervous?
P: Yeah. Because I kept asking questions about the surgery before it happened. And I guess I kept asking questions over and over again. (10)

In these two examples, participants were able to articulate what information they wanted and when. In the latter example, the participant did not specifically articulate their preferences, but those around that child understood not to divulge specifics until after the surgery. Notably, for those who preferred less information, it was parents who provided this information. One participant described the difference that hearing information from parents - as opposed to doctors - had:

R: So, how did it make you feel when they told you?
P: It felt - because my mom and dad told me – not like the doctors, [R: Okay.] Like they explained it to me.
R: Okay. How would it be different if the doctors told you, do you think?
P: I wouldn’t really understand it. [R: Mhmm. Okay.] And it’s nicer hearing it from someone you really know. [R: Mhmm.] And know that they love you and everything. (11)

In contrast to these participants who preferred less information, there were a few participants that not only knew everything about their surgery, but also became ‘experts’ in their own right. These children had an advanced understanding of medical knowledge, learned from the medical team, and shared it openly:

P: (P now begins to draw using the markers and paper provided) So… so… basically, pretend that’s my spine… (P draws a two long, curved lines resembling a spine) [R: Okay.] …That’s my head (P draws an oval on top of the spine.) Don’t care about that. [R: Alright. (Laughs)] So I have a little… thing there. (P colours in the very top section of the spine.) […] Right at the top. My first C1.
R: Oh, okay.
P: So it’s cer- blah- CER-VI-CAL VER-TI-BRAE number one!
R: Okay. So, is it called C1?
P: Yeah. C1. Exactly. So it goes all the way to my tailbone there. (P draws a line down the spine.) And to my legs. (P draws two stick legs at the base of the spine.) They don’t work right because the messages – get messed up. So they don’t go right. (9)

Yeah, so the nurses, said a lot of fancy words, too. [R: Yeah.] And not surprisingly, I took them up really fast. [R: Wow!] So, yeah, these words are literally stuck in my head now. And I keep talking about them and stuff. (12)

Um, it’s this thing, that, the body’s immune system attacks the nerves. [R: Okay.] And so, the nerves stopped working for a while, but it gets better, slowly. And, you need physiotherapy and stuff. To get- to make it faster. (11)

Overall, these participants were not only well-informed about their care, but also seemed to have developed stronger insights about their experiences, as well. One participant offered the following explanation as to the meaning that being provided information in advance had:

R: Why was it important to you that they would explain things first?
P: ‘Cause then I wouldn’t… mm, I wouldn’t… be mad at something that- ‘cause usually, sometimes if I don’t know something that’s going on, and I really, don’t, like it, when that happens, ‘cause I-I I need to know what’s going to happen. I prefer that. Otherwise… It’s just not the same. Uh, when I get, when I, um, during the surgery when that happened, I knew what was going to happen. I, uh- The doctor told me what was going to happen. […] Not, not knowing, felt… disturbing. No, not disturbing, but… anxious! [R: Okay.] Because I was scared. Scared. That’s what I mean. [R: Okay.] So it helps me relieve some scaredness of whatever it is, you know. (9)

Sometimes positive information was withheld from participants. Receiving positive information was also helpful:

So yesterday, because I thought I have had many limitations, But, but as soon as I went in there, like, the doctor was like, um, ‘Walk without your cast!’ and ‘Walk without your AFOs!’ And I’m like, ‘Whoa, I can actually do that?!’ And he’s like, ‘Go swimming!’
and ‘Do this!’, ‘You can do that!’, ‘You can play soccer as soon as you’re discharged!’ And I’m like, ‘I didn’t know I can do that! I thought you said I have to stop playing soccer for a year and a half?!’ And he’s like, ‘Noo, I didn’t say that!’ And I’m like, ‘Okay!’ and now I’m really happy and stuff. (12)

It is clear that controlled information is important to children in the hospital. Interestingly, participants did not discuss desire for control over decisions related to their care.

4.4.1.2 Subtheme: Controlling scheduling.

However, children did discuss wanting more control over their schedule. One participant commented on the relief they felt when they learned that some of the programs offered were optional:

Recreation was boring. And I I didn’t think it was optional, so I thought I had to go. So that was pretty disappointing. [R: Mhmm.] The, the, having to go to school, and hav- having therapy at the same time, that was pretty overwhelming for me. [R: Mhmm.] New students and stuff, just new things, new schedules, and stuff. That was overwhelming. (12)

It is also important to consider the context of this quote - the participant was discussing their first week, and how overwhelming this time was for them. The participant later discussed recreational events that they chose to attend and enjoyed, and the meaning these had for them. For example, they excitedly explained that the day before was a welcome (as opposed to stressful) busy day and night. The recreational therapist planned an excursion for the inpatients on the unit to a Toronto Maple Leafs game. Despite a long day of school and appointments, rushing to the game just afterwards, and not returning until 11:30 that evening (which could also be considered overwhelming) the participant described the importance of the recreational outing:

Because I just love the Leafs. And then - Just- it was a good moment to be with the inpatients. Because, like, I don’t really like going, in the lunch room, and like, sitting there and with all the inpatients and stuff, I just eat in bed and stuff. Yeah. So, like, um, yeah, I went to the Air Canada Centre, with the other inpatients, and they were nice and yeah, we became friends and stuff.” (12)
This example demonstrates that participants require options that best fit their needs. With control comes choices and responsibility. Even the quotes from young participants in this section give evidence that children understand themselves well enough to know what they need, require some degree of control over their experiences to be resilient.

4.4.2 Theme: Coping

Participants described a range of coping strategies that contributed to their ability to be resilient. Two strategies emerged: distraction and hope. Distraction was conceptualized as pausing from the current moment and hope was looking forward to the future. Both distraction and hope highlight the importance of suspending their present, difficult reality in order to continue to be resilient.

4.4.2.1 Subtheme: Distraction as coping.

Participants discussed a number of ways in which they distracted themselves from the medical challenges they faced. The activities themselves are perhaps less important than children taking a break from the difficulty of their situation, and returning to a state of what they consider to be ‘normal’. Consider the following examples discussed by participants:

R: Yeah. Yeah. So, when you’re sad, and you’re feeling, or you’re thinking about, being in a wheelchair, what kind of things help you… - What kind of things help you?
P: …Watching TV.
R: How does watching TV help you?
P: Because I get distracted because sometimes my favourite show comes on, when I’m feeling sad. (8)

R: Um, what does it mean to you when you’re doing those things?
P: It means I’m having fun. [R: Hmm.] I feel calm. [R: Mhm.] And it’s just something fun I like to do.
R: Mhm… So, is there something that makes you feel not so calm, that makes you want to, um, do arts and crafts, or baking?
P: If I have a long day at school, or like, if maybe, someone’s mean to me, I like- I like doing those things. (11)
It was fun. The lunch was pretty long. Kids go outside in normal schools, usually. Unless it’s really cold. But here, you could play board games and stuff. Although, outside is more fun. But here, you didn’t really think about that you were sick, that you have a problem. You just did it. (11)

Participants discussed hobbies and games – things that typical children like to do to pass the time. Notably, none of these strategies alleviated the burden of the challenges the participants had to face. Still, distraction was an effective way to get through times that would have normally been difficult.

4.4.2.2 Subtheme: Hope.

Some participants used events as motivation to get them through the challenges they faced. One participant described how they were hopeful that they would receive a ‘wish’, and what they would do with it. As she spoke, this participant showed me drawings they had made of all of the things they wanted to do:

And then this page, (P flips to next page of sketchbook) is things I want to do with my wish that I got. With my wish. [R: Okay.] From like, the Starlight Foundation. And like, a wish. My wish. And my wish is to go swimming, go to Jamaica to swim with the dolphins. [R: Wow.] So the things I want to do in Jamaica are visit family [...] [R: Mhmm.] Swim with the dolphins. [R: Mhmm.] Visit the Bob Marley Museum. Go to the beach. (11)

When asked about the meaning of this the participant said “I would feel really good” (11). Their desire for a wish was not just an extraordinary experience that they would get, but also connecting to their roots and garnering social support.

Another significant source of hope was children discussing the importance of a leave of absence (LOA). Generally, as children progress though their rehabilitation goals, they work their way to go home for short periods of time, to ease this transition. When describing a LOA that was set for the coming weeks, one participant noted, “It’s gonna be awesome! Because I’m going to be able to see my friends!” (8) They had not been back to their community since the accident and
were “happy” to return. Similarly, another participant described a helpful event as, “When I went home. For a night. To sleep there. And it was nice.” (10)

4.4.2.3 Theme: Positive thoughts.

All children used positivity either directly or indirectly, in the interviews. When discussing the difficulty of their surgery, one participant described the ways in which they used positive thinking to control their nervousness for surgery:

I just tried to remember, um, all, um, all the good things that the surgery is going to, you know, help my legs do. Like walk again. And go on my knees again. So I just try to remember, all the things that, if I have the surgery, like what are all the good things that are going to come out of it? Because of course there’s going to be bad things. And painful things. But you’ve gotta think of the good things that this, your surgery, will help you with. Or. Or the other surgeries you had that was helpful. (9)

This participant not only chose to focus on the positives of their surgery, but also draws upon past successes as resources for resilience, which is a key characteristic of this strengths-based perspective. This participant was more nervous entering surgery because they had two prior surgeries and knew how scary they were first hand. Nevertheless, they focused on the long-term benefits of the surgery.

When considering themselves and their limitations, participants spoke in ways that highlighted the positive - what they can do – as opposed to what they cannot.

I can’t walk. Well, can’t walk as good as some other kids can. But I can still walk with a walker. I need that special support and equipment. (9)

Similarly, in the operating room, which was scary and crowded, one participant noted: “Like, I knew that they were going to take care of me because 30 people can’t mess up on one person!” (12) When asked what is different since the accident, in which perhaps the most obvious answer would be a spinal cord injury, another participant chose to focus on the positives:

R: So, A., what’s been different since your accident?

P: Um… I’ve got better a lot. A lot better.
R: Yeah? So what things have gotten better?
P: Um… *(Long pause.*) That I’m awake a lot.
R: Mhmm. That’s one thing.
P: And I’m doing more stuff. That I used to be doing. *(8)*

There certainly were times that the participant admitted feeling upset by the fact that they would not walk again. Similarly, participants did not focus on the positives to the exclusion of negatives. They acknowledged the negatives - which were summarized in the first part of this chapter, regarding trauma and challenges - and chose to focus instead on aspects that were good.

### 4.4.3 Theme: Support.

A critical element of resilience was in participants’ ability to negotiate and receive support from others. Support came from three main groups: parents and family members, friends, and staff at the hospital. School, and more specifically teachers, were also sources of support for children, but to a lesser extent than the aforementioned groups.

#### 4.4.3.1 Subtheme: Support from parents.

Parents were discussed mostly commonly as participants’ go-to supporters. Participants felt most comfortable around parents, and would prefer to talk to them over health care practitioners:

R: You don’t talk to them, like, when you’re feeling upset, you mean? Or?
P: I usually talk to dad, not the nurses. *(8)*

R: Were there any people that helped you to stay, to be not so nervous about the surgery?
P: My mom and dad.
R: Mhmm. What did they do that was helpful?
P: Tried to make me forget about it.
R: Mhmm. How’d they do that?
P: They told me that, you know, your legs are going to be fine. So, don’t worry about it. Because you won’t, you won’t feel it. I was worried that I would feel it. But my mom and dad said you won’t feel it because you’re asleep.
R: Mhmm. Mhmm. Was there anybody else that was helpful?
P: No, just my mom and dad.
As mentioned previously, parents were often gatekeepers of information flow from health care practitioners to clients. In this role, they provided instrumental support to children. In terms of the meaning that parental support had to children, participants had the following comments:

I always felt good because they always said good things. (6)

P: She was like – I always knew that she was, she was, she could help me whenever I needed it. [R: Mhmm.] I could depend on her.
R: What does that mean to you to have someone you could depend on?
P: Very nice. Very comforting. (9)

Well, they’re parents. They help you through everything. They, um, they can make you feel better by talking to you. They make suggestions, ‘They should do this now’. They put money and time into making you happier. (11)

It seems that participants are receptive to their parents encouragement, support, and were comforted knowing that their parents would always be there for them. The ways in which participants discussed this topic seemed to suggest that parental support was so obvious or expected that it was hard to articulate. Notably, the participant’s meaning that was given to their parents support was more complex with age.

Participants were also understanding that parents (or both parents) could not always be at their bedside. One participant explained, “My mom was here every week. [R: Mhmm.] Was here every day of the week. But on the, the weekdays, the the… The Saturday and Sunday I saw my, I saw my dad.” (9) Still, their absence still caused difficulties: “Yeah, when like, when my mom leaves. Or my dad leaves. [R: Mhmm.] I feel sad.” (11) One participant described a particularly vivid scene, in which they and their dad entered the operating room. The participant’s father came into the room in a “bunny suit”, meaning that he got dressed in a sterile uniform to join his child until the anaesthesia took effect. In their own words:
P: Because my dad came with the bunny suit and stuff. Came in with me. Because I was nervous. To go in, myself. [R: Oh, okay.] So my dad came in. And then…

R: Did that help you feel less nervous, to have your dad come in?

P: Actually, I, I didn’t even look at my dad. [R: Ohh.] Because I was just looking at all of the machines. Because, like, I was nervous and stuff. [R: Yeah.] And, honestly, I think there were 30 people in the operation room! (12)

The participant later found out that their dad was very upset upon leaving the operation room and went on to describe the new perception they had of their father after considering this:

I never knew that, that dads would cry that much, because it’s mostly the moms, moms that cry, mostly, and the dads like, like they feel it inside, but they don’t show it. And then when I heard that my dad actually showed his sadness, I was like, ‘Really…?!’ Like, I also felt sad for him, but also like, um, curious, Like ‘Did he actually do that?!’ (Laughs.) Not in a way like he never does that for me, [R: Mhmm.] but weird, because dads barely do that [R: Yeah.] Yeah, yeah, so I felt sad for my dad because, um, they said he felt really bad, like, like, sick inside, because he cried a lot. (12)

Overall, parents provided support to participants in a variety of ways. One participant summarized support in the context of their care as follows: “It feels lonely. And like, you feel scared. And you don’t know what’s going on. But if you talk, to your parents, or your loved ones, or your doctor, it’ll make you feel better. [R: Mhmm.] And like, knowing there’s nurses, and like, different people that care about you around you.” (11) It is notable that siblings were not mentioned in a significant breadth or depth in this study. One participant mentioned missing their brothers, but this was the extent of the discussion on this topic. Thus, not only did participants rely on parents but others, including friends, which will be described next.

4.4.3.2 Subtheme: Support from friends.

Participants discussed the support they received from their friends in a slightly different way than parental support. Descriptions of parental support were less articulate than the qualities and behaviours that friends supported participants with, as well as the meaning this had to them.
P: One of my friends comes every Monday.

[...]  
R: What’s it like when they come to see you?  
P: It’s really fun.  
R: What do you guys do?  
P: Play games. Talk. (10)

R: What are some things that they might do to make things easier or harder for you?  
Being here?  
P: Um, my friend D., she’s my best friend, she calls me every day. [R: Oh, wow.] To see how I’m doing. And when my mom – my parents – take me home on the weekends. She comes to visit me at home. Because I can’t get out of the house. (11)

Friends seemed to understand the difficulties that participants faced, even though participants stated that they did not really talk about it with their friends. It seemed that this was not discussed, but instead understood between friends. Friends also helped to both normalize the participants’ experiences, allowing them to do ‘normal’ things together, have fun, as well as make the time pass in the hospital.

In terms of the meanings that participants attributed to their friendships, one child said that having people, especially friends, visit made them feel “Appreciated. Special.” (10). Similarly to the ways that support from parents was discussed, participants drew meaning from their friends as being reliable and dependable supports in their lives. Consider the following example:

But if I fell down at school, something odd was that, there was a whole team of my friends, around me, pulling me, literally, pulling me up, and getting me into my walker. I felt happy, because I, um, I know I can rely on my friends. To know that, I can rely on them to know that I can depend on them. (9)

There seemed to be a greater appreciation and less expectation that friends would be helpful, in comparison to parents, as evidenced in the previous quote. This could be due to participants recognizing that some people did not have those types of supports:
R: How does it feel to know you have people to talk to?
P: Really good. (R: Really good?) Because some people don’t have that. (10)

The youngest participant, a six year old, described the impact that having friends in the hospital had on them. They were asked, “Did you really like it when you first started?” The participant answered, “No, I really, I was scared when I moved into this hospital. But then I felt good, because I had friends to help me.” These friends became so important to them that they also talked about how it was hard to leave the hospital and leave those friends behind.

A few participants described the importance of having friends or roommates on the unit who understood them.

Having a roommate, is, means I can get social a lot. [R: Okay.] I can talk with some person or I can play something. (9)

Scary times… When I sleep by myself. If I sleep here by myself. It’s a little scary. But it’s okay, because I have my roommate. (11)

And, um, he also, um… is a very fun person to play with. [R: Cool.] We have a lot of things in common. [R: Yeah.] – And T., my roommate, the one beside me, [R: Mhmm.] he had recreation too, he’s pretty fun, too. [R: Mhmm.] Yeah. Things in common. [R: Yeah.] OPERATION in common. (12)

One participant discussed the fact that because they were now in a wheelchair, they were more accessible and “That I can make friends now.” (8) This is in contrast to acute recovery, when they confined to a bed. It is clear to see the resilience in this participant’s benefit finding among tragic adversity.

4.4.3.3 Subtheme: Support from health care professionals.

Children identified how many of the health care professionals (HCP) were helpful in the hospital. The professions identified by children were nursing, social work, child life specialists, recreational therapists, physiotherapists, and therapeutic clowns. In the context of the hospital as a place where children felt ‘not normal’, participants explained ways in which professionals allowed them to feel ‘normal’ and just have fun. A young participant noted that a social worker
would play a game they enjoyed while asking questions about how they were doing. The participant noted that it would not have been the same if they didn’t play games while talking: “It was just that she – we used to – when we were doing things, we used to – we used to play bowley [bowling], and that, really, that felt really good for me.” (6) Other professionals contributed to making things ‘fun’, as well. In the context of rehabilitation, which can be painful for children, one participant noted, “The therapists have a way to make it fun and not hurt.” (10). In contrast to this positive experience, one participant noted difficulties that they had in physiotherapy:

P: It just hurts so much in physiotherapy. Like, I’m like, ‘No, no no no no, don’t do it.’ But they’re like, ‘Do you want to be stuck like this forever?’ and I’m like, ‘No! But it’s painful!’ But they’re like ‘Yes! But just deal with it!’ And I’m like, ‘Okay!’ in the end. [R: Yeah.] So it’s pretty hard. (12)

This example illustrates the difficulty that can arise between professionals, who have the best interests of their clients in mind, and children, who must endure the difficulty of rehabilitation. In this circumstance, the participant seemed to be put off that they were expected to handle the pain. In contrast, other participants have described ways in which clinicians distract clients from the challenging aspects of care, or make it more fun.

Humour was discussed as being an important quality in HCP. One participant discussed the importance of humour in medicine, after a lengthy description of one outstanding, funny nurse: “Comedians make good nurses. Because the best medicine is laughing.” (9) For context, four children said that nurses were helpful to them; all citing the instrumental help that nurses provided. Only one participant described nurses as humourous. The participant went on to say, “Yeah, I think so. It distracts you from whatever th- you need to do.” (9). Support from this nurse seemed to be provided in a way that was accessible to the participant.

Humour was most associated with the therapeutic clowns. Four children discussed the ways in which the therapeutic clowns were helpful:

Well, they, sometimes I don’t talk. They just do stuff when I don’t know- they don’t even know it’s helpful. (8)
When I was stuck in bedrest, they always come around to see me. (9)

R: Is there anybody else in the hospital that’s been helpful?
P: Um… The clowns.
R: The clowns! I remember you saying you wanted to talk about the clowns. What did you want to say about the clowns?
P: Um, like, just.. You know, they make me laugh! [R: Mhmm.] And one time they actually locked me in - “locked” me in my room. (10)

In the last example, the participant described instances where the clowns had made them laugh. This is particularly significant given this child is a relatively quiet individual and their other answers were brief. The clowns seemed to recognise when children required cheering up, and connected with them in a memorable way. Some of the HCP were effective at distracting children; the importance of distraction was discussed previously in this chapter. One participant discussed child life specialists in this way: “Uhh, just helps me, distract me, and play games.” (9) Not only was child life helpful to this participant, but it was significant that this support was available when required. The support of recreational therapists was discussed indirectly, as children noted that they could choose whether they wanted to take part in the planned activities, and have free time to spend with peers. This connects to participants requiring choices, as discussed previously in the chapter.

4.4.3.4 Subtheme: Feeling understood.

Notably, two older children described experiences of people around them, including family and health care professionals. One was asked “Was there anything the people around you did to make it a bit better?” to which they answered, “Well, yeah. But, not really. Because they can’t.” (11). Similarly, another participant explained:

But sometimes I just feel like saying, ‘You guys will never feel what it feels to be disabled and stuff. Because you guys literally can’t.’ Because, like, I-I-I I’m the person who has to go to physiotherapy every day, probably get another operation in my lifetime, probably get um, um tons of injections, like, that’s not a person – that’s not something that a person without, um, without a disability would do.” (12)
The same participant also described an incident that occurred one of their HCP:

I am honest to the [HCP], um, honest to the [HCP] all the time. Like, one time I was like, ‘Why is my bone out?’ and stuff. Because now I understand that my left side is supposed to be out a little, because that’s the protocol. [R: Right.] But I just have to wait a year before it goes back to normal. And now I’m like ‘Why is it like that? And why is it like that?’ and stuff. And then, then like, my [HCP] is like, ‘Don’t be so negative, think of the positives.’ And I’m like, like, I I I I’m just thinking in my mind, ‘Right now’- Like I’m think I’m saying this to the [HCP]. To the mind I’m saying – in my mind I’m saying this to the [HCP], like, I’m like, ‘You think how many positives are there, right now, to the negatives?!’ There are like, two pros, and a million cons. And, right now, the cons are more important for me. Because I have to understand why I I I I am so weak. And, uh, like, before my operation, they were talking like ‘this was going to happen’, but when people say it in words, you think it’s going to be nothing, and you can handle it and stuff, and when it actually comes you’re like, ‘Oh my God, it’s like, the worst thing in the world.’ It was just really bad. Really bad. (12)

These comments highlight the importance of considering the real, lived experiences of clients. The profession of the clinician is less important than the lesson this serves. As practitioners, we can never understand exactly what it is like to be that client in that moment. In this case, the practitioner likely believed that their comment – to focus on positives over negatives - would contribute to resilience. Still, the clinician missed that the client required information and understanding at that time. Again, this connects to participants’ need for some control. Still, there are a number of approaches and skills we can use to minimize this gap, which will be discussed in the final chapter.

4.4.4 Theme: School as an environment promoting resilience.

The on-site school was an important environment for participants. Attending school provided structure, routine, and access to peers, teachers, and other supports. Children noted how the on-site school differed from their home schools.

BLOORVIEW school, is ac- like, customized, [R: Yup.] for your needs. [R: Mhmm.] Like, you never see a school like the Bloorview school. You never see that. Like, it’s
impossible to see that. Very rare. Like, everything in a public school was different. [R: Mhmm.] Everything! Like, you had, like cool lifts and stuff. You don’t see like, things that can carry you in public schools and stuff. (12)

And gym was not that adapted. Not like here. We were playing dodgeball, when I was in my walker. (9)

It’s a shorter day. […] At my old school, we do like math, language, music, art, everything. But here, we don’t do as many subjects.” (10)

It was good, the school was different. But, different for the good or bad, you can’t really say. People have different opinions. You had less school, but you had more therapy. (11)

Note the differences, as described by participants. The school was more flexible to participants’ needs and seemed to focus more on rehabilitation than academics. In recalling that missing school was a significant challenge for the children while in hospital, participating in this study school takes on a significant role in their days. However, participants described ways that school was enjoyable and distracted them from the challenges they faced:

Um, I miss going to school, seeing all my friends. But… It’s okay because I go to school here. And it’s fun, and I like going to school. (11)

R: What makes a good day in the hospital?
P: …Sometimes, when we have… school. (8)

It makes me forget about my surgery. And think about my work. [R: Okay.] At school. (10)

Finally, teachers in the schools were also a source of support for children in this study. Teachers seemed to facilitate connections between participants and their classmates back home, providing encouragement and ongoing support.

They acted, well, the teachers here acted normal about it. Because they know. So, which made you feel like it’s normal. [R: Mhmm.] Which was good. (12)

And she got stuff from home, from my school. And they wrote stuff to me. (9)
I had to FaceTime my home school. (10)

Participants noted the ways that teachers – and the school in general – was a place they could focus on something other than their medical challenges. The ways in which teachers were discussed in interviews suggested that their support was more indirect, by connecting them to their peers, than directly influencing participants. Thus, though not discussed to the same extent as other supports such as friends and family, or HCP, school was an important environment for the participants in the study.

4.5 Summary of Findings

This chapter detailed the descriptions and corresponding meanings children provided in the interviews conducted. All participants identified challenges they faced within the hospital. Most children described acute care as most challenging, but confirmed challenges were presented in rehabilitation as well. Most participants affirmed that they felt overwhelmed. In fewer cases, children felt that their medical challenges were unexpected and they were unprepared to deal with them. All participants drew meaning from hospitalization as an abnormal experience, and felt they were missing out on 'normal' aspects of their life. The interviews revealed that the 6 to 12 year olds included in this study did not understand the language of resilience. When simplified, all participants believed they were resilient and attributed their ability to be resilient to perseverance: toward independence, toward progress, and because of support. An important finding was children's descriptions of resilience as a dynamic process, not a static trait. Children described a number of factors that promoted and inhibited resilience, including a desire for control, a variety of coping strategies, and support from parents, peers, and health care practitioners. Finally, school was an important environment for support. The themes and sub-themes that emerged were consistent with the social-ecological model of resilience, further supporting this lens for the current study and in future practice. The implications of these findings will be contextualized within the greater scope of literature in this area. Implications for health care practitioners, especially social workers, will be offered, along with the strengths and limitations of this thesis.
Chapter 5

Discussion

5 Discussion

In this final chapter, the findings will be contextualized within the greater scope of literature describing PMT and resilience. This section determines medical challenges to be relevant to children and trauma as occurring in some cases; the implications of hospitalization and its corresponding stresses are also described. Greater context around children’s perspectives of themselves as resilient is provided. Risk and protective factors described by children will be further explored as well. Finally, this section will describe the implications this has for social work, offer the limitations of the research, and draw final conclusions.

The hermeneutic approach to phenomenology moves beyond describing an event, as in the transcendental approach, to uncover meanings that are not immediately apparent (Merleau-Ponty, 1996). These meanings were considered significant and common across participants and became the emerging themes, representing a deeper level of analysis, characteristic of hermeneutic interpretation. The necessity of going deeper into the participants’ descriptions was especially important given their age and the developmental challenges that are presented when attempting to communicate at this level of abstraction.

5.1 Medical Challenges and Trauma

All children in this study could describe aspects of their experiences in the hospital that were challenging. The type of medical challenges the participants in this study were exposed to differ in some ways from those traditionally referred to in the literature, which most often include oncology, intensive care units, unintentional injuries, and transplants (Children’s Hospital of Philadelphia, 2014). Most relevant to these, one participant was rehabilitating following oncology treatments, another had been in the intensive care unit, and another sustained unintentional injuries. The majority (i.e. five of eight) of participants had orthopaedic surgeries, mostly ‘routine’ surgeries as part of best care practices for their respective diagnoses. Once again, the definition of PMT is quite broad and the evaluation of trauma was left to the child; this was maintained as a point of exploration in this study.
In understanding whether children identified aspects of their hospitalization and presenting medical challenges as traumatic, we return to the definitions of PMT. To varying degrees, children identified that their experiences were overwhelming, unexpected, and they felt unprepared to deal with the challenge, fitting with KCHC’s (2013) definition of childhood trauma. Most significantly to the participants in this study, children’s affirmation of feeling overwhelmed provides evidence of PMT. Recall Lovett’s (2009) definition of PMT as “any overwhelming experience that is related to illness, injury, or medical treatment” (p. 60), which directly relates to participants’ answers. Children described scenarios in which they were extremely frightened, in pain, and separated from family and friends. All have been connected to traumatic stress, which impacts overall functioning (NTSCN, 2004). To this end, participants’ descriptions of being unprepared for the challenges they faced provide further evidence of PMT as a type of adversity. However, fewer children agreed that they felt unprepared or that their medical challenges unexpected than those that agreed it was overwhelming. Participants’ perceptions of their medical challenges presented a unique findings, where this was only expected to have been significant for children experiencing more sudden-onset injuries or illnesses, yet also presented importance to children with congenital issues. Some children described the ways in which they felt blind sighted by the necessity of invasive surgery and the lengthy recuperation (some even describing it as ‘the worst day of their life’), even if parents knew this well in advance. Unexpected instances of PMT have caused children to question their belief in the world as a safe and predictable place (Kazak et al., 2006). This questioning was not perceived to have occurred with the children who discussed their medical challenges as unexpected, which may be connected to the high proportion of children who described themselves as resilient. Together, children’s descriptions of PMT relate to theoretical definitions of trauma. The connections between children’s perceptions of PMT as overwhelming, unexpected, and being unprepared will be related to their perceptions of themselves as resilient as well as risk and protective factors.

5.1.1 A common process across acute and chronic medical trauma.

The issue of whether PMT can result from chronic illnesses has previously been debated in the literature (Marsac et al., 2014). The current piecemeal state of PMT literature has called for further investigation across populations (Beer & Bronner, 2010; Boles, 2013; Castellano-Tejedor, Blasco-Blasco, Perez-Campdepados, & Capdevilla, 2014; DeYoung et al., 2012; Fee
& Hinton, 2011; Kim & Yoo, 2010; Le Brocque et al., 2010; Tonks et al., 2011), as mentioned in the scoping review (Furtado, 2015). An important addition to the field of PMT, and its intersection with resilience, has been published since the scoping review was completed, unifying PMT to some degree. Price, Kassam-Adams, Alderfer, Christofferson, and Kazak (2016), leading authors in the field of PMT re-evaluated and updated The Integrative Model, originally developed by Kazak and colleagues in 2006. Recall The Integrative Model was designed to create a uniting conceptual framework for PMT. The authors completed a meta-analysis of 216 papers from 2005 to 2014, and found that the framework was still supported by the literature, which had grown significantly over that period of time. There were a number of changes to the model, which was renamed The Integrative Trajectory Model. Most relevant to the current study were the authors’ conclusions regarding the commonalities across different types of medical challenges. The authors note that there are common dimensions on the trajectory of PTSS as well as commonalities in risk and protective factors of PTSS, all of which will be discussed in relation to the findings of this study. This may partially explain why distinct themes arose in this thesis, despite a heterogeneous sample, providing further evidence for the utility of PMT as an umbrella term.

This publication by Price and colleagues (2016) fits with the study participants’ descriptions of their lived experiences. In this regard, these participants are a mix of what could be typically defined as acute PMT (i.e. MVA, GBS) and chronic PMT (i.e. congenital disorders). The interviews revealed evidence of both acute and chronic issues for most children, despite what may appear to fall under one category or the other. For example, one child was involved with a MVA and sustained a spinal cord injury, causing their legs to become paralyzed. Yet when asked about the difficulty they faced in the hospital, they discussed the more long-term effects of making transitions to and from their wheelchair. Similarly, most of the children with chronic conditions experienced acute stress reactions upon learning they required an invasive surgery. Not only are commonalities across exposure to PMT supported by theory, research, and now, lived experience of children, but also the professional opinion of social workers. Social workers on the SODR unit at HBKRH have found over their years of experience that even children and families who have successfully ‘dealt’ with chronic issues seem to return back to more acute or crisis issues similar to those faced when the child was first diagnosed. For this reason, a shift is required from perceiving children’s experiences to be dichotomously acute or chronic to an
understanding of a more dynamic process over time. Meta-analyses of children’s perceptions of PMT have also supported the concept of trauma as a process (Price et al., 2016; Van Wesel, Boeije, Alisic, & Drost, 2012).

5.1.2 The commonality of feeling different.

Participants appeared to have even greater commonalities than differences when considering the descriptions and meanings of their medical challenges. Hospitalization was one point of commonality between participants. In general, children reported frustration with their stay in the hospital and all noted that they felt they were missing out on other important aspects of their life and their identities. Overall, hospitalization was considered an abnormal experience to children. This description relates to the DSM-III’s definition of trauma as an event outside the typical range of human experience (American Psychiatric Association, 1980). This early definition of trauma was later changed when research revealed that trauma is much more common than originally presumed (Greene, 2008). Still, this definition provides insight to the difficulties of hospitalization and missing out on typical aspects of life as not just challenging, but potentially a source of trauma for children, and greater support for the commonalities in traumatic experiences of the participants. In a meta-analysis completed by Van Wesel and colleagues (2012) of qualitative research examining children’s perceptions of trauma, the impact of different types of trauma all resulted in disruption to a child’s regular daily life. Empirical and theoretical evidence from studies of children’s perceptions of trauma have defined the central intrapersonal process following trauma as attempting to maintain normalcy while feeling different (Van Wesel et al., 2012; Urman, Funk, & Elliott, 2001). Studies have demonstrated that this feeling of difference can become part of a child’s identity, causing a number of intrapersonal and interpersonal issues (Earle & Eiser, 2007). The participants in this study did not seem to internalize their differences from others as part of their identity; this may pose a risk to children exposed to PMT.

5.1.3 Acute care and rehabilitative settings.

An important distinction between this research and the extant literature is that this thesis project was conducted in a rehabilitation setting, following acute care. All of the research studies explored in the scoping review were conducted in an acute care setting. Participants noted a number of differences between acute care and rehabilitation, both in terms of the challenges they faced as well as the invasiveness of the physical surroundings. Many of the participants
identified that their greatest medical challenge occurred within a previous acute care setting. Meta-analyses confirm that PTSS decline over time (Children’s Hospital of Philadelphia, 2014; NCTSN, 2004; Price et al., 2016). Children, therefore, may have had time to recover somewhat from initial exposure to PMT. Still, all children identified challenges in HBKRH. Thus, rehabilitation still has elements of continued challenge, even if decreased, which appears to prolong exposure to PMT.

5.1.4 Paediatric medical trauma as an adverse experience.

In answering the first research question posed regarding whether children perceive their medical challenges as traumatic or not, it appears that children are exposed to adversity that is related to the characteristics of clinically-defined trauma. Most children did not use the term ‘trauma’ but of those who did (generally older participants), they agreed that they were exposed to trauma at some point, most often in acute care. All children identified aspects of their hospitalization that were challenging, but not all challenges were considered traumatic, though many had traumatic characteristics. PMT is clinically defined by the presence of abnormal levels of PTSS, or disruptions to daily life over time. It is inappropriate in the scope of this study to comment on whether children had clinical levels of PTSS, yet there are commonalities between clinical definitions and lived experiences of participants, even among a resilient group. Qualitative studies of children’s perceptions of trauma - including this thesis - continue to demonstrate the similarities and differences between lived experience and objective definitions of trauma, highlighting the need for a broad definition of the phenomena (Van Wesel et al., 2012). Together, the participants’ descriptions of their lived experiences combined with theory and research suggest that all eight children were exposed to adverse circumstances which is a requirement for resilience, described next.

5.2 Resilience

The focus of the interviews was strengths-based, and correspondingly, the majority of the findings of this paper focused on resilience. Before continuing this discussion, it is important to revisit the definition of resilience used in this paper. The lived experiences described by children indicate a fit with Ungar’s (2008, 2010, 2013) broad, social-ecological model of resilience. Participants had been exposed to adversity in the form of medical challenges, which were often perceived as traumatic events. Children described developing and utilizing a number of positive
adaptations to their environment to navigate the resources they required. Finally, resilience was not just dependent on the individual participants, but also the responsiveness of the supports and contexts in which the participant found themselves. An important aspect of the definition offered by Ungar (2008, 2010, 2013) is a focus on culturally meaningful resources. Current models of both trauma and resilience note the direct and indirect effects of culture on children (Ungar, 2013; Price et al., 2016; Van Wesel et al., 2012). Participants in this study indirectly discussed culture in their individualized descriptions of lived experiences. Despite the culturally diverse sample of children, there were more similarities than differences in this respect. Perhaps the most relevant, if least obvious, culture that participants shared was that of childhood. For this reason, being culturally appropriate also corresponds to being developmentally appropriate.

It is clear from the results that the 6-12 year old children in this study did not understand the language of resilience. Resilience has been a topic of increasingly popular interest in theory, research, and programming, but this terminology appears to not be developmentally appropriate for children. Still, children not only understood the concept when simplified, but could engage in conversations providing both explanations and the meanings that resilience had to them.

It was interesting to find that all eight children described themselves as resilient, with one notable exception of a child who felt she was resilient most of the time. The scoping review suggested that resilience overall is high in children who have been exposed to PMT, ranging from 57%-84% (Furtado, 2015). Alternatively, the range of PTSS in the most recent, comprehensive meta-analysis was determined to be approximately 30%, including sub-clinical levels. Within this context, the rate of children reporting themselves as resilient is elevated. This may be due to the sample (discussed more in the limitations section), or the differences between theoretical, empirical, and experiential methods of measuring resilience with children’s perspectives, described in the following section.

5.2.1 Resilience as a process.

An important addition that this study contributes is resilience as a dynamic process, not as a static trait. Children provided both explicit and implied evidence of resilience, which was confirmed to ‘happen over time’. Many of the studies included in the scoping review categorized participants as ‘resilient’ or ‘not resilient’ (Fee & Hinton, 2011; Kim & Yoo, 2010; Tonks et al., 2011). Resilience has been measured as a process in other PMT studies (De Young et al., 2012;
Le Brocque et al., 2009; Phipps et al., 2012) and meta-analyses (Price et al., 2016). These studies charted the trajectory of resilience by measuring PTSS over time. The pattern, or process, of resilience that emerges is generally an initial medium to high reaction of PTSS that endure for a period of time before gradually declining and eventually returning to baseline. Other trajectories include recovery (returning to baseline after more severe and prolonged PTSS), chronic (consistently high PTSS), or escalating (increasing PTSS over time). Despite this evidence that resilience trajectories are dynamic over time, the term is still conceptualized in these studies as mutually exclusive. Similarly, recall Castellano-Tejedor and colleagues (2014) unified definitions of resilience in the context of PMT as a ‘return to baseline’. This was somewhat relevant to participants in terms of their general trajectory, but lacks attention to the sophistication of children’s capabilities. Participants’ return to baseline may be best understood as the negotiation between normalcy and differences in the face of trauma (Van Wesel, 2012). Where these quantitative studies fall short, the current qualitative study, exploring children's lived experiences adds greater depth to evidence of resilience as a process. This chapter will highlight the ways children build resilience through positive adaptations to their environment over time.

Inherent to this distinction between whether PMT is an outcome or trajectory is the conceptualization of resilience as an individual trait or as a process. As discussed, previous works have approached resilience as one or the other, however, this research also contributes a new idea that resilience may, in fact, reflect both. Individual-level traits were represented in the ways that children discussed the ‘inner strength’ that allowed them to be resilient, which will discussed as hardiness further in this chapter. Yet, there was also evidence to suggest that there were process-oriented interactions between the individual and their environment that supported resilience over time. Together, this provides a more dynamic perspective of resilience, particularly within the scope of PMT.

Similarly to another study of children’s perceptions following trauma, there were limited explicit suggestions of posttraumatic growth in this study, but much more evidence of less ‘dramatic’ instances of finding positivity within adversity (Alisic et al., 2011). Salter and Stallard (2004) found that posttraumatic growth was more common among adolescents than younger children, such as those in the current study. Alisic and colleagues (2011) suggest that the abstract reasoning and self-awareness required for posttraumatic growth may not be developed in middle
age children. Importantly, posttraumatic growth extends beyond the positive adaptations of resilience, and as such, was not a specific point of exploration for this study. Thus, the limited findings in this regard may have been for this reason.

5.2.2 Children’s perceptions of resilience: Perseverance and inner strength.

When exploring participant’s explanations of why they believed they were resilient, the theme of perseverance emerged, along with the subthemes of persevering toward independence, persevering to make progress/achieve goals, and persevering because of support. Considering these themes and subthemes together, it became clear that children were describing elements of ‘inner strength’, which is theoretically conceptualized as hardiness. Hardiness is not the same as resilience; it is an intrapersonal trait that contributes to a person’s ability to be resilient (Maddi, 2013). Resilience, in contrast, is a process involving both an individual and the environment. Hardiness is thought to include three C’s: challenges, commitment, and control (Maddi, 2013). According to Maddi (2013), the three C’s are described as:

People who are simultaneously strong in all of the 3Cs tend to (1) see life as a continually changing phenomenon that provokes them to learn and change (challenge), (2) think that through this developmental process, they can work on the changes in a fashion that turns them into fulfilling experiences (control), and (3) share this effort and learning in a supportive way with the significant others and institutions in their lives (commitment). (pp. 3)

The children in this study provided evidence that they possessed all three elements of hardiness, which contributed to their inner potential for resilience. All participants described challenges and ways that they felt they overcame such challenges, providing lived experience as their evidence. Participants described commitment to their medical challenges over time and made meaning from them, particularly participants who were closer to discharge and returning home. Finally, participants also discussed the ways in which significant others contributed to their ability to be resilient, specifically, how parents were the ‘reason’ they could be resilient, and how being with other kids in the hospital going through medical challenges were the reason they got through. Hardiness has been described by researchers exploring PMT previously (e.g. Bonanno, 2004; Noll & Kupst, 2006), but the field seems to have moved on to viewing resilience more holistically. Nevertheless, hardiness is a learned trait (Maddi, 2013) and provides important
insight as to the ways in which the inner strength to persevere through can be understood and fostered.

5.3 Risk and Protective Factors

Children in this study described factors that promoted and inhibited resilience, which are referred to as risk and protective factors in resilience literature. It is important to contextualize the protective factors that children in this study already had access to, though it worth pointing out that the children in this study also had the individual capacity to navigate and negotiate for the resources that promoted their well-being (Ungar, 2008, 2010, 2013). Participants were generally socially competent, confident, positive, possessed a variety of gifts and skills, had access to many supports in the form of family, a team of healthcare professionals, and were situated in a particularly responsive environment. In this section, the themes of coping, control, and support will be discussed. Many of the themes and subthemes overlap and will be discussed together. The factors relating to implications for health care professionals (HCP) are discussed in that section instead to avoid repetition.

5.3.1.1 The context of coping: Control and distraction.

Lovett (2009) draws a connection between PMT and other forms of childhood trauma, which are characterized by a lack of control and therefore, risk feelings of helplessness and vulnerability. The children participating in this study attributed similar meanings to lack of control in their environment, specifically in reference to the information they were provided and having control over their daily activities. Power and control have been described as critical aspects of resilience (Prilleltensky, Nelson & Peirson, 2001), drawing from the seminar work of Rutter (1987), which focuses on mastery, self-efficacy, increasing predictability, and reducing chains of negative events. Most relevant to the descriptions provided by participants is the need for increased predictability, which serves to stabilize uncertain circumstances (Prilleltensky et al., 2001). It is important to note that children did not want to have control over their care, but instead wanted control over information and scheduling (i.e. knowing what is going to happen and when). Provision of information is particularly important as confusion can lead to trust and attachment issues (Webb, 2009). Consider how a child without an accurate understanding of their medical procedure could feel overwhelmingly frightened and neglected if a parent is not allowed to come
with them (Webb, 2009). But also think about the confusion that could arise when a parent is present and allowing others to conduct painful or otherwise invasive procedures (Webb, 2009).

Taking control and distraction has been described as a coping strategy by children who have experienced trauma (Van Wesel, 2012). Theories of stress and coping tend to differentiate between problem-focused (or active coping) and emotion-focused (or passive coping) (Carver, Scheirer, & Weintraub, 1989). Active coping involves strategies that directly address the source of stress through problem-solving techniques (Carver et al., 1989). Passive coping seeks instead to manage the corresponding emotions elicited by the stressor (Carver et al., 1989). Though the terminology used suggests that active coping is superior, or more adaptive, than passive coping, the evaluation is placed upon the individual and the meaning this has to them (Lazarus & Folkman 1984). Lazarus and Folkman (1984), seminal theorists in coping put forward the idea that a greater sense of control is related to more active coping strategies. This seems to be true in the experiences described by children, who described feeling a lack of control and mostly using emotion-focused strategies to manage their stress. This consideration is especially important in the context of the stress experienced by children in the hospital, as there is little within their control to address the problem itself. This concept is supported by Carver and colleagues (1989). Instead, participants described ways in which they managed their stress and distress. Again, it is important to consider the meaning that children attributed to their coping strategies. Often, the meaning they prescribed to their coping strategies provided some relief, or a form of escape from their difficult realities. Children felt calm, which indicates that they were not only able to self-regulate, but that as a result, they allowed themselves to be successful in doing so.

Consider how distraction can contribute to self-regulation as opposed to dissociation. Theoretically, distraction also serves the purpose of not attending to negative stimuli and allows an individual to evaluate a situation as more positive (Folkman & Lazarus, 1985; Gross & Thompson, 2007). In clinical mental health populations, evidence has demonstrated that distraction is an effective short-term strategy (Campbell-Sills & Barlow, 2007; Koss & Adyuk, 2008). In the context of PMT and resilience, distraction seemed to be adaptive because it was used in ways to distract children from their shorter-term physical and environmental challenges (i.e. pain, invasive procedures, hospitalization). For this reason, the strategy appeared to be effective. It is an important life lesson to learn when one does and does not have control over a situation, and to be able to flexibly apply coping strategies (Lazarus & Folkman, 1985).
Children generally use a number of different strategies and the ability to select an effective coping strategy is suggested to be a better predictor of resilience than the strategy itself.

5.3.2 Optimism: Coping using hope and positivity.

Children described using both hope and positive thinking as coping strategies. First, positive thinking was a coping strategy employed by all participants. This finding is supported by the work of Alisic and colleagues (2011), who interviewed children following trauma and found that participants tended to focus on the positive and normal aspects of their lives. Some children in this study also provided evidence of benefit finding, which has been identified as an important contributor to resilience in other studies (Castellano-Tejedor et al., 2014; Phipps et al., 2012). As discussed in Furtado (2015), positive thinking can be maladaptive if the individual becomes detached from their reality. Again, from a child-centered perspective, this evaluation is left to the participant. In the context of this paper, all children described and applied meaning to their positive thoughts in adaptive ways: to control undesirable feelings or find relief in distressing circumstances.

Morison, Bromfield, and Cameron (2003) stated, “hope builds resilience and provides a window to the future” (pp. 129). This quote is fitting with participants’ description and meaning attributed to hope: to look forward to an event and use this as motivation to continue on the path of resilience. Lester (1995) described hope as being more concerned with functionality than any given outcome. In the context of this research, hope seemed to provide a distraction from the participants’ current, difficult reality, as well function as a motivator. Most children described their hopes of spending weekends home on an LOA, connecting back to the participants’ internal drive to continue to persevere. Hope was also perceived by children to be an important coping mechanism in a population in Western Canada diagnosed with cancer (Woodgate & Degner, 2003). Finally, hope often connects to spirituality and existentialism (Webb, 2009), which is a culturally meaningful protective factor for diverse children and families. Both positive thinking, including benefit finding, and hope represent positive psychological adaptations to the adversity participants faced. These strategies were used and refined over time. Participants described how positive thoughts increased and negative thoughts decreased as time went on, and looked forward to greater improvements in the future. Together, these optimist-based meanings contribute to evidence of resilience as a process.
5.3.3 Social environment.

As was found in the scoping review related to this topic, social support and supportive environments were critical to participants’ resilience (Furtado, 2015). Recall that the studies examined found environmental level factors were more strongly associated with resilience outcomes than individual level factors (Fee & Hinton, 2011; Kim & Yoo, 2012; Tonks et al., 2011). Children in this study did not quantify whether one was more important than the other but certainly provided the impression that participants relied upon the support they received from parents, peers, and health care professionals (HCP). Children particularly discussed the enacted support they received (e.g. positive messages, emotional support, and guidance) as well as their social embeddedness, similarly to the findings of Fee and Hinton (2011). Hospitalization limits children’s opportunities to connect with their social support networks (Boles, 2013). Though this was a source of distress for children, supportive individuals in this environment mitigated it to some degree. For example, children relied on the advice of health care professionals in the absence of parents, and played with other inpatients on the unit when peers and siblings were unavailable. The social support provided by parents, peers, and HCP will be discussed, followed by participant’s description and meanings attributed to the on-site school and teaching staff.

5.3.3.1 Social support: Parents.

Parents and families are often the focus of investigation when exploring resilience in children. Children mentioned parents often and confirmed parents as the single most discussed protective factor. When considering the meaning that parents took on for children, participants described the ways they relied on their parents. Resilience literature describes the importance of at least one caring adult on which a child can count (Smokowski, Mann, Reynolds, & Fraser, 2004). Parents seemed to effectively fill this role for all participants in the study, perhaps explaining the highly resilient sample. PMT affects the entire family (Price et al., 2016), and as a result, children sometimes worry about their own parents (Van Wesel, 2012). This was eluded to by only one participant in this study, perhaps further highlighting the protective role that families from this study played. Finally, children described feeling distressed when parents were not present, which has been supported by past research (Children’s Hospital of Philadelphia, 2014).

Family functioning can also be a risk factor (Webb, 2009). Parents follow a similar resilience trajectory as children, with 78% of parents following a resilience pathway, 8% following a
recovery pathway and 14% following a chronic pathway (Price et al., 2016). There is a growing evidence-base to suggest that parental PTSS increases risk of children’s PTSS over time (Price et al., 2016). A qualitative study by Alisic, Boeije, Jongmans, and Kleber (2012) found that parental PTSS can impact daily life as well as their ability to provide responsive medical care to their child. As models for children’s coping, it is difficult to understand children’s resilience without an idea of parental modeling, and this needs to be given more attention moving forward (Alisic et al., 2011).

Most of the children in this study did not talk about siblings, thus, it was not a significant theme. Research on the effects of siblings and overall family function has been scant (Price et al., 2016). Practice-based literature has suggested siblings are as important as peers (Webb, 2009). Yet empirically, Kim and Yoo (2010) found no association between resilience rates of children with or without siblings. In a systematic review of siblings of children facing cancer, some siblings experienced PTSS and poorer quality of life, but not clinical levels of dysfunction (Alderfer et al., 2010). Together, these findings – though limited – continue to support the concept that one child’s exposure to PMT multi-directionally affects the entire family (Price et al., 2016).

5.3.3.2 Social support: Peers.

Children in this study relied upon the support of their peers, both within the hospital and with friends and classmates from home. Children in this study found common ground with other children on the unit, who understood their experiences and also provided opportunities to normalize hospitalization. The importance of social support from peers, especially those with commonalities in the hospital, has been thoroughly documented (Boles, 2013; Fee & Hinton, 2011; Kim & Yoo, 2012; Webb, 2009). Perceived lack of support can pose a risk factor to resilient pathways (Salter & Stallard, 2004). Again, this may point to the accumulation of protective factors present in the children sampled in this study, all of whom described friends as important supports.

In terms of the meanings that friendships held for participants, children appeared to be more appreciative of support from friends than familial support. Specifically, when discussing their relationship to peers, participants used the strategy of benefit finding in pointing out that they would not have met the friends they made in the hospital without their medical challenge. Van Wesel and colleagues (2012) suggested that the increased vulnerability that children faced
following intrapersonal trauma such as PMT may deepen children’s appreciation for support. Participants recognized that not all of their peers had supportive friends, but did not make the same connection to peers with unsupportive families. Further, the process of resilience in terms of participants’ social support suggested they experienced posttraumatic growth in their new appreciation for their friends, classmates, and peers.

5.3.3.3 School as a supportive environment.

Within this study, participants discussed ways in which the on-site school environment was helpful. Children discussed the school as sensitive to their needs without drawing attention to their differences, again providing meanings for this experience that relate to both normalization and distraction. The importance of schools has been supported in PMT literature (Kim & Yoo, 2010; Kahana, et al., 2006; Trickey, et al., 2012). Participants specifically noted differences between their home schools, which were not adapted environmentally for students with additional needs and focused more on academics. Adaptations to the classroom appeared to function to provide children greater control over their environment and minimize barriers to inclusion, which have been demonstrated to contribute to resilience (Prilleltensky et al., 2001). Teachers in the on-site school were also sources of support, but their role seemed more instrumental than emotional. This mimics the findings of Kim and Yoo (2012), in which teachers’ contribution to resilience was their capacity to create an inclusive space and facilitate between classmates and participants.

5.4 Implications for Social Work Practice

The implications of this study are not only relevant for social workers, but also to all health care practitioners working with children. As social workers, it is our job to advocate for the needs of our clients. Our knowledge about trauma and resilience can help ease the challenges that children face within the hospital. The single greatest takeaway that this study contributed is considering children’s perspectives in their care. We need to consider and re-orient ourselves to align with our client first and foremost – in paediatrics, this is the child. Considering children’s perspectives and placing them at the centre of their care is not to the exclusion of the family, who are affected by PMT and often are the target of intervention. It is extremely important that families are included as significant aspects of children’s care. However, it is important to consider how families can best be involved as experts in their child’s care because the degree and context of
family involvement will vary from child to child. The findings of this study support the growing evidence for social-ecological perspectives of resilience in the context of PMT (Boles, 2013; Fee & Hinton, 2011; Kim & Yoo, 2012; Price et al., 2016; Tonks et al., 2011; Webb, 2009).

Considering children from a developmental perspective has also been determined to be of great importance. Current studies are inconclusive regarding whether age is a protective or risk factor (Price et al., 2016). A study of children’s coping following MVA looked at the effectiveness of a play-based strategy (Zehender, Meuli, & Landolt, 2010). This intervention was determined to be particularly effective for school-aged children in comparison to preschool children or adolescents because play was most appropriate for this age group (Zehender et al., 2010). Further, note that age is not always an accurate indicator of development. For this reason, practitioners need to avoid assumptions about particular age groups and continue to provide individualized care.

Often, as professionals, we underestimate the amount of information children take in – even as young as six years old. As adults, we know that discussing surgery and actually going for surgery are very different, and that there is a long process in between. However, it is important to consider that from a child’s perspective, they may not know or understand this distinction, so the mere mention of a child getting surgery can be alarming. Providing care in a way that is accessible to children is their right, and an important implication for HCP to consider (Taub, 2003).

5.4.1 Children’s rights.

One of the most important implications of this study is in regards to working from a children’s rights perspective. As explained in the Introduction, children have the right to be involved in their care, and are often denied this right because they are considered to be incapable of doing so (Canadian Paediatric Society, 2004; Taub, 2003). The findings from this research indicate that children are not only capable of understanding trauma and resilience, but also have the insight to communicate their experiences and their interpretations of the meanings these experiences had to them.

Children also described a willingness to exert their self-agency. Within this study, children expressed interest in greater control over information related to their care – sometimes more, sometimes less – as well as a desire to provide input on their schedule. In contrast to the ethical concerns raised in discussions against involving children in care, which focus on decision-
making (Canadian Paediatric Society, 2004; Taub, 2003), children in this study did not want more responsibility for decisions related to their care. This research therefore, supports more recent calls for a spectrum of inclusion that is responsive to children’s lived experiences and respectful of their right and need for self-agency (Canadian Paediatric Society, 2004; Taub, 2003). The findings suggest the discourse in this area needs to shift accordingly. It is our responsibility as clinicians, with greater power as compared to children, to create spaces to allow children to fulfill their rights. Involving children in their care is also an important aspect of client and family centered care, which is a framework more health care settings are working toward.

5.4.2 Empathy and compassion.

The children involved in this study echoed a sentiment that is not new within social work. It stood out to me that participants described being frustrated by people not understanding what they go through. It is important to consider that as able-bodied HCP, we can never understand what it is like to be our clients. However, we do have the ability to use our therapeutic skills to move past sympathy to empathically and compassionately connect with clients in considerate and intentional ways. It is hoped that the quotes included in this study provide provocative examples of the lived experiences of children. By reflecting upon the difficult adverse experiences that children face, perhaps practitioners can bring a better sense of how their young clients may perceive their health care experiences in real time and begin to develop a better understanding of their experience. This is empathy. More recent clinical practices have begun to focus on compassion, which is more sophisticated than sympathy or empathy (van der Cingel, 2014). Similarly to empathy, compassion involves understanding what someone else feels, but moves beyond this to include a deep desire to be with the individual through their experience (Perry & Berry, 2009). Thus, an empathic clinician may reflect internally on their ideas about children’s experiences of PMT and resilience, but a compassionate clinician may open space to allow children to express both their experiences and their needs and work to address these, from the perspective of their client. Not only does this fit with the foundational mandate of respecting autonomy in social work, but it is further validated by the findings of this research.

5.4.3 Importance of using trauma-informed and resilience frameworks.

Though this study, as well as the scoping review focused on populations of children that have experienced unintentional exposure to PMT, this does not mean that these children are immune
to other forms of trauma. Being trauma-informed does not just make practitioners sensitive to PMT but also to all forms of childhood trauma. It is estimated that 20-48% of youth have been victimized or exposed to trauma multiple times, the range depending on the number of events measured (Saunders & Adams, 2014). Further, new research has found that both clinical and subclinical levels of PTSS have direct effects of children’s health outcomes, a new addition to Price et al.’s (2016) The Integrative Trajectory Model. Eighteen studies completed from 2005-2014 confirm this link (Price et al., 2016). There is evidence that PTSS is linked to increased risk of re-injury, as well as poorer school outcomes (Price et al., 2016).

It can be difficult to know how to engage with children who have been exposed to PMT. A trauma-informed lens brings forward the adversity that individuals face. This can be overwhelming to practitioners, especially when this adversity affects children (Webb, 2009). Despite the difficulty that kids face, they want to be treated as normal. In the context of trauma, children require some degree of normalcy and trust to recognize and accept supportive relationships (Van Wisel, 2012). Trauma and resilience have been determined to be process-oriented (Van Wisel, 2012). In the context of rehabilitation, both PMT and resilience occur simultaneously, particularly as children are exposed to stressors over time and gradually develop ways to manage themselves within adversity. Another promising aspect of resilience is that it can be learned (APA, 2016). The findings, therefore, are positive in that they reveal that children have the capability of navigating their own processes of resilience. As clinicians, it is our responsibility to provide the most responsive environment possible and help scaffold ways in which children can be resilient. The findings from this study related to risk and protective factors are particularly useful for clinicians. Specifically, participants require support, not only from HCP, but with parents and peers, which HCP can help facilitate. HCP can also seek out ways to scaffold coping strategies that have been identified as helpful and restore control to children, discussed next.

5.4.4 Providing space for self-agency.

As was found in the scoping review, the findings of this study confirm that children would like to express their self-agency within the context of their care. Providing power and control has traditionally been considered to be a individual-level quality, but in fact are the product of reciprocal determinism (Prilleltensky et al., 2001). This is particularly true when working from a
social-ecological model where the individual is inseparable from their environment (Prilleltensky et al., 2001). Given power dynamics between adults and children, practitioners and patients, it is the responsibility of HCP to create opportunities within children’s environment for greater control (Prilleltensky et al., 2001). Not everything that happens in the hospital is negotiable, but we can be creative in each of our professions to offer choices, when possible. Choices fit with both trauma-sensitivity (recognizing children’s lack of control) and resilience (restoration of control). Providing choices to children increases their sense of control and also builds trust between the adult and child (Boles, 2013). When an adult follows through on a child’s choice of options, this communicates that the adult trusts the child to be capable of making decisions. The responsibility placed on the child also contributes to their own accountability. For example, if children had choices when it came to scheduling, which participants described as being overwhelming, perhaps there would be greater engagement from patients. For example, if a child could decide whether they preferred having physiotherapy appointments in the morning or afternoon, they could provide insight as to when they would be best prepared, and consequently, get the most out of treatment.

5.4.5 Restoring normality through fun and humour.

An important finding related to HCP and resilience was the use of humour. Humour served to distract children temporarily and normalize their experience, which has been established as very adaptive in the context of PMT. The use of humour has been supported theoretically to contribute to resilience (Kuiper, 2012), yet lacks empirical evidence. Phipps and colleagues (2012) used a randomized control design to apply humour therapy, massage therapy, and no treatment to hospitalized children and found no significant differences in outcomes. These findings may have been tempered by the high rate of resilience in the overall sample, as compared to the general population. Perhaps the authenticity of the HCP’s use of humour was important; the humour used by HCP was on-the-spot, whereas a humour intervention may be too prescriptive. Some participants made comments about the timing of HCP’s use of humour. Nevertheless, the findings of this study provide support for HCP to use humour in their work with children.

Similarly, the importance of normalizing hospitalization has been determined to be important in the context of PMT. Participants described ways in which HCP made their time together
enjoyable, especially during invasive or painful procedures. Participants described the use of play as particularly important, which has been found in practice literature (Boles, 2013; Levitt, 2009; Webb, 2009) as well as research (Zehender et al., 2010).

The following is a list of tangible suggestions in which both social workers HCP can use to provide trauma-informed and resilience-based care to clients.
Trauma-informed and resilience-based approaches to care in the context of paediatric rehabilitation:

- Create a calm, child-friendly environment
- Maintain a friendly demeanour
- Provide care that is not rushed and is attentive to the client
- Listen carefully to what is said and left unsaid
- Ask patients (and parents) about how much information the client would like to know and respect their wishes, continue to read non-verbal cues
- If children prefer information: Be straightforward about what you are doing and why it is necessary
- If children prefer less information: Engage the client throughout the procedure in other ways
- Welcome questions at any time
- Inquire about any worries children might have; validate and address their concerns
- Give child as much control as possible about what happens and when: Encourage them to do whatever is most comfortable by listening to music, holding onto a stuffed animal, keeping the door open or closed, inviting a support person, etc.
- Ask children if they are ready to begin before engaging them
- Promote positive thoughts: Reframe difficulties, practice positive self-talk.
- Point out strengths or past achievements that the child has; ask them to think of things that they think might be helpful for them; inquire about things that keep them motivated
- Adapt standard procedures to make them fun, use humour
- Provide tools for children to be distracted: toys, games,
- Provide positive feedback and encouragement

Adapted from Brand (2014), Boles (2013), Rodman (2003), and Webb (2009)
5.4.6 Importance of self-care and resilience strategies for practitioners.

Another important consideration for health care professionals, and especially social workers, is self-care. Vicarious traumatization, or the secondary effects of empathic engagement, may cause HCP to experience trauma symptoms, such as withdrawal or detachment (Webb, 2009). HCP enter this area to help others and when doing so, particularly for children, is not possible, this can trigger anger and helplessness (Webb, 2009). This can prevent HCP from providing hope (Webb, 2009), which has been identified as an important coping strategy for children in this study. When working from a trauma-informed approach that recognizes the difficulties that children face, it is not only important for practitioners to support children to recognize their strengths as resources in the face of adversity, but for practitioners to practice this on themselves. McGarry and colleagues (2013) studied the effects of PMT on an interdisciplinary team in a paediatric hospital and found that overall, trauma negatively affected practitioners’ overall well-being. Practitioners with accumulated exposure to PMT reporter higher levels of secondary traumatic stress and burnout combined with less resilience and compassion satisfaction than the general population (McGarry et al., 2016). The study also found that workers less than 25 years old were at greater risk than older professionals (McGarry et al., 2016). Strategies that can assist HCP include: creating boundaries between work and personal life/identity, nurturing supportive relationships, participating in fulfilling activities, attending support groups for HCP, seeking supervision, and accepting the limits of your role (Webb, 2009). Similarly to the interventions that must be social ecological in approach, promoting resilience for practitioners must come from all levels. This means that the responsibility to practice self-care and foster resilience is not only placed on individuals, but also on health care settings to make policies and create an environment where this can be supported.

5.5 Study Limitations

This study was affected by a number of limitations. An important consideration was the sample used in this study. Of the twelve eligible participants during the recruitment period, eight chose to participate. One was intentionally excluded because the client’s experiences of trauma were considered too severe to conduct an interview exploring them in detail. The other three participants declined participation. The reasons for this are unknown, yet still introduces self-selection bias into the study. It may have been that children who felt less resilient declined
participating in an interview to discuss this topic. Avoidance symptoms of PTSS may cause participants to self-select out, underestimating rates of PTSS (Price et al., 2016) and overestimating rates of resilience. The sample size of eight represents an exploratory investigation to open up avenues for further investigation with young children with PMT and resilience. These findings can only be transferred to a similar population and are not generalizable to all PMT patients. Certainly, additional participants could have enriched the depth of findings and may have improved the trustworthiness of the study, but the current sample represents the experiences of the children on the unit during this time as accurately as possible. Finally, the heterogeneous sample of diagnoses and backgrounds could also be considered an issue. Despite theoretical and empirical validation for including a range of injuries and illnesses under PMT (Price et al., 2016), other studies note that there are nuances between PMT populations that are lost when amalgamated (Kahana et al., 2006).

Further, the context of the study certainly affected children’s perceptions of themselves, and their environment, as supportive of resilience. HBKRH as a paediatric rehabilitation hospital, is quite specialized, and as participants mentioned, very well adapted for children with physical limitations. Further, a number of psychosocial supports are available to children, including social work, psychology, child life, therapeutic recreation, and therapeutic clowns. Even among other professions in the hospital, there is a focus on strengths and working from a bio-psycho-social framework. For all of the above reasons, HBKRH may not be reflective of a typical hospital, or paediatric hospital setting.

Drisko (1997) discussed the importance of discussing the transferability of the findings to other settings as a researcher. This study provides insight as to the experiences of children facing a variety of medical challenges at HBKRH, and may be used to generalize experiences to other children in this setting (Lincoln & Guba, 1985). However, the findings may be less transferable to other contexts or settings (Leninger, 1994). Wilcke (2002) notes that because hermeneutic phenomenological studies produce results that are reflective of a particular population at a given time, findings cannot be used as the basis for novel theories or policies. Nevertheless, this approach is a reminder of the complexity of individuals and their experiences, and the difficulties that arise when these are reduced to categories (Wilcke, 2002).
Hermeneutic analysis has been critiqued for being individualistic and idealistic in nature, to the exclusion of the social and material context of participants (Kvale & Brinkmann, 2009). By incorporating a social-ecological perspective of resilience, this research attempted to overcome this limitation and recognize the ways in which social factors affect children, directly and indirectly. As a result of their social position, societal factors may affect children more, who have lesser autonomy and developmental skills to manipulate their environment.

In drawing distinction between plurality and bias, Kvale and Brinkmann (2009) discuss the difference between bias and perspectival subjectivity. When researchers unreliably interpret and report findings that support their initial ideas, this can be described as biased, whereas perspectival subjectivity makes one’s stance explicit, such that others may also understand the truth that exists from this perspective. Perspectival subjectivity leaves space for multiple truths without compromising the rigour required to conduct effective qualitative analysis. The current study is certainly not to say that this is exactly what children described, felt, meant, and drew meaning from, but it is what this author co-created and understood from their stories. Any and all forms of interpretation will introduce differences, and these are not seen as bias if they are contextualized and made explicit by the interpreter. Great effort was taken in this study to be transparent to this effect, and to validate my interpretations with participants, social workers, and the research team.

One common limitation in qualitative research is the use of transcripts. Critical elements of communication are lost in this translation, including pace, intonation, body language, and gestures (Kvale & Brinkmann, 2009). Video could have been used to avoid this issue, but brings about far greater issues, including greater risks associated with this type of media (especially given participants are marginalized in a number of intersecting ways), as well as practical issues: the equipment is difficult to set-up, especially given the flexibility required in making appointments and with inpatients. Despite this loss of rich information, transcripts are still regarded as the most important empirical data source when conducting interviews (Kvale & Brinkmann, 2009). Such interpretation requires decisions to be made by the author and need to be understood by the reader, in order to be transparent and understand what was lost and maintained. Given that I completed the interviews, and completed transcription in a timely manner, I intended to maintain some of the meanings and gestures that were simultaneously
occurring in the interview by including them in the transcript (e.g. intonation, trailing off, yelling, or gestures, pointing, actions, etc.).

Given these limitations, there are a number of suggestions for future research. This study was exploratory in nature, and requires further refinement, including analysis in other settings. The intersection of PMT and resilience is still young and requires much more validation. Future research should continue to investigate integrative models. The lived experiences of children have confirmed that PMT and resilience are more process-based and this needs to be distinguished in future research. To this end, there is now even greater evidence for the importance of trauma-informed and resilience-based strategies in paediatric health care settings. These frameworks need to be extended to practitioners in recognition of the difficult work they put in to improve the care of young patients. Finally, the main strength of this project was its inclusion of children’s voices in the context of their health care, and also in research in general. It is hoped that the rights of children will continue to be recognized, heard, and valued, by clinicians and researchers alike.

5.6 Conclusion

The intersection of literature connecting PMT and resilience has previously been sporadic and lacking cohesion. The current study was conducted with a heterogeneous group of children exposed to PMT, yet has provided lived experience confirming commonalities across PMT. All participants described medical challenges, suggesting these experiences were traumatic, particularly in acute care as opposed to rehabilitative settings. Children perceived their hospitalization as a difference and appreciated when this experience was normalized. Perhaps more importantly, all children in this study felt they were resilient, but the language around this concept needed to be simplified to be developmentally appropriate. Children provided evidence of an ‘inner strength’ that allowed them to persevere through difficulties, which was conceptualized as hardiness – a learned trait that can be promoted in children.

In terms of risk and protective factors, children employ a variety of coping strategies, including distraction, hope, and selecting positive thoughts. Though these strategies are often evaluated based on whether they are perceived as positive or negative adaptations, this evaluation is subjective to individuals and HCP need to be sensitive to this. Participants expressed a desire for control, particularly in terms of the information they are provided as well as their schedule. HCP
should attempt to provide self-agency to children to restore the lack of control that is characteristic of PMT. This highlights the importance of working from a children’s rights perspective. Current discussion in this area focuses on whether children should be involved in their care decisions, when it appears that children do not desire greater control in this area. Thus, a spectrum of involvement should be offered to children.

Support was crucial to participants, both in their perceptions of their capacity to be resilient, as well as a protective factor. Children discussed the importance of parents, peers, and HCP; with parents the most significant source of support. School was an environment that was described as helpful for participants because it was engaging and distracting, with teachers providing instrumental social support between classmates in both new and old schools. Some participants described the ways in which they felt that no one truly understood their experiences. As clinicians, it is important to continue to consider and actively inquire about children’s perspectives. Maintaining social support with family, friends, and others within the hospital can help children feel connected, heard, and understood.

The findings of this research bring to light both trauma and resilience as process-oriented, which have previously been considered as a singular trait or incident. As a process, HCP can intervene and prevent further exposure to adversity and promote protective factors. Most importantly, this research brings children’s perspectives to the forefront of their care, as well as critical sources of insight, improving the depth and validity of current research. It is hoped that researchers and clinicians alike can continue to actively involve children, recognizing the critical insights they bring to these areas.
References


Appendix A – List of Selected Abbreviations

**ASD** - Acute stress disorder

**BRI** - Bloorview Research Institute

**GBS** - Guillain-Barré syndrome

**HCP** - Health care professionals

**HBKRH** - Holland Bloorview Kids Rehabilitation Hospital

**LOA** – Leave of absence

**MVA** - Motor vehicle accident

**PMT** - Paediatric medical trauma

**PTSD** - Post-traumatic stress disorder

**PTSS** - Post-traumatic stress symptoms

**SODR** - Specialized orthopaedic and developmental rehabilitatio
### Appendix B – Literature Review Chart

<table>
<thead>
<tr>
<th>Source</th>
<th>Purpose of Study</th>
<th>Participant(s)</th>
<th>Recruitment</th>
<th>Research Design</th>
<th>Findings</th>
<th>Strengths and Limitations</th>
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<tbody>
<tr>
<td>Beer, R., &amp; Bronner, M. B. (2010). EMDR in paediatrics and rehabilitation: An effective tool for reduction of stress reactions? <em>Developmental Neurorehabilitation, 13</em>(5), 307-309.</td>
<td>Proposed Eye Movement Desensitization and Reprocessing (EMDR) as an effective intervention for children experiencing PMT stressors</td>
<td>N/A</td>
<td>N/A</td>
<td>Research summary</td>
<td>Meta-analyses have demonstrated EMDR is effective for groups of adults, can be applied to paediatric medical stress and/or trauma</td>
<td>Research has supported EMDR in different stage of life. Though plausible, is not yet supported empirically for children; requires experimentation and replication</td>
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<td>Boles, J. (2013). When everything changes: Supporting resilience in children with acquired brain injuries. <em>Paediatric Nursing, 39</em>(6), 314-316.</td>
<td>Overview of techniques that could be used interprofessionally in a clinical setting to support resilience in children with acquired</td>
<td>N/A</td>
<td>N/A</td>
<td>Review</td>
<td>Outlining main areas of resilience in children with ABIs, specific strategies at each level</td>
<td>Using play strategies as a method of coping and developing mastery age-appropriately; involving peers and families to support resilience. Lacked empirical evidence but supported theoretically and in practice. Question of generalizability from ABIs to PMT</td>
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<tr>
<td>Author(s)</td>
<td>Title and Description</td>
<td>Sample Size</td>
<td>Research Methods</td>
<td>Findings</td>
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<td>Castellano-Tejedor, C., Blasco-Blasco, T., Pérez-Campdepadrós, M., &amp; Capdevila, L. (2014).</td>
<td>Making sense of resilience: A review from the field of paediatric psycho-oncology and a proposal of a model for its study.</td>
<td>N/A</td>
<td>N/A</td>
<td>Overview of definitions of resilience, differences from other terms (i.e. posttraumatic growth, benefit finding); A model of resilience can be applied to experiences of paediatric cancer. Lacks empirical and theoretical evidence; further study required to strengthen model. Question of generalizability from childhood oncology to PMT.</td>
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<td>De Young, A. C., Kenarfy, J. A., Cobham, V. E., &amp; Kimble, R. (2012).</td>
<td>Prevalence, comorbidity and course of trauma reactions in young burn-injured children.</td>
<td>Parents of 130 children aged 1-6 (mean=2.4)</td>
<td>Convenience sampling from a specialist burn centre in Australia. Approximately 39.5% of those eligible participated. Attrition rate = 23%</td>
<td>Parents were interviewed over the telephone using the Diagnostic Infant Preschool Assessment (capable of diagnosing children using DSM-IV-TR). The majority of children were resilient (72%). Many recovered (18%) and a small proportion of children’s distress levels remained chronic (8%) over six months. No significant differences were found for child gender, parent age, parent employment status or burn size. 35% were diagnosed with at least one psychological disorder within the six month post injury period (most commonly PTSD, Age group is significantly younger than others included in this literature review. Lack of control group, thus distress may be more age-related than trauma-related. Researchers were not blind to initial PTSD status, which may have impacted interview and subsequent classification. Lost a substantial number of</td>
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Examined factors associated with resilience of boys with a chronic neuromuscular disorder (Duchenne muscular dystrophy, DMD)

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<th>Subjects were participants in an ongoing study examining cognitive skills in boys with muscular dystrophy; Convenience sampling through Dystrophy Association clinics in NYC.</th>
<th>Parent reported questionnaire of son’s behaviours (Child Behaviour Checklist), social support (CBCL), and familial support (Parenting Stress Index). Also, child’s intellectual functioning (Peabody Vocabulary Test) measured</th>
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<tr>
<td>146 boys with DMD from 6-14 (mean=9.0) years old</td>
<td>84% were considered resilient and not at risk for psychosocial issues. Individual factors (i.e. intellectual functioning and physical ability) were not significantly associated with adjustment or behaviour, suggesting a child’s perception may be more relevant than measures of proposed risk and protective factors of resilience. Social support was most important to adjustment and demonstrated an inverse relationship with problem behaviours. Similarly, parents with less stress were found to have sons with more positive behaviours.</td>
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<th><strong>Paediatrics and Child Health, 46(7-8), 431-436.</strong></th>
<th>2004 asked to complete the survey while waiting for their doctor. Approximately 27% of visiting children qualified and completed. Scale III, relationship with friends and teachers; some information verified by caregivers.</th>
<th>gender, religion, existence of siblings, mother’s age, academic performance, duration of illness or type of cancer.</th>
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<td>oncology unit in a university-affiliated hospital</td>
<td>Lack of normative data for measures; Range of scores on measures wide, suggesting some children are much more vulnerable than others and necessitates individualized strategies; generalized can be lost in averages – All limit generalizability.</td>
<td>Using a previously studied model, examined 4 types of recovery trajectories following traumatic injury: resilient (low symptoms of sub-threshold PTSD throughout), recovery (high acute symptoms and decreasing over time), delayed (low 190 Children aged 6-16 (mean=10.7) admitted to paediatric units following accidental injury (no violence or head injuries) who stayed for at least one night, and one primary caregiver. Overall, PTSS showed a decline over time. 57% of children were resilient, with slightly elevated to low distress within 4-6 weeks. 33% of children were in the recovery trajectory, where distress declined to average within 6 months. 10% of children were chronic in that they had high levels of distress that remained stable over 2 years post-injury. There was no evidence for delayed symptoms in this group. Younger children, those with fractures, dislocations, lacerations, etc. (compared to burns, internal and multiple injuries), and those with less internalizing and externalizing issues were more resilient overall. Acute stress disorder was determined to not be an accurate predictor of</td>
</tr>
<tr>
<td>Le Brocque, R. M., Hendrikz, J., &amp; Kenardy, J. A. (2009). The course of posttraumatic stress in children: Examination of recovery trajectories following traumatic injury. <em>Journal of Paediatric Psychology, 35</em>(6), 637–645.</td>
<td>Children admitted to a general or intensive care unit in three tertiary hospitals in Brisbane, Australia. Information could not be garnered about participation rates, therefore difficult to generalize to other traumatic injuries and PMT as a whole. Average age fit within childhood, therefore this study was included, but may not be generalizable to 6-12 year olds. Measures and interviewers were not qualified to diagnose but should have adequately screened for PTSS.</td>
<td>Self-report measures of the effects of trauma (Child Impact of Event Scale), parent reported child mental health (Child Behaviour Checklist) over 3 time points: within one week, 2-6 months, and 2 years post injury. Home interviews were conducted at follow-ups.</td>
</tr>
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<td>Phipps, S., Peasant, C., Barrera, M., Alderfer, M. A., Huang, M. S., &amp; Vannatta, K. (2012). Resilience in children undergoing stem cell transplantation: Results of a complementary intervention trial. <em>Paediatrics, 129</em>(3), e762-770.</td>
<td>Efficacy of resilience interventions with children undergoing Stem Cell Transplantation (STC)</td>
<td>171 patients (age 6-18) undergoing STC, staying at the hospital for over 3 weeks, along with at least one on-site caregiver</td>
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<td>Tonks, J., Yates, P., Frampton, I., Williams, W. H., Harris, D., &amp; Slater, A. (2011). Peer-relationship Examined the role of executive functioning (EF) in the brain and 21 children ages 9-15 (mean = 12.6) with ABI and</td>
<td>Children with ABI were recruited from a variety of community agencies in the</td>
<td>Self-report measures of resilience (Resilience scales for children and</td>
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</table>

70 matched healthy children were recruited from two nearby schools (UK, healthy adolescents), and 70 matched peers. Resilience risk factors were correlated with depression (Beck Depression Inventory) and anxiety (Beck Anxiety Inventory). Matched groups were different in terms of social-emotional behaviour, as children with ABIs were parent reported which may not be highly reliable. The authors suggested that children with ABIs may be less resilient because they are less able to find and use personal resources, which is combined with greater vulnerability both socially and emotionally, or children with ABIs may have greater emotional distress overall which impacts their strategies for resilience.
Appendix C - Recruitment Script

So (Client’s name), I wanted to tell you and your parents about a study that you can choose to take part in. The study is being done by researchers from Holland Bloorview and the University of Toronto. They are interested in learning more about your time in the hospital, what you know about resilience (or getting through the hard stuff that comes your way), and what things have been helpful and not so helpful. They are hoping that hearing what kids have to say will help staff better understand clients and provide better care.

The researchers are looking to talk to children once, one at a time, for about an hour. You don’t have to participate in the study. If you decide you don’t want to, it will not change the way you are treated at Holland Bloorview. I won’t know whether you decided to do the interview or not. I am not part of the study team, and if you decide to meet with them, I will not see or hear any of the information you might provide them.

If you think you might be interested in helping with the study, I can give you this piece of paper with more information for you and your parents. Both you and your parents will need to agree to take part in the study. May I leave you this information to read?

[If no]: Okay, no problem. Thanks anyway. You will not be contacted again about this research.

[If yes]: Here you go. After you have read the information, you can call the main researcher, Jessica Furtado, using the phone number provided. Jessica is a student researcher on the team. You can call if you have any questions, or to tell them that you would or would not like to join. If not, Jessica will contact you in a week to see if you are interested.
Appendix D – Recruitment Flyer

Participate in Research
Paediatric Medical Trauma and Resilience

Principal Investigator: Keith Adamson

Do you have something to say about what’s it’s like to be in a hospital? How to stay strong in the tough times?
Participate in a research interview!

What is this study about:
This study is looking at resilience in children after medical issues, illnesses, or procedures.

Who can participate?
We are looking for:
- Kids in the SODR unit
- Aged 6-12 years
- Who speak English unassisted
- And do not have a cognitive impairment

What’s involved?
- A one-hour interview where you can talk about anything that is related to the topic

Potential Benefits?
- Help others understand kids’ views of medical trauma and resilience

Potential Risks?
- Sometimes talking about difficult things can make a kid upset, but you don’t have to talk about anything you think might make you feel like that

Participants will receive a small token of appreciation to thank them for their time.

TO ASK QUESTIONS OR TO LEARN MORE, CONTACT JESSICA FURTADO

416-425-6220 Ext. 3052

Date Posted:
Version Date: November 19, 2015

REB #: 15-604
Being a Kid in a Hospital and How Kids Stay Strong

Study Title: Paediatric Medical Trauma: Exploring Children’s Perspectives

Why did you want to talk with me?
Hi, my name is Jessica. I am a student at the University of Toronto. It is a school for grown ups like me. I am learning about social work. I also help out here at Holland Bloorview by doing research. Here I work with Keith Adamson. He is helping show me how to do research.

I am sending this letter to ask if you want to be part of a research study. I want to talk to you about what it’s been like to deal with [accident, illness, injury, hospitalization etc.] I also want to talk about the people and things that have helped you stay strong. And I also want to know what were the things that did not help you feel strong. My goal is to talk to 10-12 kids from ages 6 to 12 years old. Once I have these answers, I will use them to write a report. The report will tell adults how they can best care for you.

What do I need to do?
If you want to take part, you and I would meet once for about one hour. I will ask you questions. You can tell me if you don’t understand what it means. I’ll try to ask you another way. It’s okay if you want to skip any questions I ask.

I will ask you questions like:
- Can you explain to me what brought you to Holland Bloorview?
- Have you had to face any hard times before or during your time in the hospital? Can you tell me about them?
- Have you ever heard of the word resiliency? What does it mean to you? Are you resilient?

You can decide what you do and do not want to talk about. The meeting will be at Holland Bloorview. I will talk to you and your parents to find a time when you are free.

I will use a voice recorder so I can keep your words the exact same. After that, I will type out all of your words, just how you said them. After that, your voice from the tape will be kept in a safe place. No one will be allowed to listen to it. If you say any names or give any clues to who you are, I will replace it with fake names or clues. This will make sure no one will know who you, or who you are talking about.

Assent Form
Version date: December 19, 2015
I might use your words in my report without giving away who said it. I might also ask the social workers on the unit to help me with the report. They will not hear your recordings. They might read some of your words with the fake information in it. Still, they might be able to figure out who said it, even with fake names.

I may call you or your parents after we meet. I will ask you to meet with me again to check that I got your story right. You don’t have to meet with me again if you don’t want to. If you do, the second time we meet will take one hour, too.

**What are the good and bad things about doing this?**
I don’t think that there are any very bad things about being involved. I may ask questions that may make you a bit sad. I may also change what we are talking about if I see that you are upset. You can tell me if you do not want to answer these or any other questions. You can speak with me, your Mom or Dad, or someone else at Holland Bloorview if you get upset when we talk. You can decide who you would like to talk to about how you feel.

The good thing about this study is that you might feel better about all the ways you have been strong, and that you can help other kids learn how to be strong, too. If you take part, we will give you a letter to tell you more about how you have helped.

**Will anyone know that I did this study?**
I won’t use your name or any other clues that could help someone find out who said what. I’ll keep the tape recording in a very safe place. No one else will know it was you who said the things you say. I may need to talk with someone else about what you said if I’m worried about your safety.

**Do I have to do this?**
If you do not want to talk with me, that’s okay. You can tell your parents or me that you don’t want to take part in this study. That will be okay. If you or your parents decide not to join, I won’t ask you again. This will not affect how I treat you the next time you see me. If you say yes now, you can change your mind and say no later. You can still say no. That will be okay.

**What if I am not sure?**
Your parents know about this study. Ask them questions if you don’t understand what this is about. You can also talk to me about the study before you decide whether or not you want to be involved.

Thanks for thinking about being a part of this study.
Being a Kid in a Hospital and How Kids Stay Strong

I discussed this form with ________________________________ and s/he agreed to participate.

Name of Child (Please Print)

Signature

Date

Student Researcher (Please Print)

Signature (Optional)

Date

Assent Form
Version date: December 19, 2015
Appendix F – Informed Consent Form

Informed Consent Form to Participate in a Research Study
(Flesch-Kincaid Grade Level = 4.5)

Study Title: Paediatric Medical Trauma: Exploring Children’s Perspectives

Principal Investigator: Keith Adamson, PhD, Senior Director of Collaborative Practice, Holland Bloorview

Co-Investigator: Jessica Furtado, MSW Candidate, University of Toronto; Ramona Alaggia, PhD, Associate Professor, Thesis Supervisor, University of Toronto; Eunjung Lee, PhD, Assistant Professor, Thesis Committee Member

Sponsor: Deferred funds from the Collaborative Practice Department at Holland Bloorview

Dear <Child’s Name>,

My name is Jessica Furtado. I am a Master’s student in the Social Work program at the University of Toronto. I am also a student helping at Holland Bloorview. Keith Adamson is my research supervisor. We are working with a team that wants to learn more about kids who may have had medical trauma. ‘Medical trauma’ is a fancy way of talking about the effects of injuries, pain, illness, surgery, treatments, as well as staying in the hospital can have on someone. I would like to invite you to take part in this project to learn more about your views and ideas. Before agreeing to take part, it is important that you know what you will be asked to do.

What is the study about?
Resiliency, or the ability to push through hard times, is mostly high in kids who have had medical trauma. But we are still not sure why some kids seem to do better than others. Most of what we know right now comes from what parents tell us. But parents and kids do not always see things the same way. So, we want to talk to 10-12 kids like you to learn how we can care for you even better.

You will be asked questions like:
- Can you explain to me what brought you to Holland Bloorview?
- Have you had to face any hard times before or during your time in the hospital? Can you tell me about them?
- Have you ever heard of the word resilience? What does it mean to you? Are you resilient?

You can decide what you do and do not want to talk about.

How will I be involved in this study?
We would like to invite you to meet with me once to answer questions for one hour. The meeting will be audio recorded. We then type out the whole talk. This helps us make sure we use your words...

Informed Consent Form
Version date: December 19, 2015
correctly, and not forget anything or get mixed up. The meeting will happen at Holland Bloorview. We will talk to you and your parents to find a time when you are free.

After I have met with all of the kids, I will use your answers to write a research paper. I would like to check in with four of the same kids again at that time, probably in March. This is to make sure what I am writing about your ideas is still right. So I may ask you to meet with me one extra time for one hour at Holland Bloorview.

**Will anyone know what I say?**
No, all the information we collect about you or your family will be kept private. We will not make anything that might identify you or your family public, unless we are legally told to do so. For example, if I am worried about your safety, then I may need to tell someone who can protect you.

We will ask you to tell us your age, gender, and describe the reason why you are at Holland Bloorview. This is to help us understand you better. No other personal or health information will be asked. Please remember you can choose not to answer any of the questions if you don’t want to.

The meetings will be audio recorded and then typed out. This will make sure that your words are used in the exact way you said them. All names or information that could give cues to who you are will be removed from the text. We will replace them with fake names. We will destroy the audio recording at the end of the project. If the results of the study are published, no personal information will be included.

**Do I have to do this?**
No, you do not need to take part in this study. If you want to try it out, you can change your mind at any time and stop. You can do this up until my report is handed in. I would then get rid of anything you said or did for the study. No one will get upset if you decide not to, it’s up to you. Whatever you want to do will not affect your care at Holland Bloorview.

**What are the risks and benefits?**
In talking about any issue, especially hard times you have faced, a child may become upset. I will not ask you to talk about specific, painful experiences. You can choose to talk about anything you want to about the topics during the meeting.

I may ask questions that may make you a bit sad. I may also change what we are talking about if I see that you are upset. You can tell me if you do not want to answer these or any other questions. You can speak with me, your Mom or Dad, or someone else at Holland Bloorview if you get upset when we talk. You can decide whom you would like to talk to about how you feel.

My goal is to focus on the strengths you have used to get through the hard times you might have faced. Talking about these strengths may make you feel proud to see how far you have come. You might also feel good knowing that this research can help other kids, too.

You will not give up your legal rights in the event of research-related harm if you decide to take part in this study.

**What if I have questions?**
Informed Consent Form
Version date: December 19, 2015
Please ask me to explain anything you don’t understand before signing the consent form. My phone number is 416-425-6220 ext. 3052. If you leave a message, I will return your call as soon as possible. Or, you can e-mail me anytime at jfurtado@hollandbloorview.ca. Please note I am at Holland Bloorview from Wednesday to Friday each week.

You can also contact my research supervisor at Holland Bloorview to ask questions about the study. His name is Keith Adamson. You can call him at 416-425-6220 ext. 6086. Or, you can e-mail him anytime at kadamson@hollandbloorview.ca. I have another supervisor at the University of Toronto (where I go to school) who you can also contact. Her name is Ramona Alaggia. Her phone number is 416-978-1023 and her e-mail address is ramona.alaggia@utoronto.ca.

You will receive a $10 Tim Hortons gift card for each meeting as a thank you for taking part in this study.

We will send you a letter at the end of the study to share what we learned and to thank you for taking part.

If you have any questions about your rights as a research participant, please contact the Holland Bloorview Research Ethics Board at 416-425-6220 ext. 3507.

Thank you for thinking about helping us with this project.

Yours truly,

Jessica Furtado, BASc, RECE
Student Researcher
Holland Bloorview Kids Rehabilitation Hospital
Phone: 416-425-6220 ext. 3052
CONSENT FORM
HOLLAND BLOORVIEW KIDS REHABILITATION HOSPITAL

Re: Pediatric Medical Trauma and Resilience: Exploring Children’s Perspectives

Please complete the form below and return it to the researcher. You will receive a signed copy of this form.

The student researcher, Jessica Furtado, explained this study to me. I have read the attached Information Letter and understand what this study is about.

I understand that I may drop out of the study at any time.

Parent Consent:
I agree to allow my child to participate in this study.

Parent’s Name (please print) __________________ Signature __________________ Date __________

Child Consent (if applicable):
I agree to participate in this study.

Child’s Name (please print) __________________ Signature __________________ Date __________

Researcher:
I have explained this study to the above participant/parent and have answered all their questions.

Name of Person Obtaining Consent __________________ Signature __________________ Date __________

Informed Consent Form
Version date: December 19, 2015
Appendix G- Interview Guide

Study Research Questions:

1. In what ways do children consider their medical experiences traumatic, or not?
2. How do children understand resilience?
3. In what ways do children perceive themselves as resilient, or not?
4. What factors do the children interpret as promoting or inhibiting resilience? And how do they make meaning from these factors?

Interview Guide:

[Name], the reason why you were asked to meet with me is so we can learn more about the strengths and hard times you have had during your time at the hospital and with the reasons that brought you here (i.e. surgery, illness, injury, etc.). We have about an hour together to talk about these topics. I hope that the study I am working on can help us to understand what it’s like to be a kid in a hospital and help teach others about what is helpful and not helpful to get through the hard stuff that being in the hospital can bring.

As it said in the assent form (which is a fancy word for a permission slip, just like the ones your parents would fill out for a field trip), you don’t have to talk about anything that will make you feel upset and you can skip questions that you don’t want to answer. If you’d like. If you want to stop at any point, that’s okay, too. Anything you tell me will stay confidential, meaning I cannot tell anyone what you said. Choosing to participate is not required as part of your treatment at Holland Bloorview and anything you say will not affect the care you get here.

I’ll be audio recording the session so I can make sure to get your words exactly right. Once we’re done I will type out our conversation and combine it with what I hear from other children to better understand what it’s like from a child’s point of view in a hospital. I will take out any information that would make it possible for someone to know what you’ve said. So, I’ll take out any names or places that could give someone hints. If I use a quote from you, I’ll use a number instead of a name. Does that make sense so far? Do you have any questions for me?

Have you ever heard of the word resilience? What does it mean to you?
If no: Sometimes the word resilience is used to describe times when a person faces a hard time and overcomes it

Can you explain to me what brought you to Holland Bloorview?

Have you had to face any hard times before or during your time in the hospital? ...Can you tell me about them? ...Would you say that you are resilient [or other word the child uses to describe the same phenomena]?

Prompts:

- How were you so strong in those hard times?
- Were there people that helped you through? ...Who? ...How were they helpful?
- What was most helpful to you during the hard times?
- What other things were helpful?
- What was not so helpful to you during the hard times?
- What other things (people, places, events) were not helpful?
- If you think about what you were like before coming to the hospital, would you say you’re the same or different? How?