

Balancing Grief and Survival:
A Grounded Theory Analysis of the Experiences of Children with Brain Tumours
and Their Parents

by

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A Thesis
presented to
The University of Guelph

In partial fulfillment of requirements
for the degree of
Master of Science
in
Family Relations and Human Development

Guelph, Ontario, Canada

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ABSTRACT

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While researchers have explored many important aspects of living with childhood cancer, including the multitude of strains on family members and their reactions, very little is known about the experiences of children with brain tumours and their parents. Grounded theory methods were utilized to explore the unique and shared elements of the experiences of childhood brain tumours, from the perspectives of these children and their parents. Woven throughout their stories were expressions of grief and uncertainty related to the tumour and its effects on their lives. Children and parents tried to maintain a positive outlook and a sense of normalcy, in order to cope and to adapt to the struggles and the changes in their lives. A substantive theory of Balancing Grief and Survival was developed, offering a lens through which to view the children's and parents' complex experiences, struggles and coping strategies as integrated, dynamic processes.

ACKNOWLEDGEMENTS

I would like to express my sincere thanks to each of my advisors, Professor Susan Lollis, Professor John Beaton and Doctor Eric Bouffet, each of whom contributed uniquely and enormously to this endeavor through their expertise, guidance and support. Thank you so much for all that you've shared with me and with this work.

I would also like to recognize the late Doctor Larry Librach, who believed in me, encouraged and enabled me to pursue this degree. I hope he would be proud of my work, and that he understood the depth of my gratitude.

I am forever grateful to my wonderful husband Jesse, whose faith, support and patience have been endless... as have the hours he's spent looking after our daughter while I worked, listening and helping me think things through, editing, and supporting our family in countless ways. To both of our families who have been so supportive and generous with their time, thank you so much. And sweet Lily, for helping me understand these families' experiences more deeply than I ever could have before, and for brightening every day.

My deepest thanks and admiration for the incredible children and their parents who shared such personal thoughts and feelings with me... I am honoured to have heard your stories, be inspired and learn from your strength and wisdom. I sincerely hope I've done justice to your experiences.

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Introduction

For ill children and their families, life is immediately and profoundly changed by the diagnosis of a brain tumour. The threats posed to the child's emotional, cognitive and physical health by the disease and its treatments, and the devastating possibility of the child's death, are terrifying. Practical implications (e.g. managing logistics of treatment; traveling to, or staying at the hospital; balancing employment, finances, and the care of siblings) weigh heavily on the shoulders of overwhelmed families.

Between 2003 and 2007, families of 817 Canadian children under the age of 14 years old were faced with this life-changing diagnosis; between 2005 – 2009, 214 children in the same age range died from this illness (Canadian Cancer Society, 2013). Brain tumours are the second most common form of cancer and the leading cause of solid tumour death in children, representing 19% of all childhood cancers and claiming 34% of deaths (Canadian Cancer Society, 2013). While more than 70% of children surpass the five-year survival mark, this percentage varies dramatically depending on the child's age and the specific tumour type (Smith et al., 2010), contributing to a pervasive sense of uncertainty for children and their parents (Deatrck, Mullaney & Mooney-Doyle, 2009; Jackson et al., 2007; Vance, Eiser & Horne, 2004).

Despite the frequency of occurrence, children with brain tumours have been underrepresented in research exploring the experience of families living with childhood cancers, largely because they pose challenges to researchers seeking a large, homogeneous sample, due to the range of cognitive abilities, treatment protocols and prognoses they face (Jackson et al., 2009). However, those who have studied psychosocial experiences faced by this population suggest that in addition to those elements that are shared by children with other cancers and chronic illnesses (Deatrck et al., 2009), children with brain tumours bear additional burdens (Bhat, Goodwin,

Burwinkle, Lansdale, Dahl, et al., 2005; Jackson et al., 2009; Vance et al., 2004; Zebrack et al., 2012).

For instance, compared with survivors of other types of childhood cancers, Zebrack et al. (2012) suggest that survivors of brain tumours face particular struggles in their daily lives and relationships due to the “on-going cognitive, behavioral, and physically debilitating effects” of illness and treatment (p. 637). Cognitive difficulties frequently impair academic performance, while physical or behavioral changes often result in children being bullied or excluded by their peers, all of which have heartbreaking effects on children’s self-esteem and their feelings of difference from their peers (Vance et al. 2004). Although children with other forms of cancer also experience impairments in communication and social functioning, these children’s abilities typically improve over time, whereas for children with brain tumours, they do not (Bhat et al., 2005). Furthermore, survivors of childhood brain tumours are more likely to develop psychoses, and to be unable to live independently as adults (Bhat et al., 2005). Subsequently, survivors of childhood brain tumours perceive significantly fewer positive impacts from their experience when compared with survivors of other types of childhood cancers (Zebrack et al., 2012).

From the parent’s perspective, the life- and relationship-changing nature of the tumour and effects of treatment force them to “reacquaint themselves with their children... [and] reacquaint their children with themselves, their families, and the outside world after treatment” (Deatrick et al., 2009, p. 306). Parents interviewed by Forinder and Norberg (2010) expressed “three fundamental concerns: the threat of losing their child, uncertainty as regards the present state and the future perspectives, and feelings of loss” (p. 545). Managing medical and psychosocial care for their child’s evolving needs and abilities, while constantly facing the threat of relapse and the effects of treatment (Vance et. al. 2004), parents are pulled in an emotional tug-of-war between

grieving potential and actual losses on one hand, and tremendous relief for the child's survival on the other (Deatrick et al., 2009).

As the following review of the literature will demonstrate, while these few studies shed light on some of the unique challenges and experiences of children with brain tumours and their families, considerably more exploration is required in order to gain a deeper understanding of their lived experiences. Children's perspectives have been conspicuously absent; furthermore, the primary foci of these studies have been what the diagnosis and treatment of a brain tumour *does to* families (i.e. impacts), and what families *do about* brain tumours (i.e. management, coping and supports). In-depth exploration of the *experiences of* childhood brain tumours from the perspectives of children and their parents' is sorely needed.

Review of Literature

Families of children with cancer

In contrast to the paucity of research specific to children with brain tumours and their families, a considerable body of literature has been built by studying families of children who have cancer. It is well established that cancer and the myriad unknowns associated with it place "a tremendous burden on the family" (Canadian Cancer Society, 2009), including each individual and the family as a whole, affecting all aspects of their lives. Recognizing the complexity and multi-faceted nature of the experience, researchers have examined many of its elements from a range of perspectives.

For an overview of the impacts on the family, Patterson, Holm and Gurney (2004) conducted focus groups of parents of children with cancer and catalogued the "strains" they described including: suffering from the effects of treatments; worrying about the disease, treatments and the future; struggling to manage the health care system, the child's school, parents' employment and family finances; adapting to profound changes to their "normal life"; strained

relationships among family members and with others in their communities; as well as their own, their ill child's and their healthy children's emotional struggles. Each of these issues, as well as strategies used to manage and cope with childhood cancer, have been explored in depth, contributing important pieces to this complex puzzle.

Physical suffering

In their instrumental study involving 39 children with cancer and their families, Woodgate and Degner (2003) gained enormous insight into the experience of suffering. Interestingly, the children in this study, as well as their parents and siblings, all expected some degree of physical suffering as a necessary and even an inevitable part of the process. They assumed that symptoms would get worse before they got better, and that medications would improve but not eliminate pain and discomfort. Further, when physical symptoms worsened – particularly those that interfered with participation in enjoyable activities – other challenges in their lives seemed amplified, leading to “increased sorrow and suffering for the children and families” (p. 482).

Children were willing to endure pain related to treatment when they believed it would have a positive outcome. In fact, families described their preference to be in treatment, suffering with the related side effects, rather than to have finished treatment and feel vulnerable to the cancer's return (Woodgate & Degner, 2003). Perhaps because of this feeling of vulnerability, the children in this study explained that, while they inevitably adapted to the process and discomfort of treatment, they refused to “accept” their suffering, equating acceptance with giving up the fight against the illness (Woodgate & Degner, 2003).

Witnessing their children's pain and distress related to treatment was a heartbreaking experience that was often mentioned by parents (Patterson et al., 2004). Based on their interviews of parents of children with acute lymphoblastic leukemia, the most common form of childhood cancer, Kars, Duijnste, Pool, Van Delden & Grypdonck (2008) developed the concept of parents

“being there” for their child. By being present, advocating and providing comfort and emotional support for their child, parents also addressed their own instinctive drives to alleviate the vulnerable child’s suffering, as well as provide protection by encouraging “preservation” for children who may not have recognized their suffering as a means to a healthier future (Kars et al. 2008). Parental support did appear to help children who were suffering, according to Harper, Penner, Peterson, Albrecht and Taub (2012), who stated that children whose parents earned high “empathic” ratings were able to tolerate painful procedures with lower reports of pain and distress.

The experience of suffering, then, is not strictly a physical one, nor is it restricted to the child who is ill. Rather it is a complex physical, emotional and psychological experience shared and shaped by family members, influencing and influenced by perceived meanings of illness and distress.

Worry and Uncertainty

Uncertainty about cancer, including its prognosis, effects and treatments may be “the single greatest psychological stressor facing the patient with a life-threatening illness” (Koocher, 1985, p. 92), with fears of death and relapse weighing heavily on the hearts and minds of their parents as well (Bjork, Wiebe & Hallström, 2005; Hildenbrand, Clawson, Alderfer & Marsac, 2011; McGrath, Paton & Huff, 2004; Patterson et al., 2003; Schweitzer, Griffiths & Yates, 2012; Woodgate, 2006). According to Clarke-Steffen (1997), families of children with cancer experienced a period of living in “limbo” as they discovered the child’s illness; an experience characterized by uncertainty, worry, preoccupation, vulnerability and helplessness. Poignantly, one mother in her study reported that “not knowing is the worst. Because you cannot begin to deal with what you don’t know yet” (Clarke-Steffen, 1993, p. 190).

Throughout her interviews with eleven children with cancer, Stewart (2003) elicited their recollections of feeling uncertain, noting that although they arose throughout the course of the

illness and treatment, these feelings were concentrated at the time of the diagnosis. Not knowing what to expect from medical procedures, hospital processes, side effects, and long-term outcomes were common themes. However, with time and experience, children described “getting used to it,” learning to be flexible when treatments and processes were unpredictable, and comparing current and past experiences and sensations in order to “interpret the degree of threat from their illness and treatment” (Stewart, 2003, p. 403).

Whereas children had described adapting to the unknown, mothers’ worries about their children’s risks of relapse, infertility, and concerns for their children’s psychosocial adjustment, did not lessen with time (Zebrack, Chesler, Orbuch & Parry, 2002). Parents of children with brain tumours have reported these same fears and feelings of uncertainty immediately upon receiving the diagnoses, over the course of treatments and even after years of remission (Deatrack et al., 2009; Jackson et al., 2007; Vance et al., 2004). It is not surprising then, that recurrences or repeated hospitalizations – manifestations of their deepest fears – may cause parents even more distress, uncertainty and helplessness than the child’s initial diagnosis (Noojin, Causey, Gros, Bertolone, & Carter, 1999; Grootenhuis & Last, 1997).

Coping and optimism

In the face of so much suffering and uncertainty, children and families have demonstrated remarkable capacities to cope and maintain hope (Grootenhuis & Last, 1997; Jackson et al., 2009). Researchers have considered coping from a variety of perspectives, consistently identifying maintenance of a positive, or optimistic outlook as the most frequently reported strategy used by parents and children (Fletcher, 2011; Han, Cho, Kim & Kim, 2009; Hildenbrand et al., 2011; Patterson et al., 2004).

Based on the Coping Health Inventory for Parents (CHIP), parents identified “Coping Pattern 1: Family integration, cooperation, and an optimistic definition of the situation” as

containing the most helpful strategies (Han et al., 2009; Jackson et al., 2009, p. 9). This pattern included: maintaining the belief that the child would recover, having faith in the hospital staff's care and skill, spending time with the child and being grateful (Han et al., 2009). Similarly, Patterson et al. (2004) reported that 88.5% of parents in their study used "appraisal-focused coping behaviors" including "being positive and maintaining hope," "making positive comparisons," and "believing/trusting in God" (p. 402).

Exploring the benefits of a positive outlook, Last and Grootenhuis (1998) found "being hopeful" to be the primary predictor of parents' emotional health, and suggested that positive expectations allowed them to feel a sense of control, (Grootenhuis & Last, 1997). Fotiadou, Barlow, Powell and Langton (2008) linked parents' positive outlook with higher scores on measures of life satisfaction, and fewer symptoms of anxiety and depression.

Additional strategies employed by parents included: seeking information about the child's illness and treatment from other families and professionals; seeking and offering support; advocating for their child; planning and preparing; and expressing their emotions (Han et al., 2009; Jackson et al., 2009; Patterson et al., 2004). Although children employed some unique coping strategies, such as relaxation and distraction in dealing with physical symptoms, they shared their parents' use of emotional expression, social support and most commonly, cognitive restructuring to maintain a positive outlook (Hildenbrand et al., 2011).

Disrupted "normal life"

In Stewart's research, children with life threatening illnesses strove for normalcy; unfortunately this goal was challenged by the inherent uncertainties of cancer and its treatments (2003). Being diagnosed and suddenly immersed in the foreign environment of the hospital had immediate and drastic effects on children and their families' sense of their lives (Woodgate, 2006), forcing what one parent described as "an enormous transition from normal to damage or

disaster control” (McGrath, Paton & Huff, 2005, p. 102). Bjork et al. (2005) described families’ lives as being broken, vulnerable and unfamiliar, with parents constantly trying to mend and rebuild by learning about the illness and treatment, creating new routines and maintaining a positive outlook.

While they were in the hospital, children and parents desperately longed for the comforts of home and to be with the rest of the family (Bjork, Wiebe & Hallström, 2009). When they were able to return home, children’s and families’ lives continued to be dictated by the illness, as the child’s compromised immune system and vulnerability to infection limited the activities they could engage in (Bjork et al. 2009). Being unable to participate only deepened the children’s desires to do so, as well as their wishes to feel normal, and to be treated normally by others (Bjork et al., 2009; Hildenbrand et al., 2011; McGrath et al., 2005). Sadly, when they finally did venture back out into their communities, children were often stared at because of their hair or weight loss (Patterson et al., 2004).

In time, families did learn to adapt, no longer attempting to return to the lives they lived before the diagnosis, but rather by creating a “new normal” based on “routines and psychosocial contexts that were predictable, reliable and comfortable” (Clarke-Steffen, 1997, p. 284). However, Woodgate (2006) noted that even when children were in remission, their families “could never be completely free from the experience of childhood cancer... It was like a shadow that was always following them” (p. 15).

Changing relationships

Being separated from one another while the ill child was hospitalized was an enormous strain for families, contributing to feelings of loneliness and disconnection (Hildenbrand et al., 2011; Schweitzer et al., 2012). Parents felt helpless and exhausted, while siblings left at home

often felt excluded, neglected and jealous of the attention their brother or sister was receiving (McGrath et al. 2005; Patterson et al., 2004; Woodgate, 2006).

In order to balance their families' needs and the additional burdens of caring for the ill child, individuals' roles and responsibilities were often restructured (Clarke-Steffen, 1997), with many parents leaving their jobs temporarily or permanently, and older siblings adopting additional responsibilities at home or caring for the ill child (Patterson et al., 2004). Reflecting on the impact of the illness and separation, siblings of children with cancer explained that they had both been changed by the experience and came to feel unfamiliar to each other, no longer sure how to relate or reconnect (Lollis, 2009). Similarly, extended time away from their peers and the physical and psychosocial changes they'd experienced, complicated many ill children's abilities to reintegrate with their peers following treatment.

Although relationships within the family, with friends, colleagues and community members were consistently and profoundly changed by childhood cancer, the nature of those changes varied. In many cases, family members expressed that the child's illness brought them closer together, helped them to realize how important they were to one another, and strengthened their relationships (Clarke-Steffen, 1997; Deatrick et al., 2009; Fletcher, 2011; Woodgate, 2006). Whereas some families were disappointed by the lack of support or insensitive comments they'd receive from some family and friends, others were surprised and overwhelmed by the support they received from their extended family and broader community (Fletcher, 2011; Jackson et al., 2009; McGrath et al. 2005; Patterson et al., 2004; Woodgate, 2006).

Emotional struggles and grief

Researchers have documented a range of emotions expressed by children and their parents, particularly upon learning of the diagnosis or during painful treatment regimes, including feeling sad, scared, worried, vulnerable, helpless, overwhelmed and fearful of death (Bjork et al., 2005;

Hildenbrand et al., 2011; McGrath et al. 2004; Patterson et al., 2004; Woodgate & Degner, 2003; Woodgate, 2006). In studies of families of children with special needs, chronic or terminal illnesses, or mental health issues, these same emotions have often been conceptualized as grief reactions similar to those experienced following a death (MacGregor,1994; Pianta, Marvin, Britner & Borowitz, 1996; Rentinck, Ketelaar, Jongmans, Lindeman & Gorter, 2009; Steele & Davies, 2006).

By considering their reactions through the lens of grief, drawing from the broader base of literature on childhood illness and special needs, parents' emotional experiences can be more richly illustrated. Specifically, grief was recognized as being ever-present, occurring in cycles and often felt more intensely around medical crises or missed milestones (MacGregor, 1994; Rentinck et al., 2009; Steele & Davies, 2006). MacGregor (1994) described the experience of guilt as a component of grief for parents, attributing it to "their heightened sense of responsibility for the well-being of a child. The inability to protect their son or daughter results in a serious loss of self-esteem, and parents often have irrational thoughts that they contributed to their child's illness or death... by not noticing symptoms early enough, by choosing the wrong doctor" (p. 162).

Although references to grief in the literature on childhood cancer have been very rare and concise (McGrath et al. 2004; Patterson et al., 2004), the losses that are recognized as sources of grief are clearly described. Paralleling Steele & Davies' (2006) study of parents of children with terminal diagnoses, who revealed their grief for lost hopes and dreams for their children and their lives together, Woodgate (2006) heard from children with cancer about their own lost hopes, including "not having a chance to get married, have children, or be an aunt" (p. 12). There were also threats of loss to the family, when children or parents feared that they might not survive the illness with their relationships intact. Woodgate and Degner (2003) described "multiple losses" that left family members feeling as though "something had been taken away. The range of losses

included loss of independence and function, missing work or school, missing friends and family members, and the ultimate loss: death” (p. 110).

Dual Process Model of Coping with Bereavement

Given the striking similarities between the emotions and losses described by children with cancer and their parents, and grief responses described elsewhere in the literature on childhood illness and disabilities, further examination of grief in children with brain tumours and their parents is warranted. In-depth exploration would illustrate how the complex experiences of childhood brain tumours contribute to a grief response that is unique or similar to those described by others. The Dual Process Model of Coping with Bereavement offers a lens through which to examine these conditions and experiences.

Although its original formulation was based on the death of a partner, Stroebe and Schut’s conceptualization of the grieving process reflects many of the fundamental elements described by, and observed among parents of children with cancer. The authors themselves have acknowledged the potential relevance of their model to individuals grieving other stressful life events, but have not explored those applications (Stroebe & Schut, 2010).

The Dual Process Model (DPM) is described as a “dynamic coping process” in which individuals oscillate between thoughts and emotions arising from “loss-oriented” and “restoration-oriented” stressors (Stroebe & Schut, 2010, p. 278). The concept of “*loss-orientation* refers to the concentration on, and dealing with, processing of some aspects of the loss experience itself,” specifically, thinking about the death, remembering and longing for the person who died and their time together (Stroebe & Schut, 1999, p. 212). *Restoration-orientation*, on the other hand, “refers to the focus on secondary stressors that are also consequences of bereavement, reflecting a struggle to reorient oneself in a changed world without the deceased person. Rethinking and replanning one’s life in the face of bereavement.” (2010, p. 277)

Whereas the primary loss referred to in the DPM is the death of a loved one, applied to families of children with brain tumours, a *loss-orientation* could include thoughts and feelings about the diagnosis, changes in the child's function or abilities, emotional and physical suffering, and remembering the way that the child and family were before the illness. Examples of secondary stressors encompassed within a *restoration-orientation* for these families could include trying to come to terms to the child's vulnerability, adapting to the practical and logistical demands of caring for an ill child, and revising short- and long-term plans based on treatment regimens and prognoses.

Stroebe & Schut (1999) describe oscillation between these two orientations as a necessary process, the "juxtaposition of confrontation and avoidance of different stressors associated with bereavement. At times the bereaved will be confronted by their loss, at other times they will avoid memories, be distracted, or seek relief by concentration on other things" (p. 215). They explain that this oscillation serves a regulatory function, protecting the griever from feeling debilitated by constant, overwhelming emotions brought on by one type of stressor or the other. Furthermore, they suggest "a waxing and waning, an ongoing flexibility, over time. Early on in bereavement, loss-orientation dominates, later on, attention turns more and more to other sources of upheaval and distress" (Stroebe & Schut, 1999, p. 213).

Applying these notions to what is known about families of children with cancer, this "waxing and waning" is consistent with reports of intense emotions and distress being concentrated around the time of the diagnosis, and then recurring in waves with medical crises (Bjork et al., 2005; Hildenbrand et al., 2011; MacGregor, 1994; McGrath et al. 2004; Patterson et al., 2004; Rentinck et al., 2009; Steele & Davies, 2006; Woodgate & Degner, 2003; Woodgate, 2006). Stroebe & Schut's (1999) reference to increasingly shifting attention to *restoration-oriented* stressors over time, could be reflected in families' turning their focus away from the past,

the diagnosis and feelings of helplessness, towards learning to care for the child at home, or supporting the child's return to school and other activities.

Despite these striking parallels, a significant difference exists between the death of a loved one, and a diagnosis of childhood brain tumour. Death is an unquestionably final event marking the end of a life, leaving loved ones to grieve and to try to adapt themselves, their relationships and their environment to a world without their loved one. Conversely, the diagnosis of a childhood brain tumour marks the end of life as it was before, creating profound losses for the child and family to grieve and adapt to in the perpetually looming shadow of death and other threats.

Summary

Although a great deal has been learned about the challenges faced by children living with cancer and their families, considerably less is known about the similarities and unique challenges faced specifically by children with brain tumours and their families. In particular, childhood cancer causes physical suffering and pervasive uncertainty, arouses strong emotions associated with losses related to the illness and its impact, imposes considerable strains on relationships, alters the routines and lives of all family members, and demands coping strategies in response. While each of these elements must influence the others, studies have generally focused on individual or pairs of elements, rather than taking a broader view of their tangled web. The complex interrelationships between these elements, and their unique manifestations in the case of childhood brain tumours, are at the core of my interests and this study, with a strong desire to give voices to these children and their parents.

Research questions and objectives

In contrast to the wealth of knowledge about families living with childhood cancer, researchers have just begun to explore the unique challenges faced by children with brain tumours and their families, with unfortunately little input from the children themselves. Therefore, the

primary focus of this study was to explore the experiences of childhood brain tumours from the perspectives of children and parents, in order to gain a richer understanding of their thoughts and feelings about the illness and its impacts for themselves and their families, and to learn about their experiences navigating the landscape of their changing lives. To this end, this study aimed to address the following questions:

- How do children and parents feel, express, contain and cope with their emotions?
- In what ways are children's and their parents' reactions similar or unique?
- How are family relationships shaped by the illness and their responses to it?
- By comparison with the existing literature, how is life with a brain tumour similar to, and different from life with other childhood cancers?

During preliminary analysis of interview data, I was impressed by the complexity of family members' emotional experiences, and what I interpreted as grief reactions; for while the presence of grief has been briefly acknowledged in the literature, in-depth exploration is conspicuously lacking. Furthermore, the frequency of participants' references to "normal life" and "being positive" were striking, and led me back to the literature where I discovered how commonly these themes arose in earlier studies.

Stewart (2003) noted that slowly and unevenly improving survival rates for childhood cancers, and the inability to predict their own child's future have trapped families in "a powerful paradox of increased optimism accompanied by enduring uncertainty" (p. 394). Throughout their child's treatment and beyond, Deatrick et al. (2004) described parents of children with brain tumours as living in a "dialectical context of loss and recovery... [with] simultaneous feelings of grief over their children's losses in functional status and relief about their survival." (p. 306). The complexity of these conditions led me to ask two additional research questions:

- What might be gained by considering children's and parents' emotional experiences through a lens of grief, such as the Dual-Process Model (Stroebe & Schut, 1999)?
- How do children and parents experience the opposing pulls between optimism and uncertainty, loss and recovery?

This study afforded an opportunity to explore these questions and learn from children with brain tumours and their parents, in order to begin to understand the complexities of their experiences.

This knowledge base can begin to address a crucial gap in the literature, and inform the development of meaningful strategies to support families living with childhood brain tumours.

Methods

Data Collection and Analysis

This prospective, qualitative study was designed in accordance with Constructivist Grounded Theory Methods as outlined by Charmaz (2002, 2003), building on the foundational work by Glaser and Strauss (1967). Grounded theory methods aim to generate theoretical explanations of the phenomenon being studied, using comparative analysis and conceiving of theory as “an ever-developing entity” (Glaser & Strauss, 1967, p. 32). These methods are effective in examining “what is happening” in particular interactions by offering a means of describing complex relationships between variables (LaRossa, 2005). The “discovery orientation” is useful when exploring issues about which little is known, and is “well suited to asking questions about sensitive topics that are complex, ambivalent or changeable” (Daly, 2007, p. 102). Given how little is known about the experiences of childhood brain tumours for families, and the complexity and unpredictability of what children and parents are faced with, grounded theory methods seem to be an ideal fit.

Semi-structured interview guides were developed to elicit participants' experiences related to the child's brain tumour, through the lens of parent-child communication. Open-ended questions

were posed, asking parents and children what topics were most important, hardest and easiest to talk about within their families, and what they had and hadn't discussed. Interestingly, these questions prompted participants to share a great deal about their emotional experiences related to the diagnosis, treatment, and implications for the future, as well as the impacts on their relationships. In keeping with grounded theory principles, data collection and analysis occurred concurrently, allowing the apparent significance of these elements to shift the focus of later interviews, in order to explore emotional experiences in greater depth (Charmaz, 2002).

A triadic coding scheme was employed, aided by MAXQDA software, beginning with open, line-by-line coding, generating action codes to ground analysis in participants' "views of their realities" (Charmaz, 2003). Constant comparative analysis was employed within and across interviews in order to recognize similarities and variations in participants' perspectives and experiences. These informed the axial coding stage in which relationships between concepts and categories were explored (LaRossa, 2005), including the conditions, context, and consequences of each category (Charmaz, 2003). Finally, selective coding was used to explore focal concepts in depth in order to conceive of a "theoretical story line" that illustrated relationships between variables and concepts identified throughout the process of analysis. Reflecting on memos written throughout the analysis offered direction for the selective coding stage, in which "the most frequently appearing initial codes were used to sort, synthesize and conceptualize large amounts of data" (Charmaz, 2002).

After conducting the initial 22 interviews and preliminary analyses, data collection and analysis were suspended for the duration of my maternity leave. Eight months later, upon my return, my analysis resumed and I was re-immersed in the data with a fresh perspective. A "growing sense of [my own] confidence" in the developing explanation of the phenomena

described and demonstrated by participants suggested that theoretical saturation had begun (Daly, 2007, p. 106).

Theoretical sampling strategies were used in search of “precise information to shed light on the emerging theory” (Charmaz, 2003, p. 265). To that end, three of the eleven families who had previously been interviewed were contacted and invited to participate in a second interview. These families were specifically selected because their descriptions of experiences and perspectives were particularly relevant to the emerging theory (Daly, 2007). Although two of these families replied to the invitation expressing a strong desire to participate, we were unable to schedule follow-up interviews because of logistical and health-related factors. Instead, a twelfth family was recruited and participated in a 90-minute joint interview, using a revised semi-structured interview guide to elicit their thoughts and experiences related to the emerging theoretical framework. Insights shared during this interview helped to strengthen the framework but did not offer any new information, suggesting that a sufficient degree of theoretical saturation had been achieved (Charmaz, 2002).

In grounded theory studies, theoretical saturation informs decisions about sample size. According to Thomson’s (2004) review of 50 qualitative studies, “saturation normally occurs between 10 and 30 interviews,” while Daly (2007) suggests that it often occurs between 20 and 25. Based on these guidelines, the lack of new information being shared by new participants and confidence in the theoretical framework, twenty-three interviews were determined to be sufficient for this study.

The constructivist approach to grounded theory emphasizes the significant influences of the researcher, the participant, and their relationship, on the creation and interpretation of data (Charmaz, 2002). From a Social Constructionist perspective, I tried to remain aware of my influence throughout the design of the interview guide and my behavior during the recruitment and interview processes, recognizing I was eliciting “a version of participants’ reality” (Daly, 2007, p.

34).

Engaging in the process of theoretical sensitivity throughout data collection and analysis, I attempted to be cognizant of the ways that my personal and professional experiences, and knowledge of relevant literature shaped my perspective, while remaining open to reconsidering that perspective when new information arose (Daly, 2007). Writing reflexive memos was vital to this process, as I tried to remain aware of my emotions, reactions, insights and biases, and to reflect on the ways that these would shape analysis (Daly, 2007).

My experiences working with children with brain tumours and their families in clinical and research capacities, have afforded me some familiarity with the struggles they face and the ways that their interactions and lives may be affected, informing my questions and ultimately inspiring this research. My clinical experience supporting families through the dying and death of a child or parent, has also shaped my perspective considerably, heightening my sensitivity to issues of grief and uncertainty. Becoming a new mother in the midst of this study affected me deeply, heightening my sensitivity to the heartache and helplessness that parents expressed, and the longing for the lives they had imagined for their children. Although I had always considered myself to be sensitive to the struggles that children and parents endured, my new role and early experiences as a parent cast a new light on the children's vulnerability and their parents' willingness to go to the ends of the earth to support them.

Procedures

Recruitment began following the approval of the institutional ethics review boards at the Hospital for Sick Children and the University of Guelph. Eligibility criteria specified that children were between the ages of 5 and 14 years old; had been diagnosed with a brain tumour at least 3 months earlier; had to be able to communicate in English and could not be actively dying; at least one of the child's parents had to be able to communicate in English. Eligible children and their

parents were recruited from the Brain Tumor Program at the Hospital for Sick Children in Toronto. In order to ensure that participants could share experiences relevant to this study while considering geographic convenience and scheduling, a combination of convenience and purposive sampling was used to gather participants (Daly, 2007).

Children and their parents were identified and initially informed about the study by a physician or nurse practitioner with whom they were already familiar from the Brain Tumour Program, and invited to speak with the student investigator. Prior to initiating the interviews, parents and children signed informed consent and assent forms.

Parents and children were interviewed separately, with the parents' interviews immediately preceding the children's, except in one case in which the child requested to be interviewed with his mother. With twelve parent-child dyads participating, this resulted in twenty-four participants and a total of twenty-three interviews. All children and parents were assured that interviews would be strictly confidential; no information shared by the child would later be disclosed to the parent or vice versa. It was hoped that interviewing them separately and ensuring their privacy would allow all participants to be comfortable expressing themselves freely, without concern for how their thoughts and feelings might affect the other person, and recognizing their varied access to, and preferences for information about the illness.

Children's interviews ranged in duration from 10 to 65 minutes with the majority lasting approximately 30 minutes; parents' interviews ranged from 30 minutes to 2 hours, and most often lasted 45 minutes. Two families chose to be interviewed in their homes, while the remaining interviews were conducted in private rooms at the hospital. Interviews were digitally recorded and later transcribed verbatim.

Results

Twelve children with brain tumours, including six boys and six girls, as well as eleven mothers and one father agreed to participate, despite strong efforts to include both parents in the interviews. The children ranged in age from 7 to 14½ years, with a mean age of 10½ years; parents were between the ages of 35 and 47 with a mean age of 41 years. Eleven of the children had siblings, ten lived with both parents and two lived primarily with their mothers but continued to spend time with their fathers. Two families identified themselves as being East Indian and one as Middle Eastern; two identified themselves as Canadian of Aboriginal descent, while the remaining families identified both Canadian and European backgrounds.

The children had a variety of tumours that represented different degrees of malignancy. Ten of the twelve children had surgery to resect their tumours at least once, while several of them also had biopsies or underwent surgeries for issues secondary to the tumour, most commonly shunt insertions and revisions. All of the children had been treated with chemotherapy, while seven received radiation therapy as well. Two children had been through multiple rounds of surgery and radiation, one of them receiving a second round of chemo as well, when their tumours recurred. Eight of the children were currently receiving treatment, while the remaining four children finished treatment between two and twelve months prior to participating in this study.

Interviews were conducted between three months and seven years after diagnosis, with an average of thirty-two months since diagnosis; three children were within their first six months, while four children had been diagnosed more than four years earlier. Six children, including those who had been diagnosed more than four years earlier, had experienced at least one recurrence or new tumour growth and at the time of writing, one child had died. See Table 1 for information about children and their parents; all names have been changed to protect participants' confidentiality.

Table 1 – Participant characteristics

Parent's name	Child's name	Child's age (yrs)	Child's gender	Time - diagnosis to interview (months).	Type of tumour	Malignancy	Rec'd chemo	Rec'd radiation	Underwent surgery	In treatment at time of interview?
Sharon	Henley	8.5	F	10	High grade glioma	High	X	X	X	Yes
Carmen	Andrew	7	M	48	Low grade glioma	Low	X			Yes
Darla	Abbie	13.5	F	25	Pineal blastoma	High	X	X	X	No
Karen	Carter	13.5	M	16	Low grade glioma	Low	X		X	Yes
Nuhan	Davon	10	F	84	Low grade glioma	Low	X		X	No
Alison	Casey	11	F	3	Germinoma	High	X	X	X	Yes
Sandra	Ricky	7	M	22	Low grade glioma	Med	X		X	Yes
Elizabeth	Collin	9.5	M	5	Medullo-blastoma	High	X	X	X	Yes
Asif	Nathan	14.5	M	69	Ependy-moma	High	X	X	X	No
Nancy	Melanie	10	F	60	Low grade glioma	Low	X			Yes
Lisa	Jordan	9.5	F	45	Ependy-moma	Very high	X	X	X	No
Ashley	Mitchell	12	M	4	High grade glioma	High	X	X	X	Yes

The interviews with children and their parents were full of strong descriptions and stories, some gut wrenching, others inspiring. One of the common topics that most subjects reported on was the family's unique path to diagnosis. In some cases, children had a sudden onset of severe symptoms that were quickly recognized and diagnosed, while others had more ambiguous symptoms that seemed to come and go, and were attributed to the flu or the weather. In the most extreme cases, children's symptoms were treated as behavioural or anxiety disorders for many months before their parents' unrelenting advocacy finally led to further testing and brain tumour diagnoses. Some of the interviews revealed that children seemed to recover quickly from treatment with relatively few side effects, while others suffered permanent damage from the tumour or its intervention. This latter group included two children who had strokes secondary to their tumours, leaving them with significant, and visible impairments. Families also reported detailed timelines that spanned the discovery of initial symptoms through treatment. Through these descriptions they demonstrated the emotional turmoil they endured along the way, both via their vivid recollections, as well as what they left unsaid.

Introduction to the Theory of Balancing Grief and Survival

For all the uniqueness in their stories, two contexts were particularly salient in each of the twenty-three interviews. The first context, entitled "Dealing with the Illness," includes suffering with symptoms, enduring treatments, coping, and working to overcome the impacts of the illness, both psychologically and physically. The second context, entitled "Normal Life," refers to descriptions of how subjects' lives had changed, as well as their attempts to try to get "back to normal," and do "normal stuff."

Woven throughout these two contexts were vividly told stories and perceptions reflecting diverse emotions that stretch across a spectrum. The ends of the spectrum include, profound grief and vulnerability, which alternates with hope, determination and optimism. These two polarities

were strong and synchronous processes running through all of the interviews. Taken together, they reveal the core process of “Balancing Grief and Survival” -- i.e. children’s and parents’ perpetual efforts to achieve a manageable equilibrium amidst uncontrollable and often overwhelming circumstances. It is important to note that the use of the term “balancing” is not meant to imply that it is possible to achieve a state of perfect balance, or that grief and survival act in equal and opposite directions. Rather, “balancing” is meant to reflect the active and dynamic attempts of children and parents to offset or counterbalance feelings of being pulled towards grief by experiences and circumstances, by pulling themselves towards survival.

By overlaying the processes of “Grief” and “Survival” across the contexts of “Dealing with Illness” and “Normal Life” four main categories were created, each with subcategories, that delineate the ways that children and parents experience and respond to the child’s illness. The proposed substantive theory can be visualized by arranging these main categories into four corners, with the child and parent being pulled in each direction by various health experiences, coping strategies, activities, people and time. See Figure 1 for an overview of the model.

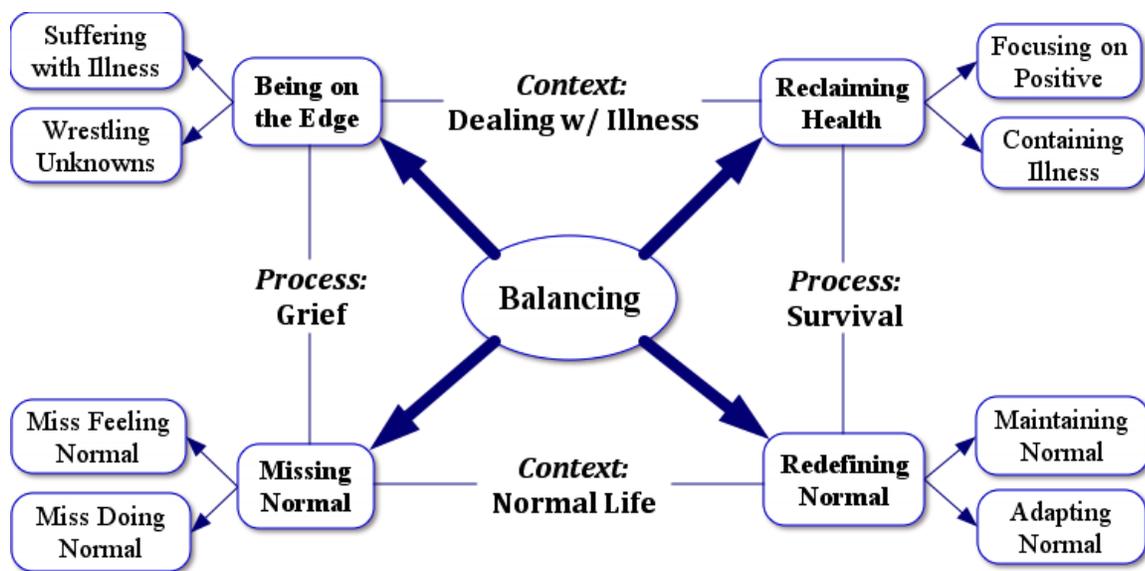


Figure 1 – Model of Balancing Grief & Survival

Overview of the four main categories

In this study, narratives and demonstrations of “Grief” were laden with emotions such as vulnerability and a sense of being overwhelmed; references to “Being on the Edge” manifested in feelings of fear and anxiety, helplessness and vigilance, and “Missing Normal Life” conveyed sadness, loneliness and hopelessness. In stark contrast, descriptions and expressions of “Survival” were full of hope, strength and positivity, though these were often tentative. In relation to “Reclaiming Health,” children and parents conveyed feelings of reassurance, competence, pride and a sense of regaining control; descriptions of “Redefining Normal” were infused with comfort, familiarity and relief.

Table 2 - Emotions Associated with Processes and Categories

Process	Grief		Survival	
Associated emotions	Vulnerability, being overwhelmed		Hope, strength, positivity	
Category	Being on the Edge	Missing Normal Life	Reclaiming Health	Redefining Normal
Associated emotions	Fear, anxiety, helplessness, vigilance	Sadness, loneliness, hopelessness	Reassurance, competence, pride, control	Comfort, familiarity, relief

In their portrayal of the core process of “Balancing Grief and Survival,” parents and children described *being pulled* in the direction of grief by things that happened to them – e.g. the onset of symptoms, being treated poorly by others – while they *pulled themselves* towards survival by thinking or doing things that helped them feel positive, hopeful and strong. The more frightening health and medical experiences they had, or the more that circumstances interfered with their normal lives, the more grief had a presence in their stories, and the harder it seemed to be to shift their focus to survival. This is not to say that grief was more intense or difficult for one

person than another, or that a person who faced seemingly overwhelming challenges would be unable to overcome them and focus on survival; only that each additional obstacle required additional emotional energy to counteract its negative impacts.

The factors and circumstances that contributed to children’s and parents’ grief, and the strategies and supports that they engaged in to focus on and feel capable of surviving, are outlined in the category and subcategory descriptions below. Discussion of these categories and subcategories will first examine concepts related to the context of “Dealing with Illness,” followed by those connected to “Normal Life.”

Main Category #1: Being on the Edge

The first category, “Being on the Edge,” captures the participants’ grieving processes related to the context of “Dealing with Illness,” such as when they were suffering with the illness, treatment and process, and wrestling with a myriad of unknowns and potential threats. Children characterized these circumstances as being sad, scary and causing them and their parents to worry. While children and parents both conveyed a strong sense of dread and the emotional burden they experienced when the child was suffering physically, parents also described a heightened sensitivity and vigilance about their children’s conditions.

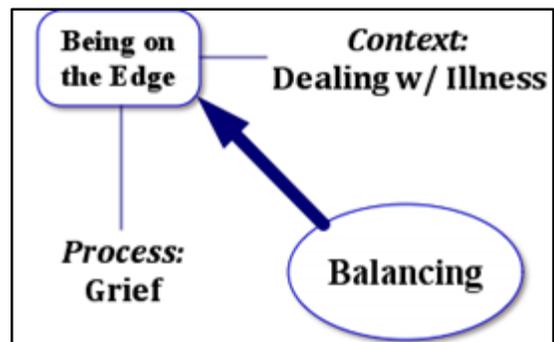


Figure 2. Being on the Edge, at the intersection of Grief and Dealing with Illness

Parents often referred to themselves as being “always on duty” during these periods, or “on the edge of drama,” waiting and expecting something terrible to happen. In hopes of averting disaster, parents paid extremely close attention to their child’s well-being, in some cases taking their child’s temperature daily or sleeping beside them “just in case.” Asif, the father of a 14-year-old boy, explained: “I notice him losing weight, when he is walking, I am noticing him... I don’t

wanna make [a] mistake because there is something I feel, something not right, I don't wanna sit down.” Within this category, two sub-categories were defined, capturing distress related to present and potential struggles: “Suffering with the Illness and Treatment,” and “Wrestling Uncertainty.”

Subcategory #1a: Suffering with the Illness and Treatment

Children's and parents' suffering was contributed to by a number of circumstances including the initial onset of symptoms and the path to diagnosis, procedures and treatment.

Symptoms & Path to Diagnosis: When asked to describe “a bit about the illness,” children and parents spoke at length about the earliest symptoms and their paths to diagnosis. Many children vividly recalled suffering from headaches, nausea, dizziness, and exhaustion; in addition, some children also suffered from vision or hearing loss, twitches, limping, weakness or a facial “droop.” While children described the sensations they felt, their parents described noticing and keeping track of their child's symptoms by often writing in a log or diary. Even without referring back to their notes, parents were able to recall exact dates of symptoms and their treatments. Elizabeth reflected on her nine year old son's experience: “it was first weekend in December, first time I think I've ever heard him say ‘I have a headache’ and it was just a, you know, that was a one-off and by the fifteenth of December he was home, off school with excruciating headaches and fatigue.”

These early stages leading up to, and learning of the diagnosis were full of physical and emotional suffering. The majority of children had symptoms that parents and physicians initially attributed to the flu or allergies, such as fatigue, nausea, headaches or sinus pain that came and went. Vague and changing symptoms led to three children being suspected by parents and physicians of seeking attention. In time, a number of parents reported acting on their “gut instincts,” responding to a profound sense that something was “not right” despite physicians' earlier reassurances or clear test results. In several cases, this intuitive behaviour ultimately saved

their children's lives. As Lisa, mother of a 9 year old girl, explained: "after her CT scan, when I insisted that she have one, [the doctor] told me to take her home and come back in six weeks. If I had'a done that she would have died and so I very much learned that if I really feel strongly about something, there's probably a good reason for it." In retrospect, some parents and children were frustrated or angry with health care professionals whom they felt had minimized or misdiagnosed the child, while other parents reflected "it's nobody's fault."

Fortunately, in most cases it did not take long to identify the true cause, as new symptoms emerged, or initial symptoms worsened, raising enough concern for parents to take their children to the emergency department. Parents remembered going to the hospital anticipating a brief stay for what they imagined was a relatively benign illness, and being caught off guard by the severity of the diagnosis and the whirlwind of intervention and admission to the hospital. Although they often described it as a "blur," many parents vividly recalled the timing of procedures, and details of conversations. Darla, mother of a 13 year old, described:

They put me and Abbie and my other two kids and my mum in a, in a tiny little room. They came in and asked my mum to take my other two kids outside...

They told us that Abbie had a, a tumour. Well I started to cry and Abbie's looking at me she goes, "Why is my mum crying?" Well I sucked it up and, 'Oh my god what did I just do,' right? And so she told me it was a lesion tumour and not going to be too, "don't worry it's not cancerous," is what the one nurse said to me, I can still picture her.

Many of the children remembered little of this process, as they were suffering from symptoms and asleep or unable to focus; for them, learning of the diagnosis came later on in their hospital stay. In contrast, Casey, an eleven year old girl, clearly remembered, "when I got to the hospital and I was in the emergency and they were done with the needles, then they started

explaining it to me and it was really, really scary ‘cause I don’t know anyone who’s had cancer, only Terry Fox, like he died from it so that’s a bad, like, person to know about.”

Dreading the worst was a common reaction for children and parents alike, as were feelings of sadness, shock and feeling overwhelmed, with many people never having heard of childhood cancers before. Nuhan, the mother of a 9 year old, explained, “When I hear tumour I couldn’t understand what they mean, tumour, ‘cause I never hear about the, these things, sickness before. We live like a normal life, happy life, then this happened.... It is big thing, means like dying or death for us, when they told us a tumour.... Scary thing, until now we live day by day, actually.” A few parents described disbelieving the news, as Asif recalled, “very, very, very tough time... the first surgery, I was fighting with the doctor, I say, “No, you are doing surgery for no reason, my son have no brain tumour.”

Although most of the children received diagnoses relatively soon after the onset of symptoms, two went through more than a year of referrals to specialists, medical tests and unsuccessful treatments, including, for one child, therapy for a suspected anxiety disorder. These two families suffered greatly during this process, with the children wondering what was wrong with them and feeling somehow to blame for their seemingly inexplicable symptoms. Accurate diagnoses, despite the severity, brought some relief to children and parents, as Casey explained, “sometimes I feel scared but sometimes I’ll feel happy that we found out what was making me tired.”

Perhaps not surprisingly, after learning of the diagnoses, parents who had suspected benign illnesses or that their children were “faking” struggled with profound guilt for the time they felt they had wasted, and for distrusting their children. Carmen, the mother of a 7-year-old boy who had developed a twitch, remembered, “My husband and I, we questioned, “well, why was he doing this?”... but there was nothing else to go by, no illness whatsoever... we beat ourselves up about

this, what we did, we didn't do anything basically.”

The initial diagnosis was not the only source of “bad news” that caused suffering; parents and children continued to grieve as they learned more about the tumour and what it would mean for their lives. Some children and parents described struggling to come to terms with the fact that the tumour would affect them for the rest of their lives, either because of medications the child would have to take “forever,” or lasting-effects of treatment, or the ever-present threat of recurrence. Whether brought on by the sickening familiarity of their physical symptoms or unexpected test results, the news of a recurrence was devastating, described by one mother as “a punch in the gut.” Children described the return of their symptoms as stressful, sad, scary and overwhelming, making it difficult to concentrate on anything. For these children the physical and emotional experiences of the recurrence were inseparable; Nathan, a 14-year-old boy summarized it all by simply saying, “I was scared ‘cause I knew all that stuff.”

Enduring Procedures and Treatments. Immediately following their diagnoses, children began their treatment regimes, which created new instances of suffering. Although some children and parents described feeling relieved that the child’s symptoms improved after surgery, the treatments themselves were often scary and invasive, and caused new side effects. Children struggled with the discomfort and claustrophobia of radiation masks and MRIs, and were often afraid of the pain associated with surgery and lumbar punctures. Some children had vivid memories of difficult procedures, including Andrew, a seven year old who recalled a lumbar puncture from nearly four years earlier: “one time they put me in a room and they put a needle in my back to check the scan... a man gave me a medicine, and he didn’t give me enough medicine inside of me, I got up and I felt it and they needed to hold me down and they put [on] a gas mask.” Other children described their fears prior to surgery, about being able to feel the pain during the procedure, or waking up a “changed person.”

Repeated procedures posed their own challenges, with many children struggling with the frequent blood work that was required through finger pokes and port accesses, making some children reluctant to come to the hospital. Nine year old Jordan explained, “you know what’s happening so it’s a little easier but after the second time, you know what’s happening but you know it’s gonna hurt and stuff, so it’s still, it’s hard.” Regular treatments also posed significant practical challenges for children and their families, such as commuting or staying at the Ronald McDonald House while separated from their families for weeks or months; coordinating childcare for siblings; maintaining a job and the financial burden of it all.

Parents recounted watching their children endure painful or scary treatments, and feeling helpless to protect their child, while struggling with their own fears. Darla expressed, “when you see her spinal fluid coming out a tube and it’s in a container beside her, I thought ‘what are we, what are we in for?’”

Without a doubt, the most difficult procedures for children and their parents, were those that did not go as planned. For some, it was a nurse inserting a needle without an adequate warning given to the child, while others reported being assured that parents could stay in the operating room until the child fell asleep, but being told at the last minute that that was no longer possible. These situations compromised children’s trust in their parents, contributing to parents’ feelings of guilt at having “misled” their children, helplessness, anger, and feeling betrayed by the health care professionals they were dependent on. Sharon became emotional, remembering her daughter’s lumbar puncture:

“She’s lying on the table and everybody else is preparing and doing everything and they’re like “Oh, y’know, you don’t need [sedation],” and I was just like, “What do you mean, you don’t need it? Because you guys said that that was what’s gonna happen so obviously there’s a reason why you would have said that to start with”... She was bawling on the table

“Mummy you said it would be alright, I wasn’t gonna feel it... but you told me mummy,” and that was when, for us it was hard because we, we can tell you these things based on what we’re told, I’ve never had a spinal tap [slight laugh] I don’t know anybody that’s ever had one, right? So I can’t tell you what to expect, we just go from what we’re told.”

In addition to the treatment process unfolding unexpectedly, there were also instances in which the treatment itself went wrong. Usually this resulted in minor side effects like a rash or fever, but in one devastating situation, a child had a stroke during surgery, significantly affecting the left side of her body. After agreeing to the surgery despite having a “bad feeling” about it, Nuhan described her daughter’s suffering from the stroke as being “worse than that tumour itself, like they can see the tumour and they can control it, but the weakness stay forever now.” While the physical effects caused her daughter to suffer, Nuhan suffered with her, carrying the weight of so many “what ifs.”

Subcategory #1b: Wrestling Uncertainty

Children and parents’ stories were riddled with “what ifs” related to the child’s brain tumour: dreading the illness and its potential effects; anticipating and trying to minimize risks; and searching for explanations. The unpredictability and lack of control were extremely difficult to deal with for both children and parents, as Casey explained, the hardest part for her was “that you don’t know what’s gonna happen next.”

Dreading the Illness, Recurrence, Risks and Death. Reeling from the shock of the diagnosis, fears and uncertainty were extremely high for children and their parents. Karen remembered, “When he was first diagnosed I couldn’t even talk about it initially because it just was so overwhelming thinking about the negative things and what could happen, and um, ‘what if, what if?’” These “what ifs” seemed to be most persistent following the diagnosis in anticipation of test results and the appearance or worsening of symptoms. Upcoming MRI’s were particularly

anxiety inducing for those who had completed their treatment regimens and started to feel better. Parents described trying not to think about the tumour and the possibility of new growth, but having no choice when the date loomed closer. Although children shared their parents anxiety about these tests, they seemed to be able to distract themselves longer, as Casey explained, “when I’m at home it’s not scary at all but when I, each [time I] come to the doctors it gets scary.”

Symptoms also caused considerable uncertainty, as it could be difficult to determine whether the tumour or treatment was the source. Davon, a ten-year-old girl, described not wanting to know about and be scared by the potential side effects; but also needing to know, so that if she experienced them she wouldn’t worry that they were caused by the tumour. Similarly, Abbie explained, “getting the chemo therapy I was worried, I was getting a lot of headaches from them. It’s like, ‘Mum, why aren’t I getting better, when am I getting better?’” Clearly, the perceived causes and meanings of the symptoms led to as much distress as the physical discomfort.

Naturally, tumour progression and recurrence were the most terrifying sources of uncertainty that children and parents faced. The constant presence of this threat was articulated by Sandra, mother of a seven year old boy: “[There’s] always the chance that something’s gonna show up again and, y’know, ‘cause they did tell us right from the beginning it can come back. It’s not, you know, you take care of it but there’s no guarantees, right? With anything cancer related, but no, I don’t really think about the future, I just try to pray that it’s not gonna come back.”

Interestingly, the only children who expressed fears about the possibility of tumour progression during the interviews were those whose tumours had recurred; these children described their recognition of familiar symptoms, and the feelings of dread that ensued. While it is entirely possible that other children wondered, or had fears about recurrence or progression that they merely did not discuss during the interviews, it may have been that some children were not aware that a recurrence was possible.

As they described the aspects of their children's illnesses that caused them the most profound worry and uncertainty, parents also described their attempts to shield their children from these same fears by filtering information about their illnesses and treatments. Although most parents described their communication with their children as being "open" often saying "we talk about everything," every parent also identified topics that they had not discussed, and did not intend to.

Most commonly and emphatically, parents stated that they had not and would not tell their child that they could die from their illness, believing that knowledge of that possibility would be overwhelming, devastating and that their child would feel hopeless and afraid. Besides avoiding direct communication about this unimaginable possibility, parents also avoided topics that could lead to thoughts about mortality. For instance, some parents withheld information about family or friends who were sick, as Darla explained, "the only thing I didn't tell her all through the treatment, and I waited 'til the end, was about her friend she lost. That was the only thing I didn't tell her, 'cause I didn't want her to think that that could happen to her."

The majority of parents explained that they had chosen not to tell their children that the tumour could return or grow, wanting to protect them from feeling vulnerable. Carmen described her son's perception: "He thinks that he's gonna be fixed, well, obviously at the end of the treatment. But there is a possibility that the tumour would stop growing and then maybe restart, we haven't discussed that with him either. The fact that he has to live with this for the rest of his life, it's hardly sunk into my head."

Several parents chose to minimize the severity of the illness by avoiding the "c" word altogether when talking with their children. Two parents had waited months or years before saying the emotionally-loaded word out loud, while two more had never used the word "cancer" when talking with their children about their tumours.

Potential lasting effects of the tumour and treatment, such as cognitive or behavioural impairments, were additional sources of uncertainty that parents avoided disclosing to their children, with infertility proving to be a particularly devastating threat. Several mothers felt unable to talk with their daughters about this, as Nuhan expressed, “it’s very, very hard for me to tell her that because she always talk about babies and she love babies and she loves to play with kids and babies. When I think about that I get crazy, ‘oh no, I never tell her that.’ At the same time the doctor tell me there is a percentage, maybe she will never get that. Why I have to tell her that and maybe she will never get it?” Although parents described filtering information as a strategy to minimize children’s fears, these efforts also seemed intertwined with parents’ own grief, fears and uncertainty.

Throughout the interviews, parents and children provided rich insights into their experiences communicating about the child’s tumour and treatment, including parents’ tendencies to avoid discussing topics they were uncertain about or grieving. While the current paper is focused on parents’ and children’s experiences of balancing grief and survival, a separate paper will provide an in-depth exploration of parent-child communication about the child’s brain tumour, the impacts on their lives.

Managing Risks. As parents tried to protect their children from fears about treatments and the future, their children would have limited information about the risks they faced. Generally, they were made aware of those risks that they could help to minimize or avoid, such as infections or injuries; these risks kept children from being involved in contact sports, or being exposed to groups of people while their immune systems were compromised. Children described it as “awful,” “frustrating” and “sad” to have to avoid these situations, and parents felt badly about the missed opportunities but clearly recognized that it was necessary and worth the sacrifice. Carmen explained, “He’s got a birthday party to attend this Saturday but now I am hearing his neutrophil

count is low... hardly likely we can risk anything.... That is hard for him and he tries to hide his symptoms when he's sick now from me because he doesn't like me worrying or he thinks we're gonna bring him here. Those are the hardest, right now, to deal with."

If there was nothing parents could do to minimize the risk of something occurring, such as the side effects of treatment, they often opted instead to minimize the burden that they imagined their child would feel if they knew those risks, by withholding that information from them. Alison, mother of an 11 year old, explained:

We have never told her the side effects of radiation, because really, why would we? I, no, I think that's way too much for anybody to handle, and we've never told her about the potential permanent side effects of chemo-therapy, and we haven't told her siblings either because they're "potential" side effects, right? [Are you] gonna like, the rest of your life wonder 'Oh could I have been two inches taller if I hadn't had radiation?' Really? ... In the general scheme of life is that what's gonna matter?

In addition to the potential risks of chemo and radiation, parents and children expressed concerns about risks associated with surgery. While children's perceptions of risks were imagined, such as being able to feel the procedure while they were sedated or waking up somehow "changed," parents' fears were based in fact. As Sandra recalled, "his surgeon went on to describe to us the procedure, that he had to remove bones from his spine in order to get to the spinal cord to remove the mass, um and y'know they tell you all the scary things that can happen."

Although many treatments, such as surgery, were not optional, occasionally parents described having to decide which treatment protocol to choose, weighing the risks of long-term side effects and the chances of "cure." Torn between her fears for the present and the future, contemplating treatment that could lead to infertility, Nuhan explained, "I feel like I shouldn't

think about anything in the future, I should think now how to treat her and how to save her life and to be healthy now as she is, not getting worse.” Children were rarely involved in this decision-making process, but still recognized the importance of receiving treatment. Abbie recalled, “if we would have waited any longer [the tumour] would have got bigger and that’s a bad thing.”

Searching for Information and Explanation. In the face of so much uncertainty, children and parents sought to understand and explain as much as they could. They searched especially for information that would be reassuring, by talking with other parents of sick children, friends with education or training in health care, professionals who were caring for their children, and by looking online. Unfortunately the reality of what they found could be devastating, as Sharon, mother of a seven year old, explained:

I’m definitely the type of person that, I wanna know as much as, y’know, everything! And I know when it [was] first diagnosed and they were like, “don’t go on the internet, don’t do research, or don’t do whatever,” and I was like, “But I wanna know, and I wanna know NOW!’ ... For the longest time, I think a month and a half, I didn’t go on the internet and then finally did and then I realised why I shouldn’t have gone on the internet. That was a really bad day, yeah, yeah; I think that was probably one of the worst days besides the surgery and stuff.

Given the potentially frightening nature of some of the information they had found online, a few parents explained that they would only use the internet when they knew their children would not be nearby, in order to protect them from that information. On the other hand, Carmen described helping her son in his own search for information: “He has me pulling up on the internet, we pull up pictures of the brain, of people’s brain and where the tumour might be.”

Often, especially while they were waiting for the diagnosis or test results, parents and

children developed their own explanations for symptoms, such as the flu or changes in the weather. Interestingly, these explanations were often linked with family histories: one mother reported a history of migraines; another compared her son’s twitch with a similar behaviour shared by her own brother; one child’s tumour had begun to grow around the time of her grandmother’s death, leading the child’s mother to suspect unresolved grief.

Children also sought explanations, particularly in relation to elements of the tumour that were abstract and hard to understand. They wondered what the tumour was made of, what colour it was, how it could cause the symptoms that it did and most frequently, how and why it had grown inside them. Although some children suspected their tumours may have been caused by eating the wrong foods or yelling too much, they continued to puzzle over this, as Andrew expressed, “I wish it do not come, but it did. I don’t know how it came, just came for no reason.... Well, they must come for a reason, wouldn’t they? They have to come for a reason, don’t they?”

Main Category #2: Reclaiming Health

Participants’ survival processes animate the second category, “Reclaiming Health,” as they were “Dealing with Illness.” For both children and parents, this entailed countering their worries and uncertainty with reassurances about how well the child had been feeling or successful test results. Both literally and figuratively, their efforts were aimed at preventing the tumour, and the stress and grief it caused, from permeating every aspect of their lives. This approach to counterbalancing feelings of “Being On the Edge” was articulated by Karen who explained:

When he was first diagnosed I couldn’t even talk about it initially because it just was so overwhelming thinking about the negative things and what could

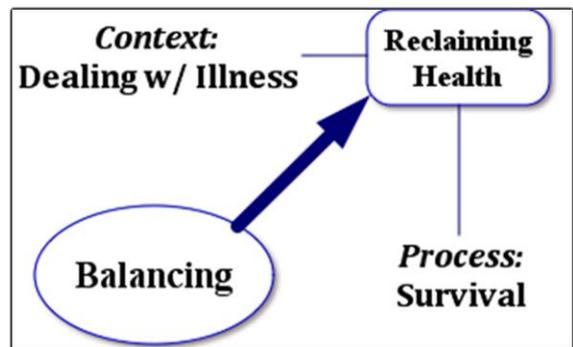


Figure 3. Reclaiming Health, at the intersection of Survival and Dealing with Illness

happen and um, “what if, what if?” Y’know? And then you sort of just go ‘Ok, stop thinking that way, he’s improving, he’s getting better... he’s sleeping and he’s doing this it’s, y’know, doing school work, he’s playing sports and he, y’know those are the things that count.

This category includes two subcategories: “Containing Illness” and “Focusing On the Positive.” These efforts serve to shift the balance, to varying degrees, away from grief and “Being on the Edge” towards survival.

Subcategory #2a: Containing illness

Children and parents demonstrated a range of strategies that seemed to help them reframe the tumour, from something that was beyond their control, to something that they could manage. In part, they did so by: minimizing their perceptions of the severity of the threats that they faced, pursuing every opportunity to address those threats, marking their progress towards recovery, and learning what to expect.

Minimizing Threats. Despite the physical and emotional suffering they had clearly endured, children and parents often employed a coping strategy of framing the tumour, treatments and associated risks as, “not that bad.” At times, parents consciously diminished the severity or likelihood of threats when talking to their children, but much more often, both parents and children minimized these threats in their own minds.

Some children and parents developed this perspective as their experiences unfolded smoother than the worst-case scenario they had anticipated at the time of diagnosis. This was particularly true if the child had a marked improvement in symptoms following surgery, did not suffer lasting effects from treatments, and had not experienced a recurrence. As Sandra explained, “there is a light at the end of the tunnel and it’s not necessarily a death sentence because that’s what you, right away you think [that], everybody does... it seems like it was so much easier than I

thought it would be. I don't know about my son, [he] might not say the same thing, but I was expecting a lot worse." For Sandra and several other parents and children, this recognition helped to shift the balance from grief towards survival.

Not only were parents reassured when the overall experience was better than expected, they seemed to experience relief following every procedure that went "better than it could have." Following surgery, several parents reported that their children had "only" suffered from one or two side effects, such as speech problems or weakness, and marvelled at the rate of recovery. As Karen recalled, "it was quite, quite good, fairly quickly, compared to what I expected. Y'know I wasn't really quite sure what to expect but he was quite good." Children and parents minimized the side effects of treatment; one child joked about losing her hair while others decided not to bother wearing wigs. After learning that radiation could affect her daughter's cognition, Alison said, "ten IQ points was what we were told. Ok, that's not too bad, she's got enough to spare."

For those whose paths were not as smooth or prognoses not as promising, more effort was required to minimize their fears. Reflecting on stressful experiences, such as being in the intensive care unit with a blood clot, or ambulance rides while children had seizures or suspected strokes, some parents chose to define these as "bumps" in their otherwise "smooth" and "perfect" recoveries. Others, like Sharon, chose to view the entire illness as the "bump" in a life that had previously been "smooth," and hopefully would be again soon: "We've looked at this as like a just a hump like, from the beginning y'know, obviously devastated at first... we're just gonna, you do these things and you just get past it and you move on... what are you gonna do, you either curl up in a ball and, y'know?"

Some families worked to diminish the very nature of the illness, referring to the tumour as a "lump," "like a wart," "almost like cancer," or deciding never to use the "c" word. A few children described themselves as "not sick," "getting better," or even "cured," while many of them

described seeing children who were “sicker than me.” One strategy that was used by the majority of children and parents was to define themselves as “better off” in comparison with families of other sick children, either based on symptom severity, lasting effects, or the burden of treatment.

As Alison expressed:

We talk about, “Y’know, if you have to have cancer, it sounds kinda dumb but you got the good kind,” and she says that. And we’re at radiation, we say, “Did you ever think you’d be lucky to only have thirteen days of radiation?” She’s like, “Yeah I know, feels really weird saying that but like, all those kids have thirty three days.”

Children and parents often referred to themselves as “lucky,” compared to other families and to the worst-case scenarios they’d imagined earlier. Children felt fortunate to have shorter treatment regimens than others, or to have been diagnosed before the tumour progressed. Parents described feeling fortunate for their children’s strength and resilience; for their children being old enough to understand what was happening; for the quality of care that they had received, to have caught the tumour early and treated it successfully; and for so many ways that it “could have been worse,” as Karen explained:

We just keep saying, “aren’t we lucky, aren’t we lucky, aren’t we lucky?”

Y’know, it could have been so much worse. There’s other kids that have it way worse, when we’re here and I see people in the waiting room, their children have many, many disabilities from their tumours, so I think we’re quite lucky...

I often think of it as a bigger plan... he was doing rugby and hockey and all these sports that, to be honest I never enjoyed them, ‘cause I was always like ‘Oh my gosh,’ I hate seeing them get hit, y’know, I think of all the horrible injuries, broken necks and things like that and I think maybe this has saved him

from a life in a wheel-chair, from being paralyzed from something and so what? He's gonna have a lifetime of other issues but, y'know, he's here and he's healthy, you weigh those off and I, I kind of just have that sense that, that there's a purpose and a meaning, we may not understand it and we can give it our own explanation but you don't usually understand it until you look back.

Interestingly, this perception that their circumstances "could have been worse" was not dependent on the severity of the child's illness. Equal numbers of children with high and low malignancies and their parents described themselves as "lucky," or even expressed feeling guilty when they compared themselves with families who seemed to be worse off.

Doing Something, Trying Everything. Parents, in particular, worked to counterbalance their feelings of helplessness by doing everything they possibly could to fight the tumour and strengthen their children. In their initial search for a diagnosis, this included seeking help from family doctors and emergency departments as well as advocating for further testing and second opinions. In the short- and long-term following the diagnosis, medical intervention was the most concrete and reassuring means of "doing something." Lisa explained, "I always feel better when she's in treatment because then I feel like we're doing something, like right now I know that there's two spots in there and we're not doing anything so it's just kinda, y'know, I hate the wait and see."

When there was not the perceived "safety net" of treatment, parents were willing to try anything to help their children. For some, this meant looking online for similar cases and promising treatments, while others sought intervention from less traditional methods such as homeopathic practitioners, organized prayer groups, or other non-allopathic healers. Carmen explained that she used exercise and massage to help her son, by "keeping him stimulated as much as possible so that his brain keeps finding new avenues and new ways to cope and his body is, is

ready.”

Throughout the treatment and recovery processes, parents continued to direct their energy towards advocating for the “best care” for their children, including new tests when their instincts told them something was wrong, and adequate resources to help their children transition back to school.

Marking Progress. Recognizing that treatment regimens were finite, and that they were getting closer and closer to the light at the end of the tunnel, seemed to be a tremendous source of motivation and reassurance for children. Casey described using this recognition to balance her worries and uncertainty, “I can’t guess what is going to happen, ‘cause if I do I’ll freak myself out, because I just have to go along with what might happen. Then I know that it, whatever does happen, it’ll be over.” Her mother, whose sentiments were echoed by many other parents, described the path to recovery, saying “we know how to get there, it’s just a matter of time.” When children and parents marked their progress, they conveyed, “we can do this.”

Knowing when it would end allowed children to count down; calendars were often used, allowing them to cross off each day’s treatment as they completed it, and to look back at all they had endured over time. The shifting balance of treatment they’d completed, compared to what lay ahead, helped children feel a sense of pride and accomplishment, and anticipatory relief as they neared their goal, often describing themselves as being “almost done.” Knowing when treatment would end was extremely helpful, highlighting the value of predictability in balancing the myriad of unknowns. This was the case even when children had a considerable amount of treatment still to endure. Henley, an eight-year-old girl, explained:

I know that I’m almost done, my mum and dad say one more year and then I’m done everything... I don’t feel sad anymore. Like when I was, when I was first in the hospital and I found out I had a brain tumour, I was a little like, “What?

What's a brain tumour?" and I was a little shocked 'cause I thought I might have to get surgery... with my mum and dad, I asked them, like, "Is it ever gonna stop? Are they gonna stop?" and they said "Yes," like with blood work and stuff, and then that made me feel better.

Parents spoke with pride and awe about their children's strength and resilience. In addition to counting down the remaining treatments alongside their children, parents tracked and celebrated progress measured by the shrinking size of the tumour and the child's improving symptoms. Several parents recounted their experiences of waiting during their child's operation, describing the relief they felt when they saw the surgeon emerge from the operating room with a smile on his face. Parents like Sandra vividly recalled these conversations: "the operation was very successful, [the surgeon] said he got ninety eight percent of it... instantly, even in the hospital, already his strength came back in his hand, he didn't, right away he wasn't waking up anymore, he could sleep, it was like, such a dramatic difference just from the surgery."

Knowing What to Expect. Children described being comforted and reassured by knowing what to expect, while parents identified these benefits both for themselves and their children. Following the chaos of their experiences prior to diagnosis, knowing what to expect offered comfort and predictability; when things went according to plan, a sense of order began to be restored. As Elizabeth explained, "everybody here has been great and they've been very clear about what's coming up and so, yeah, we feel that we have a pretty good handle on what's going on... feeling comfortable that they have given me, in terms that I can understand, y'know, what's planned... the plan's good." Knowing "the plan" was critical for parents who needed to make arrangements with employers and child care providers.

Elizabeth went on to describe the importance of information for her son, "he has to know all of it... if I don't tell him what's coming then he's gonna worry about what's coming and he's

gonna make it up, it's gonna be worse, so I'm actually coming to [realize] he needs to know all of it... he needed to know what's coming next." Casey echoed this sentiment from a child's perspective, proving that even "bad news" was better than "no news" when she said, "when they finally told-told me that I had cancer, that was a super-nice conversation 'cause I knew what was happening."

Besides having a sense of the long-term plans, children benefited from knowing what to expect from upcoming procedures, what they might feel during and after treatment, and what the recovery process would entail. At times parents described being worried about telling their children about potentially frightening procedures in advance, but after describing and preparing for the procedure, both the parents and children felt relieved. Children who could recall undergoing procedures without being fully prepared, remembered being very scared, in some cases believing they would feel extreme pain, and wishing they had known what was going to happen. Asked what he wished he'd known before surgery, Nathan replied, "you don't change after... it'll give you less headaches and after they cut you open, it'll make you feel better."

The majority of parents recognized that their children worried less when they were prepared, and felt that they deserved to know, as Sharon expressed: "it's her body, it's her life and she should, y'know she should know what's going on." They worked hard to maintain open communication about medical experiences that the child might have questions or concerns about. Additional strategies that parents used to ensure their children were prepared included seeking information from the health care team on the child's behalf or in their presence, and keeping track of treatments, procedures and the child's physical reactions. By tracking this information in a diary, log or on a blog, parents created invaluable resources that they could draw on the next time the child faced the same or similar treatments. Each of these strategies contributed to parents' sense of control and having a meaningful role and impact in their child's care.

Subcategory #2b: Focusing on Positive.

Complementing their efforts to contain the illness and its impacts, children and parents employed a number of strategies to shift their attention from the tumour to focus on the positive aspects of their lives. Having already lived through so many difficult experiences and with so much uncertainty in their future, it is not surprising that maintaining a positive focus required a focus on the present. Parents referred to accepting the way things were, taking it “day by day,” trying not to think about the way things used to be, or the “what if’s” that lay in the past or the future. Asked what advice she’d share with other parents, Nancy replied, “just take one day at a time, I don’t plan too far ahead. That’s all I can say, try to have a positive attitude even when everything feels like the world’s coming down on you, but just try and make the most of it.”

In order to counterbalance grief by working towards and revelling in survival, children and parents maintained a positive focus by: having faith, using positivity to fight the illness, being resilient, and distracting themselves from stress and grief.

Having Faith. The vast majority of families expressed their faith in a positive outcome, although some hopes were tenuous while others were unwavering. Several children and parents described their faith in a god, hope for a miracle and praying. After a particularly moving experience with a healer, Carter, a 14 year old expressed, “I now think that there is something, I don’t know what, a god, something though, that does cure people.” Other parents spoke about their faith in the physicians’ abilities to treat the child, while some seemed to want to cover their bases, investing hope in a variety of sources, as Sharon described:

I think it’s a combination probably of everything, I think it’s having awesome surgeons that know what they’re doing and that are willing to do this kind of thing, and God overlooking everything at the same time, y’know, making sure that he has a steady hand or whatever. All these kinds of things, the doctors

themselves with the research with the medicine, and I think a lot of it is positive attitude.

For some, the source of the cure was not specified; their faith was focused on the child's recovery. Children described the reassurance of hearing from others, and having faith in their own abilities to fight the illness, endure treatment, and eventually recover. As Jordan expressed, "even if you feel like you can't keep on going, keep trying... You just keep thinking in your mind that you can do it, and you just keep thinking it."

Every parent expressed their belief that the child would recover, although the degrees of confidence varied for different parents at different points along the trajectory of the child's illness. As Carmen explained: "I get scared when he gets sick, when he's physically weak or when he's admitted or they're going through whatever, like any other parent I would. But basically it's like I just believe that with all these impossible things happening around us, something good has to come out of it, that it can't all be for nothing."

Fighting Illness with Positivity. A number of parents shared their belief that "being positive" would strengthen their child's physical and emotional abilities to fight the tumour. With this perspective, parents were able to take on an active role in combating the disease by encouraging their child and creating a positive environment conducive to healing. As Alison explained:

I think as parents your job is to be as positive as possible, try and make the experience interesting and make it an opportunity which sounds really ridiculous...but I mean as my sister and I used to say to Casey when we'd do sleepovers in the hospital, "We're putting the crazy-fun back into cancer"... that sort of helped, I think, her attitude which I think, which I personally believe is, has a huge influence on how people heal.

Similarly, Nuhan expressed her concerns about emotional stress weakening her daughter's immune system allowing the tumour to "spread more and she can't fight it." To this end, parents sometimes avoided sharing information with their children in an effort to help them, as Sandra explained, "the less he knows the more he's gonna just get better because he's not gonna be burdened with the knowledge that he has this serious illness."

Being Resilient. Although it was the children who demonstrated resilience, it was their parents who recognized and admired it. Resilience was manifest in children's strength in enduring physical symptoms and invasive procedures, "bouncing back" from bouts of illness, maintaining a positive outlook, and for some, a sense of humour throughout their ordeals. These qualities in their children were inspiring for parents, as Nuhan admired:

She's very strong and she's very, very brave. She sometimes gets very sick from chemo but she never complain 'cause sometimes she doesn't want to go to the hospital, she says "I'm ok, I'm not sick"... but she fights, she doesn't want to be sick. That's why we get strength from them and they get strength from us.

Distraction from Stress and Grief. At times, parents and children both sought distraction from distressing thoughts and feelings. Some parents found that their jobs served this purpose, while others described being too distracted by concerns about the child and family to be able to function at work. Other parents found it helpful to talk with friends and family about "regular stuff," and clearly, many were distracted from their own thoughts and feelings by focusing on being present and supportive for their child.

Children, on the other hand, used play as their primary source of distraction, both at home and in the hospital. They described being able to keep their minds off of an upcoming procedure by playing and being with friends, at school or in extra-curricular activities. On the day of the

procedure, a few children identified that they began to worry when they were in the waiting room, and would try to be distracted by playing with siblings.

Parents helped to distract their children during procedures by talking with them about things they looked forward to, and in one case, a mother wore perfume to distract her son from the smell of the medication that he disliked. During clinic visits and inpatient stays, children appreciated programs run by Child Life staff and volunteers, enjoying the company as well as the activities. Andrew valued opportunities like this, “‘cause it doesn’t make me feel bored,” while Carter found that they helped to “keep your mind off of what, like ‘what if?’ and all that, and like, ‘Oh no, I’m getting chemo.’ You just sorta keep your mind off that.”

Main Category #3: Missing Normal Life

At the intersection of “Grief” and “Normal Life,” the main category labelled “Missing Normal Life” refers to children’s and parents’ experiences of losses in their lives and relationships that are the result of the tumour and its treatment. At times participants expressed grief about the child being changed by the experience, the effects on the family, as well as their present and imagined future life together. While some participants seemed to make every effort and wished for things to “go back to normal,” others, like Lisa, had a different perspective:

It affects your entire family and your life and there’s no going back after that, y’know, ‘cause it’s always a constant concern... it’s never gonna be the same way again, ever.... There’s so many risks that come along with all of the treatments that they do, so it’s, even if they survive, years down the road, y’know, they could get secondary cancers, so many different things can

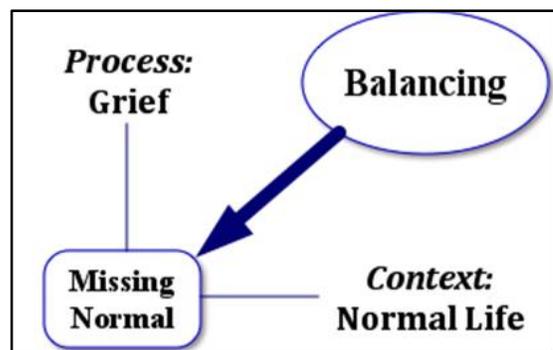


Figure 4. Missing Normal Life, at the intersection of Grief and Normal Life

happen. So I don't think, I don't think you should try to go back to the way it was, 'cause it won't be the same.

To organize participants' reflections about the grief related to the child, the family life that they had once had, and loss of the future they'd envisioned, two subcategories were identified, "Missing Feeling 'Normal'" and "Missing Doing 'Normal'."

Subcategory #3a: Missing Feeling Normal

Children expressed their longing to feel normal in their desire for others to treat them the way that they used to, and their wish for relief from the symptoms and effects of the tumour and treatment. Children who had been diagnosed years earlier, and had relatively fewer memories of life before the tumour, wished to be "like everybody else," particularly if they suffered from visible side effects. Andrew expressed, "my other friends that doesn't have a tumour, only I have [one] and I feel sad 'cause I wish I was like them." Closely interwoven themes within this subcategory included: living with the effects of the tumour and treatments; straining relationships; and seeking a sense of belonging with other sick children and their families.

Living with the Effects of the Tumour and Treatments. Children and parents identified a number of symptoms and side effects that interfered with children's abilities to feel or look like themselves. All but one of the children struggled with losing their hair, which caused them varying degrees of discomfort. Whereas their hair eventually grew back, some of the children suffered from other terrible, long-lasting effects. For example, Andrew felt deeply self-conscious of a facial twitch, Davon had left-sided weakness and Melanie had speech and coordination problems. In some instances it was the symptoms in and of themselves that children struggled with; more often, it was the way that children were treated by others as a result of their symptoms.

A few parents described the burdens they faced caring for their children; for Nuhan this burden was not only carried by her, but also by her son who looked out for his younger sister:

Before he complain “Mom, come help her,” I said “No, you have to help her, if I get sick who will help her? You.” I told him, like, he grow up with understand why we give Davon more... why I spend the whole time, whole day in the hospital with her and I send him to babysitter or to friend or whatever, because he has to know: I love him as I love her but she needs me more ‘cause she’s sick and he grow up with that and he understand and he help her and he loves her so much.

Straining Relationships. As the experience of childhood illness affected every family member, it is not surprising that their relationships were often strained by their separation, varying reactions and needs, and being treated differently by others than they had been in the past. Feeling “different” in their interactions with others was a primary component of “missing feeling normal” for both children and parents.

Separation from family was extremely difficult, whether it was during the child’s hospitalization while siblings remained at home being cared for by extended family and friends, or when a child was separated from parents during a procedure, surgery or in an ambulance. In both scenarios parents described feeling helpless and guilty about being unable to support their children, while the children described feeling alone and afraid. Andrew remembered a procedure: “they put me in the suite and I needed to go in there alone... [I was] sad, and I cried for my mom, lots.” Grieving the division of her family over her eleven-month course of treatment, Abbie expressed, “it’s been kind of bad because, we, we haven’t really been together in so long so it’s kinda like hard.”

Siblings also suffered greatly during the separation, with parents describing them as feeling sad, worried about the ill child, as well as angry and jealous about the imbalance in attention and concern. Alison recalled her daughter expressing, “it’s hard because there’s three kids in this

family and it feels like everybody's forgotten two of us." Parents were deeply concerned about their emotional well-being, maintaining as much contact as was possible by phone and with frequent visits.

Two mothers were divorced from their husbands, with their children spending the majority of time with them, visiting their fathers regularly. These arrangements added a layer of complexity to the separation during hospitalization; as their mothers were always present at the hospital, visits with their fathers meant children were navigating the tension of their parents' conflict. As Jordan expressed, "my dad, he's a little, much harder... I don't actually really talk to [him] about my stuff because he fights with my mum a lot and my mum's always with me so I don't want him to come and fight." Their mothers perceived that the limited time these fathers had with their children, and both daughters' tendencies to avoid talking about their illness with their fathers, perpetuated a cycle in which the fathers did not recognize the severity of the illness, or how much their children needed their presence and support. Alison described the range of ways that these circumstances strained their family's relationships:

Her dad has not been here for the majority of the treatment and because she is so much better than she was prior to the diagnosis, there doesn't seem to be a depth of an understanding as to the seriousness and the risks that come with treatment, the vulnerabilities, the immunity, suppressed immunity, etc., etc. So I would say that's been probably the hardest thing, when my daughter doesn't want me to know that her dad took her to the mall because she knows he shouldn't have done that.... I know a lot of married couples end up divorcing over situations like this so it would be unreasonable to expect people who already are not together, it wouldn't bring us closer.

Divorced couples were not the only ones whose relationships were strained by the stress of

the illness and their differing perspectives and reactions. Two mothers described themselves as being more worried about the severity of the illness than their husbands were, including Karen who described negotiating with her husband about their son's extra-curricular activities: "My husband is very focused, he said, 'Well, if he's got such talent we've gotta push him to do this.' So I said, 'Well, I don't know if this year is the time to push'.... He doesn't like to think of the potentials of what could go wrong."

Relationships with their peers were crucial for children, representing potential sources of support or stress. Children who suffered with visible effects of their tumours wished desperately to be treated normally, as they were frequently excluded and bullied, adding heartbreaking insult to injury. Melanie remembered: "At camp I got bullied twice for no reason, and I don't know if it's because there's a rumour about me, like somebody said I was not normal." For the others, being bullied or excluded was a regular occurrence, as Davon explained, "When I want to play with someone they kind of make fun of me and stuff like that... In front of the teachers they would tend to be nice but then they come and say, 'you're slow,' and they bully me... I think it's gonna be like that forever, probably."

Enduring this kind of repeated bullying led a few children to be reluctant to participate in social activities or meet new children, expecting that it would be one more opportunity to be treated poorly. These situations were heartbreaking for parents to see their children go through, as Nuhan expressed: "they get hurt not from the sickness, [but] from what the people are asking them or how they act with them. This is the important thing, how the people treat them."

Seeking a Sense of Belonging with Other Sick Children and Families. Although many families had made connections with others at the hospital or Ronald McDonald House, children who did not have extended hospital stays had fewer opportunities to connect with other families.

Both children and their parents expressed their longing to feel understood, as Carter

imagined, “they’re in the same situation so they know exactly how you feel.” His mother described her similar wish to be able to relate, saying, “I’ve often thought it would be nice to connect with other kids or families to have, just, y’know, discussions and go ‘Oh yeah that happens with us’.”

Despite this longing for commonality, it did not always emerge in settings where it was anticipated. In spite of having attended a number of groups and meeting other families at the Ronald McDonald House, Alison continued to feel different from the other parents she met: “I remember saying to somebody, like, ‘Please tell me we are not the only divorced parents of a kid with cancer.’ Like that just, logically that does not make sense right? But I will say I have yet to meet any.”

Further, some children and parents were reluctant to connect with others. Besides the children who expected to be treated poorly based on past experience, a few others expressed that they would rather spend time with friends from school, perhaps reflecting a preference to do what felt normal rather than defining themselves as “sick” or “different.” Several parents also chose not to attend support groups that were available to them, occasionally because they didn’t feel their children were “sick enough,” as Sandra illustrated: “I almost feel guilty that my son is as lucky as he has been, so y’know, for me to go to, like, a support group or something, I almost feel like I don’t belong.” As was the case with children’s and parents’ perceptions of being “lucky,” these feelings of guilt did not coincide with less malignant illness, highlighting the subjectivity of participants’ perceptions and coping strategies. Elizabeth shared a different perspective: “I’ve got enough to deal with and I don’t really wanna know everyone else’s sad story.”

Subcategory #3b: Missing Doing Normal

Children struggled with being unable to do the “normal stuff” they had previously been able to do, either because they were too tired or ill to participate, or because of necessary

precautions related to potential infections or head injuries. Being unable to do “normal stuff” interfered with children feeling normal, and the less they felt normal, the more they craved and missed those familiar activities and environments, perpetuating a vicious cycle. Parents’ activities and lifestyles were also profoundly shaped by the child’s illness, forcing them to make difficult decisions and sacrifices. Within this subcategory were three closely knit themes: missing familiarity; limiting activities; and making sacrifices.

Missing Familiarity. For some children this was as simple as missing their own shower or their own bed while they were “stuck” in the hospital. They missed their family and friends, their pets, their privacy and their “stuff.” Many children identified how difficult it was to be away from home, and how difficult it was to spend so much time waiting at the hospital. As Andrew emphatically explained: “I hate being here ‘cause it’s very boring waiting. Waiting is the boringest thing ever... I hate when I have to stay in the ward, even just for a day or an hour or two hours or five... it’s boring, so boring, there’s nothing there, everything’s different at home.”

Limiting activities. The children’s participation in regular activities was significantly impeded by the tumour and treatment. Upon learning of the diagnosis a couple of families cancelled trips in order to remain in close proximity to the hospital in case the child had a seizure or other side effects. While they were hospitalized or being treated in clinic, their school schedules were disrupted; as Henley recalled, “[I] really like school, sometimes I missed a lot of school, like, in the morning, ‘cause I had to go and get my brain tapped.”

Besides the logistical interference, children had to miss school, avoid parties, malls and other group activities if their immune systems were compromised. Elizabeth explained that it wasn’t the illness itself that bothered her son, rather: “the things that upset him are, like, he wants to have a sleepover with his friends and [I] said “Ok, well we gotta figure that out because of the, y’know, the hygiene protocols and things like that.” So he’ll get upset about if he’s missing

something.” For some parents, there was guilt associated with imposing these necessary limitations, as Karen expressed, “I really get frustrated when I myself don’t like having to place limitations on him, but I have to.”

Their increased vulnerability to head injuries necessarily restricted children’s participation in contact sports, while at times, fatigue limited physical exercise in general. Asked how she dealt with having so many limitations imposed on her activities, Morgan replied, “I just live with it.”

Making sacrifices. In order to be present and able to support their children through the treatment process, many parents had to make significant sacrifices, affecting their day-to-day lives. Most commonly, parents had to quit their jobs, take extended leaves or reduce the number of hours that they worked. After having to leave her job, Ashley worried about her future job search, expressing her fear, “I won’t be able to find one that would allow me to be off, like, every second Friday and if his blood counts are down... I won’t be a reliable employee.” Parents also sacrificed their social lives, as Nuhan described, “she’s home sick like this, we don’t go anywhere because Davon doesn’t feel good. We don’t have friends because she’s not good... we live with that, like our life depends on her, that time when she’s in chemo. Now she is living for us.”

A couple of parents made physical sacrifices to demonstrate their support to their children: Henley’s parents got tattoos which she described as being “very nice,” relating the pain of the tattoo needles to the treatments she had endured; Jordan shaved her mother’s head as part of a fundraiser. Lisa explained, “it’s very strange now because now everybody’s staring at me it’s like “Oh this is what Jordan always feels like,” y’know, it’s kinda like, well it’s eye opening... She kinda giggles now because “aha, they’re staring at you!””

Main Category #4: Redefining Normal Life

Where the process of “Survival” and context of “Normal Life” coincide, lies the main category “Redefining Normal Life.” This category is populated by the many ways that children and

parents adapt to life with the child’s tumour, and choose to define the child and their changing lives as normal. Some

children and parents talked about finding a “new normal” while others made every effort to “keep things normal”; in either case, these efforts were perceived as helping the whole family to cope, individually and together.

While some children expressed the wish to feel normal, others explained that they didn’t feel any different than they had prior to their diagnosis; it was merely that their circumstances and routines had changed. Sharon recalled her daughter saying, “I can’t wait to be normal again,” and then she stopped herself and she said, ‘Oh,’ she said, ‘No, I am normal,’ she said ‘I just need more medicine.’” Regardless, all children appreciated normalcy. Eleven-year-old Mitchell explained that spending time with friends, participating in activities and school “helps you feel normal,” which was important “so you don’t feel different... so they think you can do what everybody else does.”

This category includes two subcategories: “Adapting Normal,” and “Maintaining Normal.” By employing the strategies within these subcategories, children and parents shifted the balance away from grieving the loss of the lives they once had, and towards surviving, shaping and appreciating their lives together in new ways.

Subcategory #4a: Adapting Normal

Recognizing that their lives were undeniably and irreversibly changed, children and parents were forced to adapt. At times they did so by expanding their definition of “normal,” and other

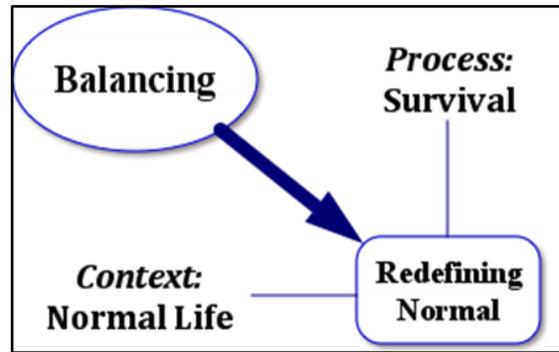


Figure 5. Redefining Normal Life, at the intersection of Survival and Normal Life

times, by adapting their perspectives, routines and in many ways, themselves, to their “new normal.” Nancy reflected on her experience of adapting to the challenges that the tumour brought:

You don’t think about things you just have to do it. Some people wonder how you manage and how you get along with life; well, you don’t have a choice. You know, some people say, “I don’t know, like, I don’t think I could ever do it.” Well until you’re in that position... I guess it’s true you can conquer anything right? If you have to. And when it’s your child, you’ll do anything.

Three themes were woven throughout the ways that children and parents described “Adapting Normal”: getting “used to it”; changing perspectives and priorities; and being supported.

Getting "Used to It." Although there were some elements of the illness and treatment that never got easier, children and parents described getting “used to” the routine and becoming familiar with the hospital and the staff. As Morgan expressed, “I’m not afraid no more... I almost feel like family now ‘cause I’ve been here plenty of times.” With time and experience, pre-procedural anxiety began to lessen, and children and parents became more comfortable talking with others about their experiences.

A number of programs and activities were recognized as helping children feel more comfortable in the hospital and to focus on play and normal activities. These included Child Life staff and volunteers; therapeutic clowns; visits from specially trained dogs; as well as group activities including games and art in supervised playrooms. Televisions and videogames that were available to children during procedures or in waiting rooms also helped them to feel “less bored” and more comfortable with all that was going on. One child seemed to normalize procedures with her nonchalant attitude, as her mother recalled, “she walked in to the operating room and hopped up on to the operating table and looked at her neuro-surgeon and went, ‘Can you hurry this up? I

wanna go to Disney World.’ Then she lied down and that was that.”

Several parents described trying to “make the most of it” when they came to the hospital. For some, this meant rewarding their children with ice cream or a new toy following a difficult procedure. For others, it was about shifting the focus of their time away from the illness and towards enjoyable activities. As Karen explained:

It always used to be an adventure and I sort of tried to make it not medical, I tried to make it fun... sometimes we’d stay at the Delta Chelsea so then it was her and I, it was an overnight, it was, we went and had fun in the game room, we swam, y’know, it wasn’t just about the medical stuff so that memories of this, isn’t just all medical.

For a couple of children, having friends who had cancer helped to normalize their experiences, making them easier to get “used to.” They could share experiences and validation, and as one child suggested, they could use humour when talking about the illness, which others may not have understood. Nuhan explained that she and her daughter felt accepted and normal within the hospital whereas outside the hospital, people stared and treated them differently: “People look around [at] her weakness, like her sickness, they don’t know about the tumour, they know about, they saw her from outside, and now, you know, in the hospital nobody can ask anyone because everyone knows that they are ill or they have something.”

Changing Perspectives and Priorities. Given the life-changing nature of a childhood brain tumour, it is not surprising that children and parents described a number of ways that their perspectives and priorities were shaped by what they went through. The most common way that children’s and parents’ perspectives changed was in recognizing and valuing the family’s strength and capacity to support one another. As Casey explained, “I think it made us all not as scared for the things that happen all of a sudden.... Because this one was an all of a sudden thing and [we]

even got through it so if there is another all of a sudden thing we can get through that one too.”

Similarly, parents described appreciating their children even more than they had before, which came hand-in-hand with the recognition of the fragility of life. Sharon expressed how her perspective evolved from her initial grief at the time of diagnosis, to her focus on survival and enjoying life with her daughter:

I think when we first heard everything I was mad of course, and kept thinking like, “well I wanna know like if it’s two months, if it’s three months if it’s a year, if it’s whatever,” I wanted some sort of a time line, like, if it’s not gonna work out and stuff. Then I started thinking other ways and so I’m like, “well you know what, people die in car accidents,” y’know whatever, all kinds of unknown things just all of a sudden happen and you don’t know, and you don’t plan, obviously, for anything like that, and so I’m like, if anything, at least we had, in the back of your minds, we have that, to like, appreciate Henley more than we did before.

As a result of their new outlooks, many children and parents described choosing to spend more time with their family, often opting out of social or work-related opportunities in order to be together. A couple of parents described their realization that they were willing to do anything to help their children, which led them to become fierce advocates, and to learn to accept help. Several parents described their children as having developed maturity and resilience through the experience, and one mother expressed sharing a deepened faith in God with her son.

Throughout the interviews, children and parents expressed their determination to help others in similar situations. Many parents cited their reason for participating in this study as wishing to make it easier for other families than it had been for them. Children frequently mentioned the importance of making friends with other children who were sick as a means of

supporting them. Carter explained that if he could look into the future, he would “want to know who has brain tumours and who’s going through the stuff so that I can help them with it and talk to them about it.” Similarly, parents described going out of their way to share information and resources with other families.

Several children and parents described their newfound dedication to raising awareness and funds for research and to support other families of children with brain tumours. Two mothers shaved their own heads, while others participated in walks or started their own fundraisers. A few children’s friends had asked for money for their birthdays and donated them all to a brain tumour support network or had participated in fundraisers in their friends’ names.

Being Supported. Children and parents relied heavily on support from their immediate and extended families in order to adapt and meet the demands of life with a brain tumour. Many described family relationships being strengthened throughout the ordeals they endured together, learning that they could count on one another and work together as a team. Children looked to their parents for encouragement, helping them to understand, to advocate on their behalf, and to help them cope with any of the myriad difficult situations they faced. When asked what advice she had for other children, Jordan suggested, “if you’re having a hard time with something or you’re thinking about something and you don’t really want to do it but you pretty much have to, then you should talk to your parents about that so they can help you.”

Many of the children and their parents identified siblings as crucial sources of support, with even younger siblings wanting to understand as much as they could about what was happening and to be helpful. In spite of the jealousy or frustration that some siblings felt, they took on extra responsibilities at home or at school on the ill child’s behalf. A three year old would comfort her brother when he felt ill; a ten year old wrote, and was in the process of publishing a story about her sister’s journey; and an eighteen year old had occasionally been the one to bring

his younger brother to clinic appointments. Parents were careful to appreciate these efforts and to avoid “overshadowing the other kids... you have to keep a balance within the family.”

Parents expressed their deep gratitude for the support their own families and in-laws had provided, helping to care for the siblings at home and visiting in the hospital. A number of parents also described “learning who our real friends are,” and being amazed at the support that some friends, colleagues and community members provided, including emotional and practical support. For many of these parents, the depth and breadth of support was overwhelming and absolutely crucial in order to meet the demands that the tumour had imposed, but accepting help did not come easily to everyone. As Karen illustrated:

We’ve been lucky, we’ve got a huge support system and a lot of friends and family have been really, really great... Accepting other people’s help, like I know my husband has a harder time with that than I do, y’know, just be gracious and say, “thanks for this.” It makes life easier right now. Don’t worry, it’s not something to worry about paying them back... accepting help when it’s offered and not feeling that you can do it by yourself.

Some of the children felt supported by their friends from school, explaining that the children they chose to tell had been understanding, encouraging and supportive, which they demonstrated by making cards, fundraising and by treating them normally. Those who talked about making friends with other sick children, generally did so in order to be helpful rather than seeking support, however Jordan described one of the benefits of meeting other children at the hospital: “Kids here... like if they ask me what’s going on with me I’m fine to tell them because they would understand and not make fun because they are dealing with almost the same thing.”

Connecting with families of sick children was invaluable for some parents as well. Staying for almost a year at the Ronald McDonald House with her husband and two children at home,

Darla explained, “you become a family, or a family away from home.” Parents shared their experiences, learned what to expect and what questions to ask their physicians, and gained hope from one another’s successes. A few parents stated that they’d kept in touch with others by phone, email and via a FaceBook group for mothers of children with cancer at SickKids Hospital. Lisa highlighted the importance of these relationships when she explained, “your friends, they don’t understand and they start whining and complaining about their kids because they’re just acting up for the day and stuff and it’s like, y’know, parents of kids with cancer don’t do stuff like that.”

Another vital source of support for children and parents was the team of health care professionals they met at the hospital. Although some parents had had negative experiences, they described those as anomalies. With regards to the vast majority of their interactions with health care providers, parents spoke with admiration and gratitude about their skills, ability to explain medical concepts clearly and without condescension, and their willingness to help and answer questions. Sandra remembered receiving the diagnosis: “that was the worst possible thing I could hear, but... everything was handled really well.”

Parents recalled turning to social workers and interlink nurses [hospital / community liaison] for guidance and assistance in talking with their child and family members about the illness, supporting the child’s return to school, and accessing financial and psychosocial resources. Children were grateful for the interlink nurses visits to their schools to explain their illness and treatments to their peers. They also clearly recalled asking physicians about their tumours and treatment, and appreciated their explanations and use of child-friendly teaching aids. Notably, children and parents greatly appreciated the care they received from health care team members and the relationships they developed. As Nuhan expressed:

I found the doctors very patient because I was very stubborn to give my daughter the medication... but they explain to me, they give me time, they

handle what I'm saying... they know I can trust them, but they know how much I scared and I worry about my daughter, and they understand that, this is amazing... [The doctor] never say, "No, we are the best, we know better," no he never say that. He's so open, he's so patient, he's very human. When he saw my daughter from far, he go "Davon!" and give her a hug, he asking about me, sometimes she doesn't have appointment with him, he just saw her in play area and he came to her, and I know how much he's busy, and how much he gets something in his plate but he always gives kids time.... I know how much he care about her and all of them.

Subcategory 4b: Maintaining Normal

While the children's tumours triggered many changes for their families to adapt to, there were other aspects of their lives that they were able to continue as they had before. These were cherished opportunities for children and parents to maintain familiarity and consistency. Taking advantage of these opportunities helped them to balance their grief over the impact of the tumour on their lives, shifting their focus towards persevering in spite of it. As Carter expressed, "It's a big deal, but then it's not at the same time because you can still live your life more or less normally." Within this subcategory, two themes were distinguished: treating the child normally, and doing normal stuff.

Treating the Child Normally. Parents often referred to their children as "just a normal kid." They consistently expressed the importance of treating the child normally, in order to remind them of their important role within the family, capacity to participate and contribute, and maintain family norms and routines. Elizabeth explained, "we're keeping things as normal as possible and make him do as much as he is capable of doing and not let him get away with things I wouldn't let him get away with ordinarily. You know, still have expectations." These expectations were also

helpful for siblings who were often struggling with feelings of jealousy, loneliness and neglect because of the attention the ill child was receiving.

Children also expressed the importance of being treated normally by others, particularly their peers. Even children whose classmates were nicer to them following their diagnoses wished to be treated normally, stressing that they were the same person they had been before and wanted to be treated that way. When asked what would be the most helpful thing that others could do to support a child with a brain tumour, Carter suggested, “just treat them like a normal person, and then be open if they wanna talk about it, but don’t force them to.”

Doing Normal Stuff. Children longed to participate in normal activities, while they were in treatment and upon their return home. School was frequently mentioned, given the presence of their peers and the familiar routines that provided comfort and support. At times, children and parents had differing perspectives; Alison described wanting her daughter to attend the academic program at the Ronald McDonald House, but her daughter was reluctant, with both of them driven by a desire for normalcy:

Basically her reason was, “I don’t wanna go, ‘cause I don’t wanna feel any more different, because it means I’m going to school not with my friends,” and also “I don’t wanna go because that is more of a commitment to being at Ronald MacDonald House versus being in my own home.” Like they all made sense, but then I came back with, “You need something that’s normal and going to school’s normal.”

Some children went back to school in the afternoons following morning clinic visits, or attended even when they felt ill, because of how badly they wanted to participate in social and extra-curricular activities. Parents and children also benefited from participating in sports and groups such as “Brownies,” or everyday activities like shopping or attending church. When asked

what advice he'd share with others about how to cope with having a brain tumour, Carter suggested, "Just, sorta like, ignore it in your regular life. Like, not 'ignore it and don't do anything about it,' but when you're not in the hospital, keep going to the extent that you can, like with your regular life."

Discussion

In this study, the perspectives provided by children and their parents begin to shed light on the complexity of living with a childhood brain tumour. Previous research has explored specific elements of families' experiences of childhood cancer, including uncertainty, optimism, and the creation of a "new normal." However, none of these elements exist in isolation, and there is surprisingly little discussion in the literature about how they interact, or how these interactions appear when using a lens of grief.

While these gaps exist in the vast literature regarding childhood cancer, they are all the more glaring in the limited research focused on families of children with brain tumours, in which the voices of the children are notably absent. As a result, the literature reviewed in this paper primarily describes studies of children with cancer; furthermore, eight of these studies focused solely on the parents' experiences. In contrast, Stewart (2003) focused exclusively on the child's perspective, as did Zebrack et al. (2012), however the latter study was retrospective, examining survey responses from survivors, some of whom were more than 20 years post-treatment. Only four studies attempted to capture a comprehensive view of the family experience of childhood cancer, incorporating interviews with parents, ill children and healthy siblings, with the samples in three of these studies including between three and seven ill children (Bjork et al., 2005; Clarke-Steffen, 1993; McGrath et al., 2004). A remarkable exception, Woodgate and Degner (2003) interviewed 39 children and their family members, and conducted many hours of observation, which provided rich descriptions and incredible insights into the experiences of individuals and

families living with childhood cancer.

Research exploring the lived experiences of children with brain tumours and their parents is scarce, with psychosocial studies of this population being focused instead on the various impacts of the tumour and children's adjustment, including physical, cognitive, emotional, social, academic domains, and their health-related quality of life (For a review, see Fuemmeler, Elkin & Mullins, 2002). As these studies rely primarily on assessments of the children's function rather than their descriptions of their experiences, they were not the focus of this review. Instead, four studies that explored aspects of the experience of living with a childhood brain tumour were included, however these researchers relied entirely on parental reports (Deatrack et al., 2009; Forinder & Norberg, 2010; Jackson et al., 2007; Vance et al., 2004).

The present study was intended to address these significant gaps, particularly the absence of voices of children with brain tumours, and the scarcity of descriptions of living with a childhood brain tumour. By interviewing both children with brain tumours and their parents, not only could each of their experiences be explored, but insights were gained into those aspects that were shared among family members and those that were experienced differently by each person. The stories and insights shared by children and parents in this study have begun to shed light on the complexities of their experiences, illustrating and integrating the range of challenges they face and their coping strategies.

The substantive theory of balancing grief and survival is grounded in participants' experiences, and conceptualizes living with a brain tumour as a dynamic process in which children and parents strive to cope with, and overcome losses they've lived and feared by focusing on positivity and living a normal life. This theory draws on the fundamental principles of the Dual Process Model of Coping with Bereavement (DPM), emphasizing the dynamic process of

oscillation between loss- and restoration-oriented stressors, thoughts and feelings (Stroebe & Schut, 1999).

Whereas the DPM refers to the “Loss Orientation” and “Restoration Orientation,” the model presented in this paper includes parallel processes of “Grieving” and “Surviving.” Both models describe reactions to loss that elicit profound grief, while recognizing that humans continue to move forward in the face of said grief, focusing on the future and striving to adapt. Both models recognize these reactions as dynamic processes, wherein individuals alternate or oscillate between reflecting on the loss and rebuilding their lives, and between feelings of grief and hope. Moreover, in both models the process of balancing is believed to evolve with time and experience.

Although at their cores they are fundamentally similar, their applications vary in that the DPM refers to losses that have already occurred, while this model of “Balancing Grief and Survival” applies to losses that have occurred in the past, as well as those current and future opportunities that are perpetually threatened. Where the DPM’s “loss orientation” is focused around stressors, thoughts, feelings and memories about the death and the person who died, “Grieving” in this model is in response to losses experienced as a result of the tumour and treatment, as well as potential future losses threatened by the tumour and related interventions. The DPM’s “restoration orientation” describes stressors, plans and activities related to rebuilding life without the person who has died; whereas in this model, “Survival” refers to individuals’ efforts to reclaim aspects of their lives from the impacts of the illness, as well as to overcome or minimize its current and future physical, practical and psychological impacts.

The process of balancing grief and survival manifested itself in a variety of ways, with an alternating emphasis on grief and survival, varying in duration and intensity for each individual, and evolving with time and experience. This variation reflects the uniqueness of each family and

their paths to diagnoses and illness trajectories. However, all of their stories share common threads, many of which reflect themes that exist in the childhood cancer literature, highlighting the similarities between family experiences of brain tumours and other cancers.

Every child and parent experienced grief in the context of “Dealing with the Illness,” including when they learned of the diagnosis; suffered the physical, psychological and emotional impacts of treatments; and imagined all the possibilities that the tumour threatened. In the midst of these circumstances, parents and children described “Being on the Edge,” – i.e. primarily focused on what was happening, what was about to happen, or what they were afraid could or would happen. With each instance of new or worsening symptoms, hospitalizations or recurrences, their worries and grief were reinforced, consistent with earlier studies of parents of children with brain tumours (Forinder & Norberg, 2010; Vance et al., 2004), and Noojin et al.’s (1999) supposition that these repeated experiences cause mothers even more stress than the initial diagnosis.

Although both children and their parents experienced “Being On the Edge,” their experiences varied, likely in part because parents had access to more information about their children’s illness, treatments and associated risks, than what they chose to share with their children. Parents described their desires to protect their children from fear, to reassure them and help them maintain a positive outlook in order to strengthen them and their abilities to fight, and overcome their illnesses. To these ends, they were selective about the information they shared with their children, minimizing the severity of the illness, and avoiding discussion of potential risks, threats of progression and recurrence, and their child’s mortality; the same issues that caused parents the most fear and grief. As a result, the content and weight of parents’ worries differed from those of their children.

Parents’ uncertainty and worries about these threats bred feelings of helplessness, vulnerability, anxiety, fear and feeling overwhelmed, reflecting experiences reported by parents of

children with brain tumours (Deatrick et al., 2009; Forinder & Norberg, 2010; Vance et al. 2004), as well as families of children with other cancers (Bjork et al., 2005; Clarke-Steffen, 1993; Hildenbrand et al., 2011; McGrath et al., 2004; Patterson et al., 2004; Schweitzer et al., 2012; Zebrack et al., 2002).

Although the children's stories clearly illustrated instances of them "Being on the Edge," they spoke less about these experiences than their parents did, which was also noted by Clarke-Steffen (1993). Whereas Bjork et al. (2009) suggested that the children in their study did not appear to be as anxious as their parents, the current study suggests that their anxiety may have been as intense but more localized than their parents and with different foci. For example, children described being worried immediately, or a day prior to a procedure; before then, they were able to distract themselves from anxious thoughts. In some cases this may be partially explained by the fact that children were generally unaware of many of the potential risks; as a result their anxiety tended to focus on the procedure itself and associated discomforts, while parents worried about the outcomes and long-term implications.

When they were focused on the future, such as wondering whether and when their treatment and associated discomforts would end, children tended to express their worries to their parents who would respond with reassuring information and tone. The concrete and specific nature of these worries are consistent with Stewart's (2003) suggestion that many of the children's questions were based in their inability to predict what, when or if something was going to happen. Children in the present study rarely expressed worries about long-term risks and mortality; this may be partially attributable to their parents' efforts to shield them from this information, as was also reported by Clarke-Steffen (2007). As a result, the children may not have realized that these were risks that they could worry or seek reassurance about.

Besides their worries and uncertainty, "Being on the Edge" was manifest in children's and

parents' experiences of suffering leading up to diagnosis and through the treatment process. Their struggles in their initial search for help were reflected in Jackson et al.'s (2007) description of "difficulties in delays around diagnosis, misdiagnosis, [as well as] difficulty having symptoms recognized," as reported by parents of children with brain tumours (p. 97). These particular challenges have not been noted in the broader literature of childhood cancer, suggesting that the nature of some of the earliest brain tumour symptoms may be the source of this particular struggle.

Although children interviewed by Stewart (2003) described "getting used to" cancer treatment, Woodgate (2003) reported that children in her study refused to "get used to it" because it implied not only "becoming accustomed to the symptoms but also learning to like them" (p. 488). Insights shared by children in the current study suggest that they became accustomed to the routine of treatment, and that their anxiety related to repeated procedures decreased somewhat as they learned what to expect, but they did not learn to like the procedures or "get used to" the discomfort that they experienced.

For some children, bouts of illness, hospitalization or recurrences were relatively fewer and farther between, allowing greater opportunities for both children and parents to let their guards down, while others had their feelings of "Being on the Edge" reinforced more frequently. In each case, it took some time after the crisis had passed before children and parents were able to shift their focus towards survival by "Reclaiming Health." They could not have focused on survival as a means of avoiding "Being on the Edge." In fact, some of the parents highlighted the important functions of their vigilance and protectiveness in that state: they noticed changes, trusted their instincts and advocated for their children, in some cases saving their lives. Rather than avoiding "Being on the Edge," strategies described in the category "Reclaiming Health," including "Containing Illness" and "Focusing on the Positive," helped children and parents begin to balance their grief with survival only after the immediate threat had passed.

When they were ready to shift their focus to survival, children and parents often defined themselves as being “better off” than other families with sick children, and described themselves as “lucky” for a variety of reasons. Parents often expressed that things were “better than they could have been” in light of the worst-case scenarios they had envisioned early on, and the risks they had faced in the course of treatment. Having been shielded from the knowledge of many of these risks, children more often defined themselves as “lucky” based on visible differences they saw when comparing themselves with other children who looked “sicker” or had longer treatment protocols. Other researchers of childhood cancer have described these “better off” perspectives as: “appraisal-focused coping,” (Patterson et al. 2004, p. 401); “cognitive restructuring” as an “approach coping strategy” (Hildenbrand et al. 2011, p. 349); and ways of perceiving stressors so that they feel more manageable. Schweitzer et al. (2012) suggest that these perspectives help parents of children with cancer maintain a sense of groundedness.

Parents described their determination to “do everything” they could to help their children, including medical intervention and prayer. Previous research reports the same desire among families of children with brain tumours (Jackson et al. 2007) and other forms of cancer (Woodgate & Degner, 2003). Regarding medical treatment in particular, Stewart (2003) proposed, “after the crisis of a diagnosis with a life-threatening illness, pursuing a plan of treatment represents stability and order, and provides markers of one’s progress toward recovery.” (p. 404)

Marking progress was frequently reported by children and parents in the current study, as well as by children with other forms of cancer and their parents (Hildenbrand et al. 2011; Schweitzer et al. 2012). Woodgate (2003) suggests that marking the completion of “each event further helped children and their families to feel more certain that they could deal with or manage the cancer experience” (p. 113). Keeping track also helped them to know what to expect, which was endorsed by Hildenbrand et al. (2011) and Patterson et al. (2004), who suggest that these

efforts to plan ahead offered parents of children with cancer a sense of control.

In the current study, one of the most frequently reported strategies employed by children and their parents was focusing on the positive, including: having faith in god, medical treatment, and the child's strength and resilience; and keeping their minds off of their grief and uncertainty. Patterson et al. (2004) described these as "active behaviours that allow families to carry on and sustain their emotional energy," noting that these behaviours have been observed in the broader population of families of children with chronic illnesses as well. Based on her interviews with mothers of children with cancer, Fletcher (2011) defined these as efforts to find a "silver lining," while Bjork et al. (2005) framed them as strategies used by children and parents while "striving to survive" individually and as a family.

In addition to the grief that they felt in the context of "Dealing with the Illness," children and parents also grieved in the context of their "Normal Lives." The two contexts were intricately connected, as the illness was the cause of the changes to their "Normal Lives" and was ever-present. However, grief described in the category of "Being On the Edge" was driven by present suffering, risks and future threats, whereas the category "missing normal life" primarily refers to grief over losses that had already occurred, or that would occur as a result of those losses.

Although their experiences and struggles varied, every child and parent expressed grief related to losses in one aspect or another of their "Normal Lives", reflecting the consistent identification in the literature of disruptions to normal life as a result of childhood cancer and other chronic illnesses. Interestingly, the losses or strains most commonly expressed by participants in this study were related to relationships with family members and peers. Many of the parents and children in this study struggled with being apart from family members during hospitalization, and recognized this as a shared burden for those left at home, especially siblings. This was a common struggle for families of children with other cancers as well (Bjork et al., 2009; Hildenbrand et al.,

2011; McGrath et al., 2005; Patterson et al., 2004; Woodgate, 2005). Forinder and Norberg (2010) referred to “disparate coping strategies” as a potential source of stress among parents of children with brain tumours (p. 547); a strain identified by parents in the present study as well.

However the relationships that were most frequently reported by children as being strained by their illness and treatments, were those with their peers. Every child explicitly stated their wish to be treated normally, including a few who’d been treated better since their illness, several who’d been very secretive for fear of being treated differently, and several who were excluded or bullied as a result. Similarly, Forinder and Norberg (2010) reported that the majority of parents described their children as having lost most or all of their friends since their brain tumour diagnoses, while Vance et al. (2004) identified exclusion and bullying as sources of “much distress” for families; behavioural, cognitive or physical changes caused by the tumour were believed to have contributed to their peers’ behaviours. In contrast to the prominence this issue was given by children in this study, there is relatively little in the literature about the way that children are treated by others, beyond these two articles. Patterson et al. (2004) described children with cancer, based on their parents’ reports, not wanting to be “put on a pedestal,” while Hildenbrand et al. (2011) reported children being bullied because of visible scars.

Children’s engagement in normal activities were significantly impacted by the effects of the tumour and its treatment, either because they were not physically able to participate and had to avoid the risk of further injury, or because their peers excluded them based on their perceived differences. These differences included cognitive and motor impairments, hair loss, scars and the effects of strokes, which have been reported by children with brain tumours (Vance et al., 2004), but are rarely discussed in the broader literature on childhood cancer. Woodgate (2003) acknowledged that “changes that prevented the children from functioning as “complete” human beings [were] especially difficult to accept” (p. 484). However, Patterson et al. (2004) reported

that only 15.6% of parents identified losses of limbs, abilities or fertility as “cancer-related strains” (p. 395).

In addition to their detrimental impacts on peer relationships, functional changes also interfered with children’s abilities to participate in the normal activities they longed to return to, especially school, physical activities and social engagements. Reduced energy, avoiding risks of injury or infection were cited by children and their parents as reasons for limiting participation; these factors and the sadness, frustration and loneliness that children felt as a result have been reported among children with brain tumours (Vance et al. 2004) and children with other cancers (Bjork et al., 2009; Hildenbrand et al., 2011; McGrath et al., 2005; Patterson et al., 2004; Schweitzer et al., 2012).

Some of the children in this study described that they felt normal, with “Normal Life” being affected only during bouts of illness or hospitalizations; others suffered from lasting, visible effects of the tumour, and subsequently faced unrelenting struggles with peers. The latter group expressed the wish to be “just like everybody else,” and had fewer opportunities for respite in comfortable, familiar and enjoyable “Normal Life.” Parents generally endorsed their children’s perspectives, and longed for their own and their families’ lives to “go back to normal” or to establish a “new normal.” Regardless of their frequency or accessibility, opportunities to *feel* normal and *do* “normal stuff” were treasured by children and parents alike, helping them to balance their grief about the losses felt in the “Normal Life” with a focus on survival, redefining and re-immersing themselves in their lives beyond the illness. The importance of this process is reflected in Stewart’s (2003) assertion that normalcy is “a predominant goal for children facing life-threatening and chronic illnesses” (p. 404).

Children and parents adapted to their “new normal” as they became familiar with the treatment routine, and staff and programs. Similarly, McGrath (2004) identified that the “cancer

ward” was a “home base, a comfort zone” for families (p. 363) while their health care providers began to feel like family members (Patterson et al. 2003; Woodgate & Degner, 2003). Connecting with other children and parents while the child was hospitalized also helped them to adapt by feeling understood and supported. Fletcher (2011) observed the same benefits among mothers of children with cancer, while a parent of a child with AML explained, “We are all going through the same thing. And I find like we’ve made an instant family.” (McGrath et al., 2004, p. 363). However not all parents in the present study wanted to attend support groups, having mixed feelings about hearing others’ stories; Jackson et al. (2009) reported the same reluctance among some of the parents of children with brain tumours in their study.

The heartfelt gratitude children and parents expressed for the support they felt from family and friends (Woodgate & Degner, 2003), as well as their perceptions that the experience strengthened their relationships and brought them closer together (Deatrick et al. 2009; Patterson et al. 2003; Schweitzer et al. 2012) has been reflected in the literature on childhood cancer. The shifts that participants described in their perspectives and priorities have also been noted among families of children with cancer, including an increased appreciation for life (Fletcher 2011), choosing to spend cherished time as a family rather than working or socializing (Bjork 2009; Clarke-Steffen 1997; McGrath 2005) and wanting to “give back” by supporting other families and participating in fundraisers (Fletcher 2011; Patterson et al. 2003; Schweitzer et al. 2012).

Complementing their efforts to adapt to their “new normal,” children and parents strove to maintain normalcy by “doing normal.” Many of the strategies they employed have been reported by others, including maintaining routines and expectations of the child, returning to school, and parents resuming their employment (Bjork et al., 2005; Kars et al., 2008; Woodgate, 2006). Participating in activities and unstructured play with other children in the hospital have been endorsed by parents of children with brain tumours (Jackson et al. 2007) and those with other

types of cancer (Bjork, 2009).

Although each child and parent had a unique story and perspective, shaped by their personalities, relationships, histories and illness experiences, they all experienced grief in the contexts of the illness and their normal lives, described as “Being On the Edge” and “Missing Normal Life,” respectively. Each individual and family employed strategies to cope with these medical and emotional experiences, using strategies defined as “Reclaiming Health” and “Redefining Normal,” to balance their grief with a focus on survival. Grief was renewed with each instance or threat of illness, demanding more effort from the children and parents in order for them to find a comfortable equilibrium. Repeated struggles compounded the experience of grief, while time in between these bouts of illness allowed children and parents some respite, and opportunities to practice and strengthen their coping strategies and focus on survival.

When the crises had passed, at least temporarily, some children and parents embraced their “new normal,” making the most of their time at the hospital, and developing strong relationships and feelings of belonging with other families with sick children. Other children and parents invested their energy and focus on retaining what was familiar, including their routines and relationships with friends, relying on them for understanding and support. Whether they turned to old or new friends and routines, both groups of participants sought the same thing: to feel a sense of belonging, familiarity and, ultimately, normalcy.

Limitations

Limitations to this study must also be explored, primarily the under-representation of fathers in this sample. Despite efforts to include fathers, with one exception, those who were present when the study was introduced deferred to their wives to participate on their behalf. Fathers who were not present in the clinic when the study was introduced to families were invited to participate via their wives with whom this researcher was in contact. Nonetheless, there was

only one father who was willing to participate, and although his contribution was critical, it cannot be assumed that his experience reflects those of other fathers. Further study could focus on fathers' perspectives in order to begin to address this significant gap in the literature, and provide insight into the differences and similarities between mothers' and fathers' experiences.

An additional limitation in this study is that all of the children had recently been in treatment; as such, there were no participants who were in the midst of a crisis prior to receiving that treatment, nor were there children who were ineligible for curative treatment. Although it is conceivable that families in either of those circumstances would have been much less likely to want to participate, their perspectives on grief and normal life may well have been quite different than those of the participants.

That said, purposive sampling was carefully conducted to include children with a range of ages, diagnoses, malignancies, and at varying points along their illness trajectories. While some might consider this variety within the sample to be a limitation to the study's generalizability, in fact it was a strategic decision made in order to elicit a range of perspectives and to focus on the commonalities of the experiences of children with brain tumours and their parents.

Implications for Research and Clinical Practice

The wealth of experiences shared by children and parents in this study have contributed important new knowledge, which can inform future research and clinical practice. Most notably, the emotional experiences of children with cancer and their parents have not been explored in-depth using grief as a lens. Applying this lens has allowed for the collection of rich descriptions of participants' emotional responses at various points along children's illness trajectories. Drawing on the principles of the Dual Process Model has helped to conceive of a framework to apply to the complex and dynamic processes employed by children and parents to balance synchronous and complex emotions. In turn, this exercise suggests strategies to support their expression and

coping.

Although researchers have studied many elements of families' experiences of childhood cancer, the way that children and parents experience uncertainty, combined with optimism and the impacts on their normal lives, have not been explored, particularly in relation to grief. Thus, the substantive theory of grief and survival offers a new lens through which to understand and explore these aspects of living with a childhood brain tumour. The relevance of this theory to the broader population of children with cancer also merits exploration.

Children with brain tumours and their parents have been under-represented in the literature on childhood cancer, with children's voices largely absent. This study has contributed important new insights into the many commonalities between the two groups, and has highlighted some of the unique challenges expressed by children with brain tumours and their parents. In particular, as there is limited discussion of peer exclusion and bullying in children with other cancers, it is not known whether children with brain tumours suffer from these circumstances more than others. However, it is conceivable that a greater risk of observable differences would make children with brain tumours more likely to be victimized by their peers. Certainly, the children in this study who had the most visible effects were the ones who reported the poorest treatment by their peers.

If there is a greater probability of a child's cognitive, behavioural and physical function being affected by a brain tumour or its treatment than those risks associated with other childhood cancers, then the occurrence or threat of these impacts may contribute to a unique grief experience for children with brain tumours and their families. Fewer perceptions of positive impacts by brain tumour survivors than survivors of other childhood cancers (Zebrack et al., 2012), and fears expressed by parents about their children's abilities to live independent lives as long-term survivors of brain tumours (Bhat et al., 2005; Vance et al., 2004), suggest that this might be the case. Further exploration should be given to the relationships between functional changes and risks

associated with the tumour, the quality of children's peer relationships, and the grief experienced by children and parents, particularly given the significance of these issues for families.

Finally, this study focused explicitly on the importance of doing, feeling and being treated as normal, from the perspectives of children with brain tumours and their parents. Factors contributing to their sense of normalcy or difference were described; however, there remains more to understand. Future research could offer insight into how and why some children and parents decide to reach out to existing friends and strive to resume familiar routines and activities, while others seek support through new relationships with sick children and their parents, and become involved in new activities geared towards children with brain tumours and their families. These insights could help to shape support programs, and suggest who might benefit or be most interested in participating.

Participants' descriptions of their experiences suggest a number of implications for clinical practice supporting children and their parents who are dealing with uncertainty, striving for normalcy, or seeking peer support. First of all, clinicians should be aware of the intensity of the uncertainty that children and parents face, and the ways that it can manifest. Clear and accurate information about the tumour should be provided to children, ensuring they have repeated opportunities to ask questions, and to reassure them that although they have a tumour, there is nothing inherently "wrong with them." Anxiety related to upcoming procedures could be addressed with developmentally appropriate preparation and education, by teaching relaxation techniques to children and parents, and by encouraging them to bring activities with them to use as distractions while they wait.

Although some parents may want to shield their children from certain information, clinicians can talk with parents about the benefits of children having access to the information they need, and the common fears and misconceptions that arise when that access is not available. The

results of this study could inform training modules for clinicians who might engage in this type of education and advocacy with parents of children with brain tumours.

To assist families in gaining familiarity and maintaining a sense of normalcy, clinicians can help them to develop new routines, and create a sense of predictability for children by using calendars. To increase their comfort within the hospital, families can be encouraged to bring familiar items and normal activities from home, and should be informed about existing hospital and community-based programs that they can participate in. Finally, parents may need help determining which activities their child can participate in, and any accommodations that can or should be made, to maximize the child's opportunities while minimizing the risks of infection.

With regards to peer support, it is important to speak with each child and parent to find out their preferences and needs. For those who would like to connect with others, either in-person at the hospital, in a community setting or online, a list of available resources would be beneficial. However, it would be ideal to be able to discuss the range of peer support options with families in order to address any questions or concerns they may have.

An important consideration for clinical programming or research is to explore the potential for peer-support programs that could be delivered in the clinic waiting room, and on inpatient units, in order to help families connect with one another during their brief time at the hospital. With many families travelling considerable distances to the hospital, and typically not knowing other families in their communities who can relate to their experiences, online chats or Skype-based peer support groups could offer tremendous benefits. Participating from the comfort of their own homes, and without the pressure of being face-to-face, may be appealing to some children and parents who are more reluctant or anxious about participating in a support group. For single parents this may be especially valuable as it could minimize their need to arrange alternate child-care in order to attend a group.

Conclusion.

Although there is much more to learn, the perspectives shared by the children and parents who participated in this study have made a significant contribution to a foundation of knowledge about their complex experiences, as individuals and as a family, living with a childhood brain tumour. Their stories illustrated their experiences of grief over the losses they've suffered and those that they've feared, in the contexts of their normal lives and in dealing with the illness. They demonstrated their determination and capacities to balance their grief with a focus on surviving the tumour and its effects on their lives. They did so with positivity, strength and by coming together as a family and a community, supporting one another and adapting their outlooks and their lives to the demands and limitations that the tumour imposed.

The stories and insights shared by these children and parents have provided important pieces of a puzzle, helping to illustrate the ways that grief, uncertainty, optimism and normalcy coexist and interact. While the knowledge and theory gained in this study are grounded in experiences of childhood brain tumours, they may also be relevant and meaningful to a broader population of children with other serious illnesses. Most importantly, in keeping with their expressed wishes, the experiences, advice, and inspiration shared by these remarkable children and parents can guide future research, clinical interventions and support programs that will help other families receive the support that they need and the reassurance that they are not alone.

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Appendix A: Interview Guide – Parent Interview

“You are in this study because we want to learn more about how families talk about a child’s illness, and the ways that kids understand the information that is shared with them.”

Background of illness and impact on family

1. Could you tell me a bit about your child’s illness?
2. Could you tell me what that’s meant for you and your family?

Talking about the illness, in general

3. Can you tell me what aspects of his/her illness you have been able to talk about with your child?
4. What would you say are the hardest things to talk about with your child?
5. What do you think are the most important things to be able to talk about with your child?

Specific conversations or issues

6. I’d like you to think about a specific conversation you’ve had with your child about one of the topics you just described, and that you’d be comfortable for me to talk about with your child. Can you tell me what you remember about that conversation? (Possible probing questions: What was it like for you to talk about that with your child? How often do you and your child talk about that? OR Have you talked about that with your child again since your first conversation about it?)
 - a. How did you decide to talk with him/her about that?
 - b. Do you have a sense of how he/she understood that?
7. Is there anything that you haven’t yet been able to talk about with your child?
 - a. Do you think you will talk about that at some point? (Possible probing question: Can you tell me about why you haven’t talked about that up to this point?)

- b. Is there anything you would prefer not to talk about with your child? (Possible probing questions: too detailed / technical / emotional?)
- c. Is there anything that would help you, or that might open the door to have these conversations?

Talking with other siblings

- 8. (*If there are other siblings*) Are there any differences in the ways that you talk about illness with your child who is sick, compared with your other child(ren)?

(possible probing questions: maybe what you chose to talk about or how often or how it feels to talk with one child or the other?)

Advice for others

- 9. Is there anything that has helped you to talk with your child about his/her illness?
- 10. Is there anything that people need to know about parenting a child who has cancer?
- 11. Do you have any advice for other parents who have a child with cancer?

Appendix B: Interview Guide: Child Interview

“You are in this study because we want to learn more about how families talk about a child’s illness, and the ways that kids understand the information that is shared with them.”

Background of illness and meaning

1. Could you tell me a bit about your illness?
2. Could you tell me what that’s been like for you and your family?

Specific conversations

3. Your mom / dad mentioned that you’d talked about _____. Can you tell me what you remember about that conversation? *(if the child doesn’t remember that conversation)*
Maybe there’s another conversation you remember that we could talk about instead?

Communicating with family members about illness in general

4. What are some of the important things that you’ve talked about with your parent(s)?
5. Are there any important things that you’d like to talk about but you haven’t yet?
6. What are some of the things that are harder to talk about with your parent(s)?
7. Is there anything that would stop you from talking about that/those things?
8. Is there anything that would help make it easier to talk about your illness with your parents?

Social supports

9. Do you ever talk about your illness with your friends or other kids at the hospital?
10. Are there people or activities that help you to cope / deal / live with having cancer?

Advice

11. Is there anything you think that people need to know about being child who has cancer?
12. Do you have any advice for other kids with cancer?

Appendix C: Revised Interview Guide – Parent Interview

The parents I've met with have talked about a range of ways that the child's illness and treatments affected their own life, the child's life, and their whole family. Many of the parents and kids that I've spoken with have talked about "normal" – sometimes it's about doing stuff that feels "normal" or "keeping things normal" or wanting to "go back to normal." I'm hoping to learn more about the different meanings and importance of "normal" for children and families.

1. Can you tell me about any ways that "normal life" may have changed for you and your family since your child has been ill? Have there been any positive changes?
2. Have you found it helpful for you, your child or your family to continue to do familiar activities that feel "normal"? Why do you think this helps / doesn't help?
3. In some of my conversations with parents it sounded like there were times that they were grieving the changes to their "normal life" and other times that they were focusing on positive, or continuing to do "normal stuff".
 - a. Can you describe how this fits with or differs from your experience?

If the above description fits in some way:

- b. In your experience, do feelings of grief and positivity alternate back and forth or are there times that they occur together?
 - c. Looking back at the time since your child first became ill, have there been changes to the way that you experience grief and positivity? If so, can you describe them for me?
(*Probe: it sounded to me as though some parents felt mostly grief in the beginning, and then over time, more and more moments of positivity seemed to creep in. Could you describe how your experience has been similar or different than that?*)
 - d. What do you think might help to tip the scales from one (grief or positivity) to the other?

4. By focusing on this theme of “normal life,” are there important changes or experiences that I would be missing or misrepresenting? Could you please tell me about these?
5. A few parents I spoke with said they felt like they were “always on duty,” or “on the edge of drama” when their children were sick. Do you relate to those descriptions?

If the above description fits in some way:

- a. Can you describe how being “on the edge” might fit with, or be different than grief?
 - b. It sounded like some parents went back and forth between being “on the edge” on one hand, and something more comfortable, less worried, more reassured on the other. What words would you use to describe that other side?
 - c. Are those “on edge” feelings always present to some extent or do they come and go?
 - d. Can you tell me about anything that triggers these feelings, or anything that helps to calm them?
 - e. Looking back at the time since your child first became ill, have there been changes to the way that you experience these feelings of being “on the edge”?
6. Some parents talked about times that other people said things to them like, “I don’t know how you do it, I wouldn’t be able to handle it,” and they felt like, “you just do it.” Have you had experiences like that?

If “yes,”:

- a. Can you tell me more about it?
 - b. The piece about, “you just do it,” what would you call that? What would you say you’re “doing?”
7. Is there anything that you think about, or that you do, or that someone else does, that helps you to deal with your child having a tumour?
 8. If you could go back in time and talk to yourself right after you first found out about the

tumour, what would you want to tell yourself?

9. What advice do you have for other parents who have a child with a tumour?

10. Is there anything I haven't asked about that you think that I should know?

Appendix C: Revised Interview Guide – Child Interview

“You are in this study because we want to learn more about how families talk about a child’s illness, and deal with illness.”

The kids I’ve met with have talked about different ways that the illness and treatments have affected their lives, and their families. Some kids have talked a lot about “normal” – doing stuff that’s “normal,” being treated “normally,” and wanting to “go back to normal.” I’m hoping to learn more about the different meanings and importance of “normal.”

1. Can you tell me about any ways that you feel different since you’ve had a tumour?
2. Can you tell me about any ways that “normal life” has changed for you and your family?
Have there been any changes that feel like good changes?
3. Has it been helpful for you to keep doing things that feel “normal”? Why do you think this helps / doesn’t help? (*Probe: Some kids have said that doing “normal stuff” helps to keep their mind off of being sick, or any worries that they might have. Does that work for you? What kinds of activities do you find helpful?*)
4. Some kids said that they didn’t feel sick, they felt “normal,” while other kids said they wished they were “normal” or just like everybody else, and some kids seemed to go back and forth. Have you ever felt any of those things? Could you tell me about that?

If the child says they haven’t felt that way or doesn’t seem comfortable with this, ask:

Could you tell me what you think those other kids might have meant when they said that they didn’t feel sick, or that they wished that they were “normal”? How do you think they could go back and forth between those two kinds of feelings?

5. In some of my conversations with kids it sounded like there were times that they missed their “normal life” and other times that they were doing lots of “normal stuff.” Does that sound similar or different than how you’ve felt? Can you tell me more about that?

6. Some of the kids I talked with sounded like there were times that they were sad and missing their “normal life,” and that they sometimes felt scared or worried about their tumour coming back or getting worse, especially if they were feeling sick. Do you think those feelings – sad about “normal life” and scared about the tumour – happen at the same time or separately or a bit of both?
7. If you could go back in time and talk to yourself right after you first found out about the tumour, what would you want to tell yourself?
8. Is there anything that you think about, or that you do, or that someone else does that helps you to deal with having a tumour?
9. What advice do you have for other kids with a tumour?