Siblings of Young People with Cancer: Medical Knowledge, Well-being and Adjustment

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ABSTRACT

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Childhood and adolescent cancer is a significant health issue globally, with varying survival rates across countries. While advancements in cancer treatment have improved survival rates, the impact of cancer on the affected child's family, particularly siblings, remains poorly understood. Siblings often experience disruptions in family dynamics, attention disparities, and increased responsibilities due to their brother or sister's illness. Psychological consequences, such as anxiety and depression, have been reported in siblings, yet psychological support for them is limited. The long-term effects of cancer on siblings and their adjustment to non-normative events require further investigation. This study aimed to explore the needs of siblings of young people with cancer in the Quebec context. Thematic analysis of qualitative interviews revealed six primary needs of siblings of young people with cancer: attention and acknowledgment, emotional support, medical knowledge and preparatory information, inclusion, nurturing family relationships, and instrumental support. Addressing these needs through improved family functioning and tailored interventions can better support siblings throughout and after the cancer experience. The findings of this study contribute to the existing literature and provide insights for healthcare professionals, educators, and parents to offer appropriate support to siblings of young people with cancer during the cancer journey.

Keywords: childhood and adolescent cancer, siblings, family dynamics, needs, attention and acknowledgment, medical knowledge, preparatory information.

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Introduction

Children and adolescents' cancer, although relatively rare, remains the second leading cause of death in children in Canada (Statistics Canada, 2015). It is estimated that 1000 Canadian children (Canadian Cancer Statistics Advisory Committee, 2019) and 400,000 children worldwide (World Health Organization, 2021) are diagnosed with cancer every year. There is a wide variation from country to country in terms of survival rates (World Health Organization, 2021). According to the World Health Organization, high-income countries have a cancer survival rate in children and adolescents of over 80% compared to 15-45% in low- to middle-income countries. Over the past few decades, there have been remarkable advancements in cancer treatment for children and adolescents, resulting in significant improvements in survival rates (Bhatia & Landier, 2005). These advancements include enhanced efficacy and delivery of medical treatments, as well as the development of risk-adapted therapies specifically tailored for young patients. Thus, medical advancements in the field of cancer have led to a growing population of childhood and adolescent cancer survivors (Bhatia & Landier, 2005). However, cancer treatments and therapies are often invasive, lengthy, and highly challenging for both the affected child or adolescent and their family (Long et al., 2015). For many children, the effects of cancer and its treatment can last a lifetime (Statistics Canada, 2015). Children and adolescent cancer survivors often live with physical and psychological consequences of the disease and subsequent treatments, which can include delays in growth and development, neurocognitive dysfunction, cardiopulmonary illnesses, and subsequent cancers (Bhatia & Landier, 2005). Thus, the short-term and long-term challenges associated with childhood cancer may persistently and chronically disrupt the family system. The evolution of cancer treatments has brought about fascinating transformations in research over the past few decades, as research on siblings of children with cancer has shifted in the past few decades from focusing on grief and bereavement to the psychological, emotional, and social consequences of cancer on non-bereaved siblings (Houtzager et al., 1999; O'Shea et al., 2012).

Cancer in children and adolescents can be devastating and has been described as *all-consuming* for all members of the family (Long et al., 2015). The adverse life event of childhood and adolescent cancer and its impact on the family system can be considered through the interaction of individual, environmental, and familial aspects of the family system. It is without saying that the family's response to cancer is affected and affects both the ill child's and their siblings' behaviour (Long & Marsland, 2011). Although numerous studies focus on the physical, social, emotional, psychological, and relational aspects of cancer survivors (Aldridge & Roesch, 2007), their parents (Sultan et al., 2016), and the family system (Pai et al., 2007), the impact of cancer on siblings remains poorly understood (Alderfer & Hodges, 2010). Unfortunately, through the cancer experience, siblings are often left out of the family unit (Long et al., 2015), intervention programs, and psychosocial research (Alderfer & Hodges, 2010).

It has long been established that the cure for cancer in children and adolescents does not solely include positive biological outcomes for the patient but expands to their social, emotional, and psychological health (Van Eys, 1999). However, this *all-inclusive* definition of *cure* does not seem to apply to all members of the family through the cancer experience. Siblings of children and adolescents with cancer have long been ignored from this inclusive definition of cure, and some have argued that psychosocial and medical systems ought to include all family members, especially children and adolescents (Alderfer & Hodges, 2010). Incorporating all family members into the intervention aimed at *curing* cancer in children and adolescents brings benefits not only to the healthy recovery of the child with cancer but also to the overall well-being of the entire family unit (Buchbinder et al., 2011).

Review of the Literature

Defining Important Concepts & Key Terms

For the context of the current project, some important concepts and terms are important to define.

Cancer Experience. The term "cancer experience" will be referred to as the overall journey and impact of having cancer on the individual's and their family's physical, emotional, and psychological well-being. It encompasses the various aspects of living with and going through a cancer diagnosis, treatment, and survivorship.

Cancer in Young People. The term childhood cancer and pediatric cancer typically refers to any cancer that occurs between birth and the age of 14 years, according to the National Cancer Institute (National Cancer Institute, 2023). Adolescents with cancer refer to a population between the ages of 15-19 years old (Public Health Agency of Canada, 2022). This definition of childhood cancer is largely used across English-speaking communities. However, a national program from the Government of Canada aims at providing data on both children and adolescents with cancer under the umbrella term *Cancer in Young People* (CYP) (Public Health Agency of Canada, 2022) The wide range of individuals within the young population poses challenges when defining cancer in this group. Adolescents are often considered in the “Adolescents and Young Adults (AYA)” cancer population but are often treated in pediatric healthcare centers. Accordingly, the term "cancer in young people" will be employed as an inclusive and encompassing designation for a population of individuals under the age of 19 who are diagnosed with cancer.

Sibling Participants. In the context of this study, the term "sibling participants" will specifically pertain to the brothers and sisters of children and adolescents with cancer who have willingly agreed to participate in this research.

The Impacts of Cancer on Siblings within Cancer-Stricken Families

Psychological Distress and Psychological Adjustment

Sloper and While (1996) determined that risk factors for psychological adjustment of siblings of children with cancer included the degree of disruption in the family life, resources available to siblings, and siblings' perceptions of the impact of a cancer diagnosis on their life and the life of others. Lower family income, non-Caucasian families, and unmarried parents were factors associated with higher levels of distress in children (Long et al., 2013). Moreover, sibling reports of lower parental acceptance, higher psychological control, and lower family function showed greater sibling distress and traumatic stress (Long et al., 2013). Parent reports of family functioning variables did not predict sibling distress (Long et al., 2013), which may indicate that distressed siblings perceived a higher level of family dysfunction than non-distressed siblings or that inattentive parents fail to report distress in their children. Contrariwise, birth order, time since diagnosis, and gender did not show a significant association with siblings' psychological health (Long et al., 2013). An extensive review of the literature presented by Long et al. (2018) reported that siblings of pediatric cancer patients are at higher risk for emotional and behavioural issues, as well as stress- and trauma-related conditions.

Siblings often reported some reluctance to share their feelings and emotional states with both their parents and healthcare professionals (Long et al., 2017). Inaccessibility of feelings, emotional numbness, and unwillingness to face the reality of cancer was associated with the siblings' general reluctance to share their feelings and seek support (Long et al., 2017). Siblings often reported withholding their feelings to protect their parents and avoid additional stressors for them. Moreover, siblings expressed some delays in their emotional reactions and comprehension of the gravity of the cancer diagnosis (Long et al., 2015). Siblings, especially younger adolescents, expressed their confusion regarding the seriousness of cancer but eventually understood the potential long-term consequences of childhood cancer (Long et al., 2015). Lastly, parents were also reluctant in sharing their concerns for the mental health of their other children with healthcare professionals (Long et al., 2018)

Posttraumatic Stress Symptoms & Posttraumatic Stress Disorder. Kaplan et al. (2013) reported noteworthy levels of cancer-related traumatic stress in siblings of children and adolescents with cancer. Sixty percent (60%) of their sample reported experiencing moderate to severe posttraumatic stress symptoms (PTSS), and 22% fulfilled the strict criteria for posttraumatic stress disorder (PTSD). Accordingly, Long et al.'s (2018) literature review suggested that one-quarter of the siblings in their sample met the criteria for PTSD, and between 50% and 66% reported symptoms of moderate or severe cancer-related stress issues. Furthermore, 56% of siblings reported symptoms of avoidance, and 82% met the criteria for arousal according to the PTSD guidelines (Kaplan et al., 2013). Seventy-five percent (75%) of siblings reported their symptoms interfering in at least one domain of life, whereas 47% indicated interfering with their general happiness. Hobbies, school work, chores and responsibilities at home, friendships, and family relationships were domains of life that appear to be significantly affected by symptoms of posttraumatic stress (Kaplan et al., 2013). Symptoms of traumatic stress commonly reported by siblings included irritability, trouble sleeping and concentration, being overly careful or jumpy (Kaplan et al., 2013), flashbacks, and nightmares (Porteous et al., 2019). More than half of the sample in Alderfer et al.'s (2003) study reported that the cancer treatment was "scary hard", and such beliefs were associated with higher levels of PTSS.

Parents of children with cancer also showed signs of elevated PTSD and PTSS (Kazak et al., 1997). However, siblings' exposure to traumatic aspects of cancer is infrequently studied (Alderfer et al., 2003). Siblings of children with cancer are not always exposed to the traumatic aspect of cancer in the same ways as the ill child themselves, who undergoes invasive treatment, and parents, who are involved with difficult decisions and often witness their child’s emotional and physical pain (Alderfer et al., 2003). Siblings still experience some level of exposure, as they are exposed to the physical and emotional pain of their ill brother or sister and still witness invasive and long-lasting cancer treatment (Alderfer et al., 2003). Many siblings feel high levels of fear, and some believe their brother or sister will die from the disease (Alderfer et al., 2003). It is without saying that such thoughts and beliefs can have detrimental long-term consequences on children and adolescents growing up in this environment. Moreover, it appears that levels of traumatic stress are more elevated in siblings than in survivors themselves, which is hypothesized to be caused by fewer sources of support for siblings (Alderfer et al., 2003). Survivors typically receive increased parental attention, support, and professional help, enabling them to better cope with traumatic experiences compared to their siblings. Siblings, despite witnessing their brother or sister's pain and suffering, often face the traumatic impact of cancer without comparable support. The cumulative aspect of the burden on siblings, which can include a shift in roles and responsibilities, long-term parental absence, a decrease in parental attention, and parental distress, can limit the ability of siblings to cope with the stressors and traumatic experiences (Alderfer et al., 2003).

Anxiety and Depression. Consistent with previous findings (Alderfer et al., 2003; Kaplan et al., 2013, Long et al., 2018), it is reported that only 5% of siblings fall into the clinical range for self-reported anxiety and only 3% into the clinical range for self-reported depression. However, levels of anxiety and depression were significantly associated with posttraumatic stress. Siblings who exhibited moderate to severe PTSS also had higher self-reported anxiety and depression levels compared to siblings with lower levels of traumatic stress (Kaplan et al., 2013). These findings are consistent with previous findings (Alderfer et al., 2003) and contribute to the argument that a small subgroup of siblings are at increased risk for psychological maladjustment.

Strong Negative Emotions. Regardless of the stage of cancer, siblings of young people with cancer often expressed a sense of extreme sadness (Woodgate, 2006). However, some siblings reported that the days and weeks following the cancer diagnosis were especially difficult for them as they expressed being shocked, overwhelmed, sad, afraid, and helpless (Long et al., 2015). Although siblings experienced a wide range of emotions, from fear, worry, jealousy, to anger and guilt, sadness was reported as the most predominant emotion and often lasted for years following the cancer experience (Woodgate, 2006). This feeling of sadness was said to stem from the magnitude of changes they had to endure over the course of the cancer treatment and the suffering of their siblings (Woodgate, 2006). Meltdowns were not uncommon for healthy siblings, especially when the health of their brother or sister worsened (Long et al., 2015). Some siblings described their emotional reactions as a *roller-coaster* of mood states and emotions, ranging from moments of relief to feelings of disappointment, as they navigate the ups and downs of the treatment journey (Long et al., 2015). Although parents were aware of and acknowledged their healthy children's feelings of sadness, they reported not understanding the extent of those feelings at the time (Woodgate, 2006). Fear of mortality was associated with strong emotional responses and was reported as the most difficult aspect of the sibling experience as siblings struggled to come to terms with this possibility (Long et al., 2015).

The Impacts of Cancer on the Family Unit

Siblings' reactions and emotional responses to cancer might be directly related to the changes associated with the family system (Long & Marsland, 2011). Thereby, siblings should not be considered independent agents but should always be considered in the context of the family. Some findings indicated that family adjustment is the most prominent factor that affects siblings' adjustment to childhood cancer (Houtzager, Oort, et al., 2004). The Circumflex Model of family functioning developed by Olson et al. (1979) integrated two aspects of family functioning: family adjustment and family cohesion. Family adjustment is simply defined as the ability or the tendency of a family to adapt to change, whereas family cohesion is defined as the family's mutual involvement and closeness (Long & Marsland, 2011). According to this model of family functioning, a moderate level of adjustment and cohesion is the most favourable for positive outcomes and balanced family life. Thus, siblings with higher rates of psychological distress usually come from families with a chaotic system. Furthermore, research has suggested that family adaptation plays a crucial role in navigating the changes associated with a child's cancer diagnosis (Houtzager, Oort, et al., 2004). However, it is important to note that while these adaptive changes can be beneficial in the short-term, they may have negative consequences for the children if they become long-lasting and ingrained in the family structure.

It is important to acknowledge that the focus of this study is on siblings, and not on parents. However, it is crucial to recognize that parental adjustment and family dynamics inherently affect the ability of siblings to cope and adapt to the challenges that arise from cancer. The potential interplay between parental adjustment, family relationship, and sibling well-being is a complex and interconnected aspect that should be taken into consideration in understanding the overall impact of the cancer experience on siblings.

Family Functioning

Siblings have expressed a sense of loss regarding their family way of life compared to their lives before the cancer diagnosis (Woodgate, 2006). Siblings reported a strong emotional response to the amount of change their family had to endure following the cancer diagnosis and how all aspect of their family life was disrupted (Woodgate, 2006). Moreover, numerous siblings reported that the ambiguity surrounding the cancer experience, which persisted after the diagnosis and extended to all phases of their cancer treatments, was extremely difficult to accept (Long et al., 2015). This ambiguity about family functioning, daily routine, the ill child's prognosis, and the general consequences of childhood cancer on the family system was deemed physically and emotionally taxing for each family member (Long et al., 2015). Changes in the family system appeared to occur in a non-linear fashion, as challenges and barriers differ depending on the trajectory and prognosis of the cancer diagnosis (Long & Marsland, 2011). Siblings have reported that all family events and activities tended to be oriented towards the ill child's needs and interests, and promises were often broken, which was believed by parents to be extremely difficult for siblings to deal with the unpredictability of the disease and treatment (Sidhu et al., 2005). Moreover, siblings reported having difficulty maintaining relationships with their other siblings and parents due to each other's psychological distress and reported that hospitalization periods were especially difficult on the siblings' relationships (Woodgate, 2006). Siblings of female patients and younger patients appeared to experience more problems in family functioning and relationships through the cancer experience (Erker et al., 2018). Consistently, approximately one-half of siblings reported unhealthy family functioning during and following the cancer treatment (Long et al., 2018). According to Long and Marsland's (2011) review of the literature, levels of family functioning did not show statistical differences compared to normative levels. Nonetheless, a subgroup within the study indicated ongoing and persistent impairment in family processes. The ability of a family to change and adapt to the challenges raised by a cancer diagnosis might be key to positive outcomes in the psychological adjustment of children (Long & Marsland, 2011), which contributes to the argument that family functioning is a crucial aspect of childhood cancer. Nonetheless, most studies addressing family functioning fail to consider the healthy siblings as members of the family, as important as the parents and the ill child.

Parental Attention

Multiple studies have consistently reported that a notable shift in the family dynamic is primarily characterized by a decrease in parental attention following a cancer diagnosis. (Long et al., 2017; O'Shea et al., 2012; Tasker & Stonebridge, 2016; Wilkins & Woodgate, 2005). Parents were not only emotionally unavailable to siblings, but they were also often physically absent from their homes and spent an increasing amount of time with the ill child at the hospital (Prchal & Landolt, 2012). Siblings reported feeling extremely lonely and disliked living in an empty home (Prchal & Landolt, 2012). All siblings in Woodgate's (2006) study reported not being cared for and having unmet needs because the entirety of their parents' attention was directed at the ill child's needs. Moreover, parents were no longer available to help siblings with homework, have meals with them, and discuss their day (Prchal & Landolt, 2012). As a result of feeling rejected by the lack of parental attention, siblings reported a sense of loneliness, anxiety, behavioural problems, school problems, increased somatic complaints, and other social, affective, and behavioral issues (Kramer, 1981, as cited in Sidhu et al., 2005). Parents themselves reported paying little attention to their healthy children in the first few months following the cancer diagnosis (Long et al., 2017). They even indicate avoiding discussing their needs and emotional states, fearing they might not be able to handle the possibility of poor psychological adjustment in their other children (Long et al., 2017). When siblings were asked how their parents could have supported them better through their experience, most responded by expressing that parents need to pay more attention to their healthy children (Woodgate, 2006). Despite this drastic reduction in parental attention, siblings expressed the need to be present for their parents and to spend time with them (Woodgate, 2006). Siblings expressed that although they enjoyed time spent with their friends and extended family, the time they spent alone with their parents was extremely precious and reduced their feelings of isolation, no matter the activity (Woodgate, 2006).

Parental Distress

Parental distress was also identified as a major aspect of cancer in children and adolescents (Prchal & Landolt, 2012). Siblings reported finding it difficult to see their parents psychologically impaired, burdened, weak, irritable, or sad (Prchal & Landolt, 2012). Siblings were aware of the psychological suffering of their parents and realized how each cancer-related event only escalated their suffering (Woodgate, 2006). In addition to added chores and home responsibilities, some siblings were left to care for, protect and comfort their parents or other siblings (Prchal & Landolt, 2012). Siblings expressed wanting to help their parents ease their burden, as well as being extremely careful to protect their parents from additional sources of stress or worries (Woodgate, 2006). Parents expressed that one of the sources of their psychological distress was trying to meet everyone's needs through the difficulty of cancer treatment (Sidhu et al., 2005).

Changes in Daily Routine

The first months following a cancer diagnosis appeared to be the most chaotic for families and caused a clear disruption in family relationships and routines (Long et al., 2017). Following the diagnosis, every family member tries to adapt, and the whole family system makes efforts to adjust to provide the ill child with the appropriate treatment (Porteous et al., 2019). Findings indicated a general stabilization of the family disruption months after the diagnosis, indicating remarkable resilience and adaption (Houtzager, Oort, et al., 2004). Still, changes in the family appeared to be present for the large majority of families with a child diagnosed with cancer (Prchal & Landolt, 2012). Parents reported that their knowledge of their other children's psychological adjustment and emotional state was limited because of the disruption in routine, notably because of the repeated hospital visits (Long et al., 2017). Siblings rarely attended medical appointments and hospitalization, often remaining at home with a parent or a family member, which in turn kept them away from crucial medical knowledge and medical decisions, and limited parents in their knowledge of their emotional state (Long et al., 2017). Such visits were often held during school time, which made it difficult for siblings to attend (Long et al., 2017). Siblings also tended to spend more time at home, often by themselves (Prchal & Landolt, 2012). Parents reported spending days, weeks, or months at the hospital (Long et al., 2017). Siblings also reported some additional disruption in their family life which included cancelling family vacations or spending the holidays with extended family members instead of with their parents (Prchal & Landolt, 2012).

Family Roles

The cancer-related logistical demands require changes in the family roles, responsibilities, and daily functioning, which might be especially disruptive for younger children (Long & Marsland, 2011). An important shift in roles and responsibilities is often observed as the family adapts to the challenges associated with having a child with cancer and as healthy siblings often take on some of the roles and responsibilities previously carried out by parents (Long et al., 2015). Such tasks can include childcare, cooking, cleaning, doing laundry, bringing food to the hospital, assisting in daily routine (Prchal & Landolt, 2012), communicating information with family and friends, or coordinating visits to the hospital and collecting resources offered by their social support (Porteous et al., 2019). Prchal and Landolt (2012) and Porteous et al. (2019) reported that although siblings, especially older siblings, did not take on these additional chores voluntarily, they reported welcoming the opportunity to help their parents and believed it was rewarding to be part of a team that facilitated the cancer treatment. Woodgate (2006) found that siblings reported feeling better when they were able to contribute to the family unit's needs, despite constant feeling of guilt for not being able to do more. Siblings admitted to enjoy assuming extra responsibilities for the household as it made them feel like they were contributing to their brother's or sister's recovery and protecting their parents from additional sources of worries (Long et al., 2015). However, some siblings expressed feeling overwhelmed by those new tasks and having to make decisions they felt were too big for a child or adolescent to make on their own (Tasker & Stonebridge, 2016).

These findings underscore the possibility that the adjustment and psychological distress experienced by siblings of young people with cancer may, may in part, originate from the family system (Houtzager, Oort, et al., 2004). These findings contribute to the argument that children should be considered within the whole family system.

Predictors of Siblings' Adjustment

Individual Characteristics

In the context of childhood and adolescent cancer, the most commonly reported individual variables in the literature are related to gender and age. Although gender and age appear to be significant factors, findings are notoriously mixed and contradictory.

Gender. Some findings suggested that female siblings exhibited and reported higher levels of PTSS compared to male siblings (Alderfer et al., 2003); others stated that this gender difference was not statistically significant (Kaplan et al., 2013). It is hypothesized that female siblings might be subjected to a larger increase in family responsibilities, which might increase exposure to traumatic events and thus lead to higher traumatic stress levels (Alderfer et al., 2003). Another hypothesis summarized by Alderfer et al. (2003) suggested some gender differences in terms of empathy and the notion that female siblings might be more emotionally attuned than males, making them more vulnerable to negative and traumatic events. In general, given the same level of exposure, it is not rare that girls experience more negative effects compared to boys (Foa & Street, 2001). Yet some findings indicated that male siblings of young people with cancer are at higher risk for depressive symptoms later in adulthood (Buchbinder et al., 2011). However, as female siblings appear to be less sensitive to developing depressive symptoms compared to males, it is hypothesized that females spend more time caring for and supporting the ill child, which might allow them to open up and express their feelings during and after the cancer treatment (Buchbinder et al., 2011). Consequently, boys of all ages are usually granted more freedom and independence than girls (Hamama et al., 2000), and might be less involved with family members, which could leave them at higher risk for depression (Buchbinder et al., 2011).

Age. Age is also believed to be a crucial individual factor (Alderfer et al., 2003; Kaplan et al., 2013) in the adjustment of siblings of young people with cancer, but again neither the trajectory nor the significance of age as a factor of psychological outcomes on siblings is clear. Kaplan et al. (2013) reported no association between age and PTSS and PTSD in siblings of pediatric cancer patients. Conversely, children over the age of 6 appeared to be more at risk of developing psychological adjustment issues than younger siblings, according to Alderfer et al. (2003). Adolescent siblings are less likely to have a decrease in their quality of life, even after the end of the treatments, than younger children (Houtzager, Grootenhuis, et al., 2004). It is believed that because older children form better memories of events and have higher cognitive abilities, they develop a better understanding of cancer and its consequence (Alderfer et al., 2003). Older siblings might be better cognitively equipped to quickly understand the seriousness of the cancer diagnosis, as younger siblings reported some delays in their understanding of the potential life-threatening outcomes of the disease (Long et al., 2015). Hamama et al. (2000) reported lower levels of anxiety in older siblings, stating that their higher cognitive function and ability to understand the consequences of the disease might help them cope with their emotional response. Yet, Houtzager, Oort, et al. (2004) reported higher levels of anxiety, loneliness, and insecurity, lower quality of life, and more emotional involvement with the illness in older siblings.

As expected, distress is not expressed in the same way at different periods of the sibling's development. For instance, adolescents' impaired functioning is usually expressed with internalizing problems, whereas younger siblings often express impaired functioning and impaired quality of life (Houtzager, Grootenhuis, et al., 2004). Moreover, siblings between the ages of 7 and 11 years of age are believed to have greater impairment in their physical functioning compared to older age groups (Houtzager, Grootenhuis, et al., 2004). This finding could be explained by their low comprehension of the disease, which might spark fear in them of developing a chronic illness themselves, leading to increased somatic symptoms (Houtzager, Grootenhuis, et al., 2004).

The age of the sibling in relation to the ill child appears to be associated with global psychological distress, with an increased risk for siblings younger than the cancer patient (Buchbinder et al., 2011). Siblings younger than the ill child might be more at risk as they may be more sensitive to the decreased parental attention during the cancer treatment, as older siblings might be more equipped to find other sources of support (Buchbinder et al., 2011). These differences in the psychological outcomes and adjustment of siblings highlight the importance of a developmental approach to childhood cancer (Buchbinder et al., 2011), as some aspect of the cancer experience appears to be especially difficult and altering for some specific age groups.

The interaction between age and gender is also believed to play an instrumental role in the adjustment of siblings of pediatric cancer patients. That being said, female adolescents showed higher levels of self-reported depression (Barrera et al., 2004; 2005). These findings highlight the need to develop highly specific intervention programs to target the specific needs of siblings, especially in adolescent females who might feel more pressure than male or younger siblings to take on more responsibilities at home (Barrera et al., 2004).

Social, Emotional, and Instrumental Support

Studies have reported that social support (Alderfer & Hodges, 2010), emotional support (Prchal & Landolt, 2012; Tasker & Stonebridge, 2016), and instrumental support (O'Shea et al., 2012; Patterson et al., 2014) are crucial for the psychological adjustment of siblings during and after cancer in the family.

Greater self-reported social support from friends and peers is believed to be significantly correlated with fewer symptoms of withdrawal, depression, and risky behaviours (Alderfer & Hodges, 2010). Barrera et al. (2004) observed that siblings with higher perceived social support tended to have fewer behavioural problems, anxiety, and depressive symptoms. Parents reported that siblings with higher perceived social support demonstrated less anxious behaviours than those with lower perceived social support (Barrera et al., 2004). Support from parents was also significantly associated with lower scores of depression but was not significantly correlated with anxiety and cancer-related posttraumatic stress symptoms (Alderfer & Hodges, 2010).

Instrumental support is defined as the tangible support provided to individuals in need, which can include transportation, meal preparation, and help with household chores (Schultz et al., 2022), which is also believed to be crucial and allows healthy siblings to ease their loneliness (Tasker & Stonebridge, 2016), maintain their own activity (Tasker & Stonebridge, 2016; Wilkins & Woodgate, 2005), maintain a regular daily routine (O'Shea et al., 2012), and ease the burden associated with household chores (Patterson et al., 2014). Instrumental support provided by school workers and teachers appeared to significantly reduce attention problems, rule-breaking behaviours, and other behavioural problems (Alderfer & Hodges, 2010).

Medical Knowledge

Numerous studies suggested that parents are often uncomfortable in providing information to their healthy children about the medical condition and prognosis of their ill child (Houtzager et al., 2001; Prchal & Landolt, 2012; Sidhu et al., 2006), as they feel it might be frightening and upsetting (Craft, 1993). Nonetheless, it appears that sibling maladjustment to childhood cancer is associated with low or the lack of medical knowledge about the disease

(Evans et al., 1992; Kramer & Moore, 1983), and that interventions to increase the medical knowledge of siblings are useful in reducing symptoms of maladjustment in siblings of childhood cancer patients (Li & Lopez, 2008; Sidhu et al., 2006). Moreover, increased medical knowledge is associated with increased social competence (Evans et al., 1992), reduced fear of the disease, improved mood states (Carpenter & Sahler, 1991), and reduced anxiety levels (Sidhu et al., 2006). Most siblings reported they appreciated being informed and included in the medical decision but also mentioned some discomfort in discussing nothing other than the illness of the child within the family (Prchal & Landolt, 2012).

A systematic review of the literature assessing the impact of increased medical knowledge on siblings of childhood cancer provided preliminary evidence that providing medical knowledge to siblings can effectively reduce the risk of psychological maladjustment (Prchal & Landolt, 2009). Enhanced medical knowledge appears to be negatively correlated with behavioural issues and negative perception of the illness in siblings of children with chronic illnesses (Lobato & Kao, 2002). Consequently, as medical knowledge of the disease increases, both parents and siblings tended to report a decrease in negative feelings, negative adjustment, and behavioural issues. Labay and Walco (2004) stated that increased medical knowledge did not appear to be directly related to psychological adjustment during cancer treatment but increased empathy, which in turn may influence long-term psychological adjustment. Decades-old studies (Carpenter & Sahler, 1991; Evans et al., 1992; Havermans & Eiser, 1994; Kramer & Moore, 1983) have provided some preliminary evidence identifying accurate and age-appropriate medical knowledge for siblings as a factor influencing siblings' adjustment to chronic diseases. However, it is worth noting that recent studies investigating the potential impact of medical knowledge on the psychological adjustment of siblings have been limited in number.

Stressors

Cancer-related Stressors. Some siblings reported that one of the main stressors in their cancer experience was witnessing the pain and suffering of their brother or sister (Prchal & Landolt, 2012). Exposure to the physical and emotional pain of their ill brother or sister and witnessing invasive and long-lasting cancer treatment was associated with symptoms of traumatic stress (Alderfer et al., 2003). Some physical changes that were especially difficult for siblings to observe were the loss of hair, drastic weight loss or gain, seeing them connected to medical equipment, and seeing them experience high levels of pain and discomfort (Prchal & Landolt, 2012). Most siblings felt helpless and did not know how to react (Prchal & Landolt, 2012; Woodgate, 2006). Moreover, when left unaddressed, the physical and emotional side effects of cancer treatment often made siblings worried about the prognosis and left children to doubt the efficacy of treatments (Prchal & Landolt, 2012). Furthermore, behavioural changes in the ill child were also reported as very hard to handle for siblings (Prchal & Landolt, 2012).

As a side effect of the medication, ill children were often reported to be aggressive, moody, passive, unreasonable (Porteous et al., 2019; Prchal & Landolt, 2012), demanding, and prone to outbursts (Long et al., 2015). Even with the knowledge and understanding that these behavioural changes were directly related to steroid-induced emotional fluctuations (Long et al., 2015), it was very difficult for siblings to witness and deal with these changes (Porteous et al., 2019; Prchal & Landolt, 2012). Cancer-related stressors, including witnessing their sibling's emotional and physical pain, resisting treatment, being noticeably impaired, and feeling unhappy during and after the cancer treatment, was commonly reported by siblings (Porteous et al., 2019). Missing their siblings or knowing that their siblings could die or be permanently impaired by cancer and the ensuing treatments was also a significant stressor for siblings of children with cancer (Porteous et al., 2019).

Cancer-related variables are rarely considered in the analysis of factors for psychological distress in siblings of young people with cancer. However, some findings suggested that the type of cancer (Buchbinder et al., 2011), the severity of the prognosis (Hamama et al., 2000; Houtzager, Oort, et al., 2004), the time since diagnosis (Cheung & Mok, 2013; Hamama et al., 2000), and the duration of the illness (Erker et al., 2018), might be relevant cancer-related factors that impact psychological adjustment. For instance, a diagnosis of sarcoma was found to be linked to a higher risk of somatization in siblings (Buchbinder et al., 2011). Sarcoma diagnoses typically involve intensive chemotherapy, radiation therapy, and surgical procedures, which can affect the musculoskeletal growth of the affected child. It is believed that a constant physical reminder of the cancer experience might generate higher risks for somatization in siblings. Siblings of patients with leukemia or lymphoma experienced increased family disruption compared to other types of cancer (Erker et al., 2018). Erker et al. hypothesized that leukemia and lymphoma diagnosis typically require more parental attention, which may lead to a higher sense of isolation from the siblings.

Bereaved siblings indicated more signs and symptoms of psychological distress, which was not only associated with the death of the child but also with the unfavorable prognosis, difficult course of the illness, and the severity of their sibling's prognosis (Houtzager, Oort, et al., 2004). Cheung and Mok's (2013) investigation did not report any association between time since diagnosis and subjective psychosocial adaptation in siblings. However, Hamama et al. (2000) reported higher anxiety levels in siblings whose brother or sister had been diagnosed more recently, findings that can be explained by the natural tendency for adjustment to stressors over time.

School and Academic Performances. At first glance, the school environment appears to maintain a sense of normalcy for siblings of pediatric cancer patients and a domain of life that is not immediately affected by the health of a sibling (Prchal & Landolt, 2012). However, some findings indicated that siblings were confronted with several challenges, particularly during the period following a cancer diagnosis (Prchal & Landolt, 2012), and tended to have poorer school performance and greater absenteeism than their peers (Long et al., 2018). Virtually all siblings interviewed by Prchal and Landolt (2012) reported a decrease in academic achievement following the cancer diagnosis of their siblings. The main reason for these changes in academic performance is likely caused by distracting thoughts about the health condition of their siblings, the consequences of the illness, and the subsequent treatment on the life of everyone in the family (Long et al., 2015; Prchal & Landolt, 2012). French et al. (2013) reported that siblings of pediatric cancer patients missed significantly more days of school than the average students. One-quarter of the sampled siblings missed more than 13 days of school during their sibling's cancer treatment, which is almost double the student average and just as much as cancer patients. It has been suggested that the high absenteeism rate of healthy siblings occurs to facilitate cancer treatments (Tsimicalis et al., 2018). Siblings reported a strong wish to remain at home or go to the hospital to stay and support the ill child instead of going to school (Prchal & Landolt, 2012). It was also hypothesized that high rates of school absenteeism could be due to a general acceptance by the family or because of the enduring psychological distress that may be experienced by siblings during this time (French et al., 2013). Some siblings mentioned that they had less time for school and homework since their brother or sister had been diagnosed as they had other responsibilities and wanted to actively participate in the recovery of their ill sibling (Samson et al., 2016). Moreover, parents were less physically and emotionally available to support siblings in their schoolwork and activities at school (Prchal & Landolt, 2012). Lack of supervision from parents regarding school performance and attendance may also add to the psychological costs of siblings of young people with cancer (Tsimicalis et al., 2018).

Social Activities. Other than the direct educational consequences of school absenteeism, healthy siblings also missed social time with their friends and peers, in turn increasing their feeling of isolation (Tsimicalis et al., 2018). Siblings reported a sharp decrease in social activities, especially in the months following the diagnosis, as they spent most of their free time at the hospital (Prchal & Landolt, 2012; Sloper, 2000). Concerns related to germs and catching infectious viruses, the lack of transportation, extra responsibilities, and the amount of time they spent at the hospital were some reasons suggested by siblings for this decrease in time spent on social activities (Long et al., 2015). Although friends were likely to be a great source of support, siblings often reported difficulty in maintaining these relationships through the cancer experience and conveyed how difficult it was for them to reintegrate into their friendship group after some time away (Prchal & Landolt, 2012). The changes in the routine, family dynamic, and roles appeared to cause a decrease in social activity in siblings, which might be especially unfavourable for them as peer support is known to largely improve siblings' psychological adjustment (Alderfer & Hodges, 2010).

Multiple Concurrent Stressors. Distress and psychological maladjustment of siblings of young people with cancer appear to steam from the multiple concurrent stressors' siblings have to endure through the cancer experience (Porteous et al., 2019). The overlap with other life stressors contributed to the burden of siblings during the cancer experience. Consequently, many siblings reported encountering simultaneous events and stressors, encompassing both acute stressors (such as parental separation, death of extended family members, other major illness/surgery for themselves or other family members, and moving) and long-term and chronic stressors (including schoolwork and exam pressure, social problems, family conflict, the birth of new siblings, and family financial difficulties)(Porteous et al., 2019). Lastly, siblings were often the family member who retained most of their daily activities, thus were most often the family member who was confronted with questions and curiosity from others (Prchal & Landolt, 2012). Siblings reported feeling emotionally fatigued due to these questions and always having to repeat the same information, or by the fact that they did not know how to answer some of these inquiries.

Siblings' Needs

Several studies have extensively documented various needs experienced by siblings of young people with cancer (O'Shea et al., 2012; Patterson et al., 2014; Porteous et al., 2019; Tasker & Stonebridge, 2016; Wilkins & Woodgate, 2005). These needs may arise due to the unique challenges and emotional impact that cancer diagnosis and treatment can have on siblings. Understanding and addressing these needs can be crucial in providing comprehensive support for the well-being of siblings during this challenging time. Through this literature review, five significant needs have been identified among siblings of young people with cancer: the need for attention, the need for open communication and access to medical information, the need for emotional support, the need for instrumental support, and the need for normalcy.

Need for Attention

The need for attention and acknowledgment is indeed the most commonly reported needs in siblings of young people with cancer, as highlighted in numerous studies (Porteous et al., 2019; Tasker & Stonebridge, 2016; Wilkins & Woodgate, 2005). As indicated above, studies have shown that the family dynamic can undergo a significant shift following a cancer diagnosis, often resulting in a decrease in parental attention (O'Shea et al., 2012; Patterson et al., 2014; Porteous et al., 2019; Tasker & Stonebridge, 2016; Wilkins & Woodgate, 2005). Porteous et al. (2019) reported that feeling left out was the cancer-related experience that was associated with the most distress in siblings. Tasker and Stonebridge (2016) highlighted the need for attention and acknowledgement through meaningful and genuine efforts and involvement from others "through physical affection, time, conversation, caregiving, monitoring, and showing interest in the well-sibling's wellbeing, desires, activities, and school life" (Tasker & Stonebridge, 2016, p. 716). Participants expressed a sense of being overshadowed and overlooked, which can contribute to feelings of frustration, loneliness, and need for validation (Porteous et al., 2019). For instance, a sibling in Tasker and Stonebridge (2016) even reported being completely ignored by the characters of a theme park during a family visit granted by a non-profit organization for children with chronic or life-threatening illnesses. This lack of attention from parents, family members, and medical professionals came with a sharp increase in the attention and interest directed at the ill siblings (Porteous et al., 2019). Porteous et al. (2019) reported intense frustration from siblings as their family, peer group, and larger community were solely inquiring about their ill brother or sister and often failed to inquire about their own feelings and health. When discussing how isolated and unsupported they felt through the cancer experience, siblings often had strong emotional reactions, even if interviewed years after the cancer experience (Prchal & Landolt, 2012).

Siblings often felt guilt associated with feeling left out and about their sibling receiving attention, gifts, and special activities (Porteous et al., 2019; Prchal & Landolt, 2012). Furthermore, it was reported that siblings had some difficulty verbalizing they felt their needs were unmet to their parents, as they believed it would come across as insensitive (Porteous et al., 2019). Although most siblings understood why their parents and others directed their attention to the ill child, they still found it difficult to accept. This increased understanding came with age and being involved in treatment, and medical conversations (Porteous et al., 2019). Nonetheless, siblings reported not holding any lasting resentment towards their siblings and recognized why their parents had to direct their attention to their ill child (Woodgate, 2006).

Need for Open Communication and Access to Medical Information

The need for honest and open communication among the family has also been commonly reported by the literature on siblings' experiences with cancer (Tasker & Stonebridge, 2016). Researchers are unanimous in believing that children should be informed of their loved one's medical conditions (Eilegård, 2012). Yet, siblings remain inappropriately informed by parents and medical staff, are often excluded from discussing their sibling's prognosis, and their grief is still overlooked (Stroebe et al., 2001).

Communication with siblings about the prognosis and health condition of the ill child becomes even more crucial if the child succumbs to the disease. Numerous studies identified poor end-of-life medical information and preparation for the death of the cancer patient as a major risk factor for adverse bereavement outcomes in healthy siblings (Lövgren et al., 2016, 2018; Rosenberg et al., 2015), whereas positive communication and the opportunity to say goodbye was identified as potential protective factors (Wallin et al., 2016). Despite the difficulty in addressing such issues with healthy siblings, it appears to be crucial for the psychological adjustment of siblings, as they often reported wanting to be involved in medical decisions and informed about treatment, possible outcomes, side effects, prognosis, and emotional health (Tasker & Stonebridge, 2016). Without honest and transparent communication from parents, siblings often felt unsure about, when, how, and even if they should talk about their sibling's cancer and health condition (Tasker & Stonebridge, 2016). Thus, setting a strong foundation for communication between parents and siblings might in turn help siblings feel less reluctant in sharing their thoughts and feelings about the disease with family members and healthcare professionals.

Numerous siblings reported the need to be included in medical decisions during the cancer treatment and to be told what was happening with their siblings (Porteous et al., 2019; Tasker & Stonebridge, 2016). Most siblings in Long et al. (2015) reported a long delay between the diagnosis and when their parents shared it with their other children. However, siblings mentioned sensing that something was terribly wrong from their parent's emotional state and the numerous visits to the hospital. Many siblings reported feeling psychologically and physically isolated from being excluded from the medical discussion, as some decisions affected the whole family (Prchal & Landolt, 2012; Tasker & Stonebridge, 2016). Siblings emphasized the importance of parents discussing medical treatment and prognosis with them for several reasons (Prchal & Landolt, 2012).These included the fact that siblings could discern parents hiding information from the behaviours of adults around them. Additionally, they were frequently questioned by their social circle (e.g., neighbours, friends, relatives) about the health status of the ill child, and in situations of uncertainty, they tended to assume the worst.

Siblings often expressed the importance of being provided with accurate medical information about the diagnosis, treatment, and prognosis of their ill brother or sister (Long et al., 2015). By providing medical information and knowledge to siblings, parents, and healthcare professionals removed some of the burdens on siblings of having to figure out themselves what is going on and facilitated coping in siblings (Long et al., 2015). When not provided with the appropriate information, siblings often use the Internet or medical textbooks to further their knowledge, which was sometimes helpful but risked reading inaccurate information which highly increases cancer-related anxiety in most (Long et al., 2015). Siblings also reported the importance of teaching the actual medical terminology to siblings when discussing the medical situation of the ill child to better prepare them to engage in medical conversations and ask questions to healthcare professionals (Long et al., 2015). Lastly, siblings often reported some fulfillment in being present, helpful, and part of the process. Although parents reported how difficult medical conversations were with their healthy siblings, parents should try not to undermine the need for open communication and access to information from their children (Houtzager, Oort, et al., 2004).

Need for Emotional Support

Siblings often tried to suppress their emotional responses and experience without talking about it, especially following the diagnosis (Porteous et al., 2019). They often reported avoiding the topic of cancer as they did not want to burden their friends and family members (Porteous et al., 2019). Siblings expressed the need for emotional support to navigate the difficulty of the childhood cancer experience (Tasker & Stonebridge, 2016). Peer-support groups for siblings of young people with cancer appear to be very beneficial as fellow healthy siblings might be more likely to understand and empathize with their cancer experience (Prchal & Landolt, 2012; Tasker & Stonebridge, 2016). Even years after the child recovered from the disease, siblings expressed how they wished they could still be part of a support group and receive individual and family support (Tasker & Stonebridge, 2016). Siblings who did create strong relationships with other siblings of children with cancer, either during peer-support groups or through their time at the hospital, remained in contact, even years after the cancer episodes. Moreover, siblings reported the need to know that their emotional response to cancer was valid and normal (Tasker & Stonebridge, 2016). They often reported being uncomfortable with feeling such strong and negative emotions. However, developing relationships with other families of patients can also be a stressor for siblings, as they have to witness the changes in appearance and suffering of other children or adolescents (Prchal & Landolt, 2012). They might also realize that some children die from cancer, which can evidently be distressing for siblings (Prchal & Landolt, 2012). Additionally, parents believed that a peer-support group, particularly camp experience, was highly beneficial for their children as it provided an opportunity to meet peers with similar experience and who understood their reality (Sidhu et al., 2005).

Need for Instrumental Support

Instrumental support appeared to be helpful for the well-being of siblings (Tasker & Stonebridge, 2016). This support allowed healthy siblings to ease their loneliness (Tasker & Stonebridge, 2016), maintain their own activity (Tasker & Stonebridge, 2016; Wilkins & Woodgate, 2005), maintain a regular daily routine (O'Shea et al., 2012) and help with household chores (Patterson et al., 2014). Siblings also reported the need for support from their teachers and school workers to navigate their absences and psychological issues by maintaining academic presence and staying connected to the school through activities, clubs, and sports (Tasker & Stonebridge, 2016). Some siblings described the school-based support as inconsistent, although most teachers were lenient about assignments and examinations (Long et al., 2015).

Need for Normalcy

Siblings reported an intense desire to re-establish a sense of order and predictability during and after the cancer treatments (Long et al., 2015). Strategies reported by siblings to maintain a somewhat ordinary life included keeping busy, having distractions, and keeping a regular routine (Porteous et al., 2019). Siblings expressed the wish to 'just be kids', to remain free of responsibilities, and feel "free from feeling responsible to a parent for their feelings" (Tasker & Stonebridge, 2016, p. 719). Participants particularly appreciated when their friends did not act differently following the cancer diagnosis and maintained a sense of normalcy around them (Prchal & Landolt, 2012). Lastly, the need to maintain family humor and light-heartedness through the cancer experience was reported by siblings and families of young people with cancer (Tasker & Stonebridge, 2016). Through the strain and difficulty of cancer, siblings expressed the need to have fun with their family and friends, without feeling guilty (Patterson et al., 2014).

Interventions for Siblings of Pediatric Cancer Patients

Because the mechanisms and processes behind the psychological adjustment of siblings of young people with cancer are yet unclear, it is difficult to adequately develop intervention programs for this specific population and their specific needs (Buchbinder et al., 2011). Some intervention-based programs have been designed for siblings of young people with cancer (Barrera et al., 2002, 2005; Sidhu et al., 2006). However, the lack of psychosocial screening tools for this specific population has been identified as a barrier to the development of thoroughly designed interventions targeting the specific needs of siblings of young people with cancer (Long et al., 2017). Child Life Services in Canada and the United States has been a vital component of the hospital experience for ill children for many years and has more recently included the importance of providing support to siblings of ill children (Newton et al., 2010). That being said, the availability and access to these services are still unknown and appear to be highly variable depending on geographic regions and healthcare centers. A worldwide survey of pediatric psycho-oncologist services assessed the experience of more than 780 medical professionals from 63 countries and suggested that adequate medical, social, and psycho-emotional support was provided to only 21% of patient's families (Wiener et al., 2012). Similarly, Newton et al. (2010) compiled data on the emotional and instrumental support provided for siblings of hospitalized children in 217 major pediatric hospitals across the United States and Canada and highlighted shocking statistics about access to such programs. Only 48% of pediatric hospitals affirmed to provide support for siblings. Consequently, more than half (52%) of those pediatric centers did not offer support for siblings (Newton et al., 2010). Moreover, those programs did not always include the entire family, as family-oriented support was only offered in 24% of the pediatric hospitals. Unfortunately, no specific data regarding the support provided to siblings in the province of Quebec has been identified at this time.

Staff availability, funding, and lack of physical space to hold programs were commonly identified as barriers to providing appropriate support for siblings of hospitalized children (Newton et al., 2010). Moreover, the need for emotional support for siblings in hospital settings is undermined by the lack of evaluation tools. As shown in Newton et al.'s survey, hospitals that provided support for the siblings tended not to have the appropriate tools and procedures in place to evaluate, assess and adapt the support provided to siblings. Newton et al.'s and Wiener et al.'s large-scale studies highlighted two troublesome findings. First, siblings are frequently excluded from the care and treatment of cancer and long-term hospitalized children. Second, when support is provided, it is rarely evaluated and assessed to ensure the highest possible positive outcomes.

The Current Study

Cancer-stricken families are facing unique sets of challenges that may leave siblings with some long-term psychosocial issues (Barrera et al., 2005; Gerhardt et al., 2015; Hamama et al., 2000; Houtzager, Oort, et al., 2004; Porteous et al., 2019). Although severe psychopathology is rare in siblings of young people with cancer, several studies reported that siblings experience higher levels of anxiety (Barrera et al., 2005; Hamama et al., 2000; Houtzager, Oort, et al., 2004; Porteous et al., 2019), depression (Kaplan et al., 2013; Lähteenmäki et al., 2004) and posttraumatic stress (Kaplan et al., 2013; Long et al., 2013). These findings indicated that a small subgroup of siblings of young people with cancer may be at greater risk for maladjustment. Psychological support for siblings is often limited (Newton et al., 2010). Siblings often remain inadequately informed, get excluded from discussions about their sibling's prognosis, and their grief is commonly overlooked (Stroebe et al., 2001). It is without saying that a non-normative event such as having a sibling diagnosed with cancer is likely to have drastic outcomes on one’s life. Thus, it is crucial to deepen our understanding of the social, emotional, physical, and psychological impacts of cancer in siblings of young people with cancer, as well as the mechanisms that underlie these consequences. This knowledge will enable the development of appropriate and equal support for siblings, as they deserve and need the same level of concern as their ill brother or sister (Cheung & Mok, 2013). Moreover, studies focusing on the importance of medical knowledge on the psychological adjustment of siblings have been scarce. Some studies have highlighted the importance of enhancing the medical knowledge of siblings of young people with cancer in order to decrease their level of anxiety (Sidhu et al., 2005), improve their moods, and change their perceptions of the effects of cancer on their lives (Carpenter & Sahler, 1991). Multiple studies have underscored the various needs of siblings of young people with cancer, often entailing the need for accurate medical knowledge (Long et al., 2015; Porteous et al., 2019; Tasker & Stonebridge, 2016). To our knowledge, no studies have directly addressed the impact of medical knowledge on siblings' ability to cope with having an ill brother or sister.

Aim and Purpose of the Present Study

This study aimed at providing preliminary qualitative data on the importance and the availability of medical knowledge in siblings of childhood cancer patients and its impact on psychological adjustment throughout and following the cancer experience. Moreover, this study aimed to highlight the needs reported by siblings of children with cancer to contribute to the limited existing knowledge of the impact of cancer on siblings and to better inform the development of supportive tools. Thus, this study answered three objectives described as follows:

Objective 1

The main goal of this project was to explore and address the following questions: What are the needs expressed by siblings of young people with cancer, and how can these needs be adequately fulfilled? Through the cancer experience, siblings often appear to be left out of both the family system (Long et al., 2015), intervention programs, and psychosocial research (Alderfer & Hodges, 2010). Their needs are often considered as being less important and are often unmet (O'Shea et al., 2012; Wilkins & Woodgate, 2005; Woodgate, 2006). Tasker and Stonebridge (2016) presented a thorough portrait of the needs expressed by sibling adolescents of children with cancer in British Columbia (Canada). The purpose of this project was to extend the literature on siblings' needs while contrasting the similarities and differences reported by Tasker and Stonebridge in the context of the province of Québec.

Objective 2

Objective two aimed to investigate the influence of accurate and age-appropriate medical knowledge of the disease on the psychological adjustment and well-being of siblings of young people with cancer. Considering the high variability in siblings' psychosocial functioning and psychological adjustment (Long et al., 2018), it is crucial to further our understanding of the mechanism of adjustment to better inform the development of intervention and support programs. The importance of providing an age-appropriate medical knowledge in order to facilitate the psychological adjustment of siblings of children with cancer deserves some serious research attention. It is of utmost importance to expand upon the limited existing knowledge of the needs of siblings during a cancer episode. This will enable the development of age-appropriate and individualized approaches to cancer, taking into account the well-being of the siblings within the context of the cancer journey.

Objective 3

Objective three aimed to analyze the research findings using the framework of existing developmental psychopathology theories, specifically the cumulative risk factor approach. It also aimed to address the limited evidence regarding the support provided to siblings of children and adolescents with cancer in the province of Quebec (Canada). One common criticism of the existing work on the impact of childhood cancer is the lack of connection of the findings with prevailing developmental psychopathology frameworks and theories (Alderfer & Hodges, 2010; Long et al., 2015). Thus, most studies fail to connect their findings within developmental trajectories in terms of the interplay of disease factors, the ability of the family system to cope and adapt to cancer-related events, and its interaction with the individual characteristics of the siblings (Long et al., 2015). Moreover, some studies fail to connect the findings with the general socio-demographic context of the recruitment setting. Therefore, objective three aimed to provide an overarching understanding of the cultural and economic context specific to Quebec, where this study took place. By considering this context, the research can bridge the gap between the findings and the broader socio-cultural factors that may influence the experiences of siblings of children and adolescents with cancer in Quebec.

Methods

Participants

Potential participants for this study were young adults who have a sibling who has or had cancer as a child or as an adolescent. Selection criteria included: 1) being between the ages of 18 and 35 at the time of the study, 2) having a brother, sister, stepbrother, or stepsister who has or had one or multiple cancer before the age of 19 (according to the childhood and adolescent cancer diagnosis of the Public Health Agency of Canada (2022), 3) to be living with their ill sibling at the time of the disease, 4) being comfortable speaking English or French, 5) living in Canada during the time of the disease. A retrospective study method was selected to provide more self-aware, informed, and articulated data (Lehna, 1998; Pompeo, 2009) from the vantage point of adults who are not presently immersed in the cancer experience, a similar protocol was used in Tasker and Stonebridge (2016). Participants were recruited from non-profit agencies which advocate and provide support and resources for families impacted by childhood cancer who agreed to share the recruitment information with their community (Appendix A). A similar method of recruitment is commonly used in recruiting such a population (i.e., Porteous et al., 2019; Prchal & Landolt, 2012; Tasker & Stonebridge, 2016). Participants who expressed interest in participating reached out via email and were sent an informative email (Appendix B) detailing the study. Before the interviews with the primary investigator took place, written consent (Appendix C) was obtained from the participants.

The present study involved six siblings as participants. According to O'Cathain et al. (2015), a sample size ranging from 5 to 20 is considered adequate for feasible qualitative research. In this particular qualitative study, a sample size of six proved to be sufficient for data saturation (O'Cathain et al., 2015). Data saturation refers to the point in qualitative research were collecting additional data no longer provides new or unique insights or information (Saunders et al., 2018). At this stage in the data collection, no new themes, categories, or significant information emerge from the data, indicating that the data set is comprehensive and sufficient for analysis and drawing conclusions. Data saturation is a critical factor in ensuring the depth and richness of qualitative research findings and was deemed to be achieved during the twelve interviews with the six participants.

Data Collection

Two methods were used to collect information from the sibling participants. First, a sociodemographic and cancer-related questionnaire (Appendix D) based on variables identified in the literature (Cheung & Mok, 2013; Evans et al., 2013; Hamama et al., 2000; Houtzager, Oort, et al., 2004; Long et al., 2013; Sloper & While, 1996) was administered to participants. Second, siblings participated in a semi-structured interview (Appendix E), which was based on the Sibling Illness Questionnaire (SIQ; Evans et al., 1992), the Sibling Perception Questionnaire (SPQ; Carpenter & Sahler, 1991) and Porteous et al.'s (2019) interview protocol. Acquiring rich data through intensive interviewing is believed to be a powerful way to provide an in-depth analysis of a phenomenon (Creswell & Miller, 2000). A second interview was scheduled a few weeks after the initial call to seek feedback and input directly from the participants. The purpose was to ensure that our interpretations and conclusions accurately reflected their experiences.

Although an in-person interview might usually be preferred to enable interpersonal contact (Brinkman, 2018), conducting an online interview allowed us to recruit participants from a broader geographical setting and allowed for more scheduling flexibility. The interviews were then conducted on Microsoft Teams, with the participant and the primary researcher present. The interviews were recorded, with the oral and written consent of the participants to later be transcribed for analysis.

Measures

Sociodemographic Characteristics. Marital status, family income, ethnic background (Long et al., 2013), and social support (Sloper & While, 1996) were reported to be associated with levels of distress and psychological adjustment in siblings of children with cancer. In addition, gender, income, parental education, single-parent households, teenager parenthood, non-White ethnicities, and psychological risks, such as life events, violence, family conflict, child separation from family, harsh and/or unresponsive parenting, and parental psychological distress have been identified as risk factors for maladjustment in siblings (Evans et al., 2013). Thus, it is important to examine the sociodemographic characteristics of each family to better understand the impact those have on the adjustment and mental health of siblings. The sociodemographic characteristic of the family was assessed through a questionnaire administered to sibling participants (Appendix D).

Cancer-related Variable. Cancer-related variables are rarely considered in the analysis of factors for psychological distress in siblings of young people with cancer. However, some findings suggested that the type of cancer (Buchbinder et al., 2011), the severity of the prognosis (Hamama et al., 2000; Houtzager, Oort, et al., 2004), the time since diagnosis (Cheung & Mok, 2013; Hamama et al., 2000), and the duration of the illness (Erker et al., 2018) might be relevant factors that impact psychological adjustment of siblings. Thus, questions about the type of cancer, the time since diagnosis, the length of the treatment, and the duration of the illness were included in the questionnaire to gain more knowledge about the impact of cancer-related variables on siblings' psychological outcomes. This questionnaire was administered with the sociodemographic questionnaires (Appendix D).

Medical Knowledge. Medical knowledge and understanding of the disease appear to be an instrumental factor in the psychological adjustment of siblings of children with cancer, as increased medical knowledge of the disease in siblings of pediatric cancer appears to decrease anxiety levels and general psychological distress (Houtzager et al., 2001). Medical knowledge and information about the disease can be provided both through formal intervention from the medical staff or through open communication from parents. Thus, questions regarding the source, the quality, and the quantity of the medical information received were asked during the semi-structured interview with the healthy sibling. The interview questions were based on the Sibling Illness Questionnaire (SIQ; Evans et al., 1992) a set of semi-structured questions designed to gather information about knowledge of the siblings about the illness. The Sibling Perception Questionnaire (SPQ) developed by Carpenter and Sahler (1991) was also used to guide interview questions to assess the healthy sibling's perception of the impact of the illness, on four domains: interpersonal, intrapersonal, communication, and fear of the disease (Sidhu et al., 2006).

Emotional Health and Well-being. Mental functioning, psychological health, and different aspect of well-being have received increasing attention in research; however, the body of work is fragmented into many different concepts and terms, which leads to a subjective definition of emotional well-being (Park et al., 2022). In 2018, Feller et al. initiated a national public health initiative focused on developing a unified definition of emotional well-being (EWB), as well as highlighting key concepts and approaches to measurement (Park et al., 2022).

Feller et al. (2018) defined EWB as:

> […] an umbrella label for several related psychometrically defined concepts, including psychological well-being, positive mental health, health-related quality of life, thriving, and subjective well-being. These concepts encompass several psychological dimensions, including positive emotions and moods (e.g., happiness); the relative absence of negative emotions, moods, and states (e.g., stress, sadness, loneliness); life satisfaction; sense of meaning and purpose; quality of life; and satisfaction with other life domains (e.g., work satisfaction, satisfaction with relationships) (Feller et al., 2018, p. 137)

Since EWB is associated with positive health outcome (Feller et al., 2018), it is a salient measure to consider when addressing psychological consequences of a traumatic event such as a cancer in a young sibling. Thus, this all-encompassing definition of well-being was used in this study. Participants were not asked to directly comment on their perceived emotional well-being, however, questions related to positive and negative emotions, moods, states, life satisfaction were discussed through the interviews to properly gain information on the impact of cancer on the general emotional well-being of siblings of young individuals with cancer.

Data Analysis

The interviews were conducted in French and transcribed and coded in the same language. Subsequently, certain quotes were selected and translated into English, while the original quotes can be found in Appendix F.

A five-stage data analysis method was used based on the framework presented by Pope (2000). Stages of the data analysis are as follows: 1) familiarisation and immersion in the raw data, 2) identification of thematic framework, 3) indexing systematically all data in textual form, 4) charting and rearranging the data according to the appropriate thematic framework and 5) mapping charts with defined concepts. This approach aims at capturing the voice and meaning of the participant’s perspective. Thus, after reading the transcripts and drafting a list of key ideas and recurring concepts, as described in the first stage of data analysis (Pope, 2000), key issues, concepts, and themes were examined and contrasted with previous literature on the subject. As described in the second stage of Pope's data analysis approach, the end product is a detailed index of data labelled with themes and subthemes. Through this process, numerous themes were identified. Transcripts were then annotated according to the previously created index, and passages of text were then broken down into smaller textual forms and indexed under the appropriate theme. Lastly, the data was charted and mapped according to the appropriate thematic framework. To ensure the data's representativeness and uniformity in identifying themes, the analysis approach followed Tasker and Stonebridge's (2016) protocol, given the absence of a current standard (Braun & Clarke, 2006). Themes included in the analysis were chosen based on the convergence of response patterns from at least 2 out of the 6 participants.

To enhance the credibility and trustworthiness of our findings, we employed respondent validation and peer debriefing as reliability tools. Respondent validation, also called member checking (Creswell & Miller, 2000) is believed to be "single most important way of ruling out the possibility of misinterpreting the meaning of what participants say and do and the perspective they have on what is going on" (Maxwell, 2013, pp. 126–127). Respondent validation involved seeking feedback and input from the participants themselves to ensure that our interpretations and conclusions accurately reflected their experiences. This process helps to validate the authenticity and validity of the data gathered. Thereby, to avoid any misinterpretation from the researcher, the participants were asked to comment on the findings and interpretations during their second meeting. Peer debriefing was utilized as a means of obtaining an external perspective on our research process and findings. Input and feedback from colleagues and/or experts in the field was sought and they reviewed our methodology, data analysis, and interpretations. Their insights and critiques provided a valuable source of verification and served to enhance the rigour and trustworthiness of our study. Cresswell and Miller (2000) stated that peer debriefing, or the process of having an experienced colleague review the findings and conclusion of your research is also an effective validity procedure. Peer debriefing was conducted to increase the trustworthiness and credibility of the research conclusion at different points during the development of the interview questions, and analysis process, including throughout the coding procedure (Creswell & Miller, 2000).

Critical Analysis: Cumulative Risk Factor Approach

Long et al. (2013) present a model of cumulative risk and distress in siblings of children with cancer where the higher levels of cumulative family risk were associated with higher sibling psychological distress. Such findings support the developmental psychopathology notion that child functioning can be better predicted by a higher number of factors than by the strength of any one factor alone (Long et al., 2013). Moreover, it has been established that children enduring harm and experiencing multiple risk factors were significantly more likely to develop psychological disorders and developmental issues (Rutter, 1979). These family risk factors might be related or overlapping (e.g., unresponsive parenting and parental distress) or independent (e.g., housing quality and absenteeism of parents). In both cases, it is suggested that the accumulation of risk factors has the worst developmental consequences compared to a singular risk factor (Rutter, 1979). Risk factors include sociodemographic variables, such as gender, income, parental education, single-parent household, teenager parenthood, and non-White ethnicity, and psychological risks, such as life events, violence, family conflict, child separation from family, harsh and/or unresponsive parenting, and parental psychological distress (Evans et al., 2013). In the context of childhood cancer, cancer-related risk factors are added to the pre-existing risk factors of the families. Therefore, the accumulation of risk factors is likely to increase adverse developmental consequences in siblings of pediatric cancer patients. Few studies examined the impact of cumulative risk factors on the development and psychological adjustment of siblings of children with cancer (Evans et al., 2013; Long et al., 2013), but these findings contribute to the argument that this model should be further investigated with this specific population.

Sample

Sibling Participants' Sociodemographic

Six sibling participants from different families agreed to participate. The sample was comprised of 5 female identifying siblings and 1 male identifying sibling, between the ages of 19 and 32 years old (M=25.90, SD= 4.78) at survey. At the time of the initial diagnosis, the sibling participants were aged between 3 and 19 (M=11, SD=6.26). Most were recruited through a non-profit agency which advocates and provides support and resources for families impacted by childhood cancer. Table 1 summarized the sociodemographic variables for the sibling participants.

Table 1. Sociodemographic Characteristics of Sibling Participants

Variables	
Sibling Participant	
Gender	N (%)
Female	5 (83.33)
Male	1 (16.67)
Age (years)	M (range)
At diagnosis	11 (3.00-19.00)
At survey	25.90 (19.00-32.10)
Birth Order	N (%)
First Born	3 (50.00)
Second Born	3 (50.00)
Sibling dyad	
Gender	N (%)
Female-female	4 (66.67)
Male-female	2 (33.33)

Participants Description

Participant 1 was the eldest child in her family, and her sister was diagnosed with cancer at the age of 2, while Participant 1 was 4 years old at the time. Nearly 30 years had passed since the cancer diagnosis when the survey was conducted.

Participant 2, also the eldest child in his family, experienced his sister's cancer diagnosis at the age of 6, while he was 12. His younger brother was 9 at the time of the diagnosis. Over 10 years had passed since the cancer diagnosis when the survey was conducted.

Participant 3, the middle child in her family, had her sister diagnosed with cancer at the age of 12, while she was 18, just a few months before the interview. Participant 3 also has an older brother. At the time of the first interview, her sister had been undergoing treatments for a few months.

Participant 4, the youngest of her family, was 14 years old when her older brother was diagnosed with cancer at the age of 16. Over 15 years had passed since the cancer diagnosis when the survey was conducted.

Participant 5, the eldest of her family, experienced her brother's cancer diagnosis at the age of 18 months, while she was 3 years old. He was diagnosed with a second cancer at the age of 12. At the time of the survey, her brother was still living with cancer but was not undergoing active treatment. It had been 20 years since the first cancer diagnosis when the survey was conducted.

Participant 6, the youngest in her family, was 14 years old when her older sister was diagnosed with cancer at age 15. Over 15 years had passed since the cancer diagnosis when the survey was conducted.

Family's Sociodemographic and Cancer-related Variables

The family's sociodemographic information was collected and summarized in Table 2. The six families all lived near main urban centers of the province of Québec. Sixty seven percent (67%) of the families lived in the Montreal Greater Area. All the families spoke French at home except for one family who reported speaking both French and English. All the siblings lived with both parents at the time of the disease. One sibling reported a divorce during the cancer

Table 2. Sociodemographic Statistics of Families and Caregivers

Variables	
Families	
Home Area at Diagnosis	N (%)
Greater Montreal*	4
Charlesbourg	1
Sherbrooke	1
Language at home	N (%)
French	5
Other	1
Caregivers (n=12)	
Age	M (range)
At diagnosis (years)	41 (27-60)
Education	N (%)
Undergraduate Degree	6 (50.00)
Trade School	2 (16.67)
Non-specified	2 (16.67)
College Diploma	1 (8.83)
Graduate Degree	1 (8.83)
Employment Status at time of disease	
Full-time work	7 (58.33)
Homemaker	4 (33.33)
Part-time	1 (8.83)
Religion	
Catholic or Christian	8 (66.67)
Not Applicable	4 (33.33
Marital Status (n=6 couples)	
At diagnosis	
Married or union	6 (100%)
At the end of treatment	
Married or union	5 (83.33)
Divorced or separated	1 (16.67)

*Laval, Ville Mont-Royal, St-Hubert, Montréal

treatment, all the other parents were married or in a legal union during the cancer treatment and at time of the survey. During the time of the cancer, four families, as reported by the sibling participant, had at least one parent leave their employment, work part time, or take a long leave of absence. Interestingly, the four parents who stayed home were female, regardless of their education level. Thus, the female caregiver appeared to leave their employment, even when they had a higher educational level than their male partner.

Table 3 summarizes the cancer-related variables. It is interesting to note that most of the participant's ill sibling were treated at CHU Ste-Justine, a pediatric healthcare center in Montreal, except for 2, who were treated at CHU Laval (in Quebec City) and CHU Sherbrooke (in Sherbrooke).

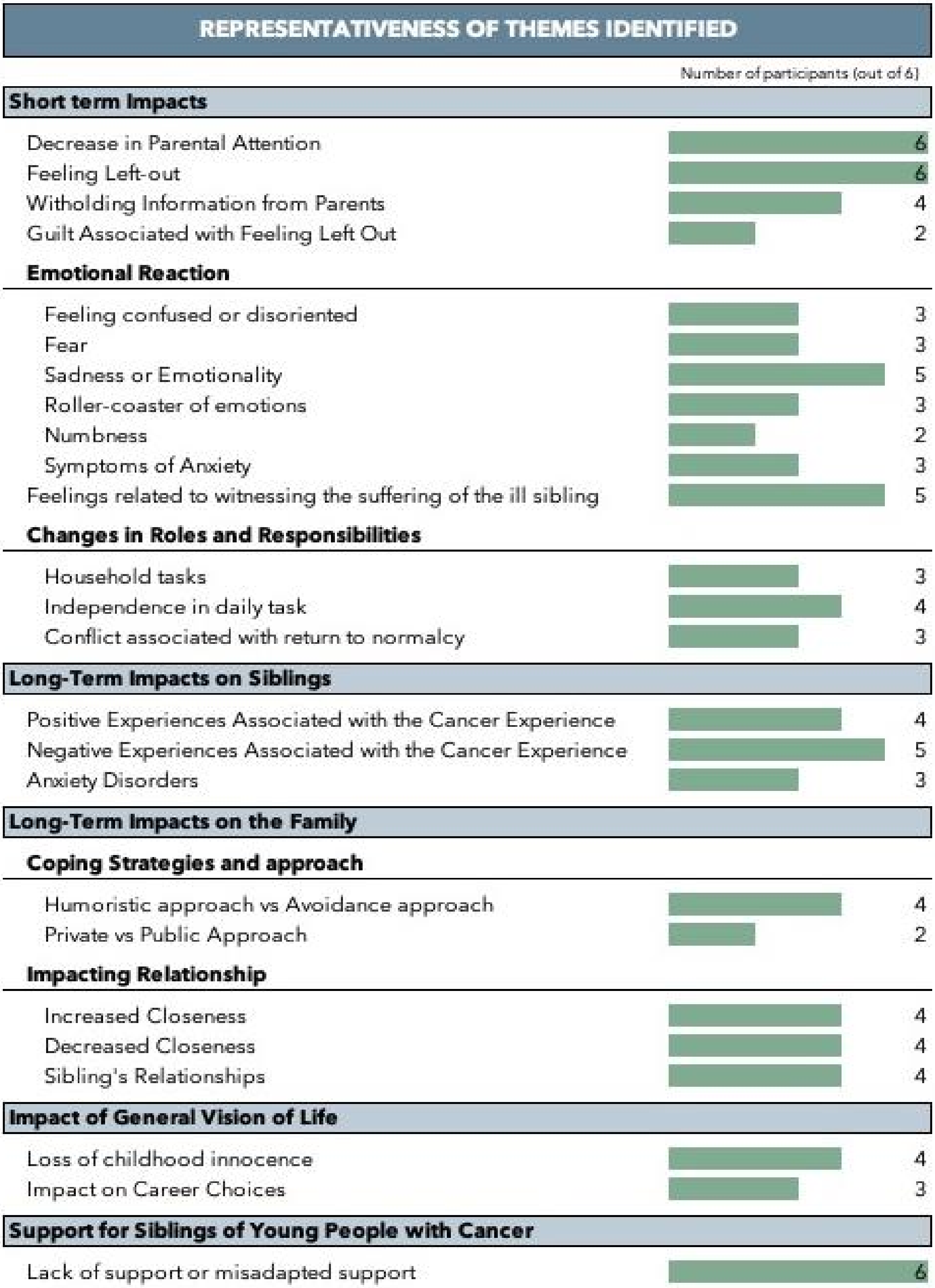
Table 3. Cancer-related Variables

Variables	
Cancer-Related Variables	
Age (years)	M (range)
At diagnosis 1 (n=6)	9.08 (1.50.15.00)
At diagnosis 2 (n=1)	12
Type of cancer	N (%)
Hodgkin's lymphoma	2 (33.33)
Ewing's sarcoma	2 (33.33)
Acute Lymphoblastic Leukemia	1 (16.67)
Metastatic Medulloblastoma	1 (16.67)
Types of treatment received	N (%)
Chemotherapy	4
Radiotherapy	3
HSTC	2
Experimental Chemotherapy	1
Amputation	1

Results

As mentioned earlier, the present thematic approach was developed using the five stages of data analysis proposed by Pope (2000). This approach aimed at capturing the voice and meaning of the participant's experience. There is no current standard to ensure representativeness and commonality in whose data contributed to the selection of themes (Braun & Clarke, 2006). Thus, in an effort to ensure representativeness and commonality, themes included in the analysis were decided based on a converging response pattern in 2 of the 6 participants. The analysis protocol was inspired by Tasker & Stonebridge (2016)'s study.

Figure 1 illustrates participant representativeness through the themes identified. Based on the themes identified, numerous categories were developed to regroup the patterns of responses. It is important to mention that the data collected through participant interviews were rich and in no way can all be included in this paper, thus this data analysis method described in Pope (2000) and the protocol presented in Tasker and Stonebridge (2016) were instrumental in deciding which pattern of answers would be included, to ensure representativeness of each participant.



Note: The visual representation of the importance of each domain is based on quantification of qualitative data.

Figure 1. Representativeness of Themes

This section will highlight the different themes identified in the thematic analysis as follows: 1) the short-term impact of cancer on siblings; 2) the long-term impact of cancer on siblings; 3) the impact of cancer on families; 4) the impact of cancer on the general vision of life of siblings; 5) the support of siblings of young people with cancer.

Short-Term Impact of Cancer in Siblings of Young People with Cancer

General Decrease in Attention

> It feels like you're being pushed out of orbit... as if your sister or brother is the center of that universe. You have the parents, the caregivers, the people orbiting around that center, but slowly, you're being pushed farther away from the center. You start feeling like a mere parasite spinning around. [Quote 1]

In accordance with previous findings (Porteous et al., 2019; Tasker & Stonebridge, 2016), siblings of young people with cancer patient reported feeling left out and feeling like their whole world was centered around their ill sibling, as poignantly illustrated through the previous quote. Tasker and Stonebridge (2016) reported that some siblings notably felt like everything revolved around their sibling. Likewise, some participants felt like people only asked about her brother and did not inquire about the well-being of the other family members. Participant 5 said:

> [...] even today, sometimes I have people reaching out to me and asking, "Oh, how's your brother doing?" It's not that it bothers me, but there's something more to it. ... it's also difficult for the people in the surroundings. [Quote 2]

Similarly, Participant 6 stated:

> I understand that we might be less important than the parents, but we are still a part of the family unit. [Quote 3]

Parental Attention. As aforementioned, numerous studies reported a shift in the family dynamic leading to a decrease in parental attention following a cancer diagnosis (Lähteenmäki et al., 2004; Long et al., 2017; O'Shea et al., 2012; Tasker & Stonebridge, 2016; Wilkins & Woodgate, 2005). This sense of decreased parental attention in siblings was mainly expressed as a feeling of isolation, rejection, and feeling excluded from the family unit. Participant 1 mentioned:

> It is very lonely. [Quote 4]

The lack of parental attention, and consequently the feeling of being rejected or abandoned and feeling like their needs were not as important, were the most commonly reported outcomes of pediatric cancer and was reported by all 6 participants. In accordance with previous findings (Prchal & Landolt, 2012), some participants expressed that parents were not only emotionally unavailable for siblings, but they were also often physically absent from their home and spent an increasing amount of time with the ill child at the hospital. Participant 2 shared his feeling of being isolated while his parents were physically absent from the home:

> Of course, during the first three to four months of the hospitalization, my brother and I felt somewhat isolated because my parents were never at home; they were always at the hospital. [Quote 5]

Similarly, only after a few weeks postdiagnosis, Participant 3 shared that her parents were noticeably caring less for her and more for her recently diagnosed sister.

> I saw a difference, of course…It's not that my parents do not take care of me anymore, but… yes kind of… [Quote 6]

Feeling abandoned within the family unit was reported quite often by siblings.

> The feeling of being abandoned is pretty present. [Quote7]

Feeling left out was also commonly reported, as stated by Participant 5:

> I spent more time with my grandparents, my godmother, and my godfather. I was everywhere at once. I felt sidelined, like I was being left out. [Quote 8]

Siblings expressed that although they enjoyed time spent with their friends and extended family, the time they spent alone with their parents was extremely precious and reduced their feelings of isolation, as also observed in Woodgate (2006). Participant 6 said;

> You can have family members come in to help care for the other children. I think it is the best compromise in the end. But ultimately, it is not replacing the presence of a parent. [Quote 9]

Both feelings of abandonment and isolation have been identified as being one of the most commonly reported outcomes of decreased parental attention in cancer-stricken families (Prchal & Landolt, 2012).

Withholding Information from Parents. Woodgate (2006) reported that all participants felt like they were not being cared for and had unmet needs because the entirety of their parents' attention was directed at the ill child's needs. The lack of parental attention had a significant consequence, as it often led to a feeling among siblings that they had to be the *"child who is doing okay"*. Some reported feeling like they had to be performing well in school, others felt like they had to be physically healthy, and some mentioned that they had to hide their emotionality, to avoid from adding to the family burden. They often stated they felt their needs were not as important as the other members of the family or did not feel like their parents had the time to care for their needs.

Two participants, adolescents at the time of the disease, reported hiding important health concerns from their parents. A participant shared her experience of hiding an important health concern from her parents during the treatment of her sister's cancer. She recalled:

> I was suffering on my own. But I had to make sure it wasn't showing. My parents only had one child left who was doing well. I didn't want to be the child who was also struggling. But it didn't help because it was extremely painful. [Quote 10]

Another shared a similar experience during the cancer treatment of her siblings:

> I didn't even feel comfortable bothering my parents about it. And yet, I have a really open family [...]. But in my mind, I didn't want to bother them because, to me, it wasn't important. [...] You make yourself small and only go to them when you really need to. [Quote 11]

The same participant also recalled another event occurring after the cancer treatment, she confessed:

> Then, on the other hand, I think the biggest impact then or now… I've had a tumor afterwards as well. And I hid it from my parents until the end because I thought to myself *yet another problem that they will have to manage*. I did not want to add to it [...]. I think in my personal life today, it's just that I really keep things to myself. When it is necessary, I say it, I had to have surgery (to remove the tumor), so I told them about it. When it is necessary, it is necessary, but otherwise I do not talk about it. I don't want to add to the anxiety of my family, I don't want to be another case. [Quote 12]

These two participants highlighted a crucial concern regarding feeling like their well-being was not their parents' priority and the pressure to appear *okay* to avoid adding to the family's burden, even years after the disease. Participant 1 reported constantly hiding things from her parents to protect them, and still does to this day, whereas Participant 3 reported hiding her emotional reaction from her loved ones:

> At first, I was hiding a little more. Now, she is doing better so I don't have to hide as much. It's been difficult for everyone, so I didn't want to add to it. [Quote 13]

Those findings are in accordance with previously published studies reporting that siblings often withhold their feelings to protect their parents and avoid additional stressors and sources of worries (Long et al., 2017; Woodgate, 2006). Furthermore, our results showed that this withholding of feeling and important aspects of their life did not subside after the cancer experience, and siblings reported still hiding or withholding information from their parents, even years after the cancer experience.

It is indeed noteworthy that previous studies have not explicitly highlighted the change in role and perception experienced by siblings, wherein they feel compelled to appear *okay* during and even after the cancer experience. This pattern of behavior and its implications deserve further exploration and investigation.

Siblings' Guilt in Seeking Parental Attention. Although siblings understood why their parent's attention and time were directed at their ill sibling, they still felt isolated. Participant 2 remembered:

> My brother and I felt isolated, but since it was for my sister, I did not mind. I knew she was sick. [Quote 14]

Another participant reported an outburst of frustration and anger towards her parents; she recalled:

> One time I told my parents and yelled *I know I have no rights to say this, but you are no longer taking care of me*. [Quote 15]

This feeling of guilt has undoubtedly impacted the siblings interviewed, as also reported by others (Kramer, 1981, as cited in Sidhu et al., 2005).

Perceived lack or decrease in attention was decisively the most potent and commonly reported impact of having a sibling with cancer. Whether siblings felt a decrease in attention from their parents, other family members, institutions, or the medical system, we must bring an educated approach to intervention that is oriented toward the needs of siblings of young people with cancer.

Emotional Reaction

All participants expressed feeling some kind of emotional reaction at the time of the diagnosis and later during the treatments of their ill siblings. Participant 3 said:

> I felt disoriented. I did not understand what was going on. [Quote 16]

Similarly, Participant 2 remembered feeling confused:

> Of course, I was still pretty young, so at first, I didn't really understand what cancer was. At 12 years old, I didn't fully grasp the implications. [Quote 17]

Participant 5 felt equally confused by the cancer diagnosis of her little brother. She said:

> It was, of course, a lot of incomprehension. At 3, I don’t think you are realising everything that is going on. [Quote 18]

The disbelief and perplexity of receiving a cancer diagnosis in a young sibling are consistent with the literature (Long et al., 2015). Long et al. reported that nearly all siblings confessed feeling shocked at the diagnosis.

Fear was reported in 3 out of the 6 participants. Additionally, almost all siblings testified to their extreme sadness and high emotionality when recalling the diagnosis. This feeling of sadness was believed to stem from the extent of changes they had to endure over the course of the cancer treatments, as well as witnessing the suffering of their siblings (Woodgate, 2006). Accordingly, Participant 2 confessed that seeing the suffering and psychological and physical changes in his sister through the treatments was particularly sad to witness. Alternatively, Participant 4 attested to experiencing heightened emotionality, resulting in increased sensitivity.

> That day, I cried like crazy. I was at school, and I just cried, like, *Oh my God, my brother might have cancer*. I didn't go to class that day. I just stayed in the common area, crying my heart out with my then-boyfriend. They let me skip class and just cry. [...] Honestly, emotionally, I was handling it pretty well, I think. Other than being really emotional. Even my teachers noticed the difference, and this was in grade 9. I went from being a happy little girl to *I would cry over anything*. If you even slightly upset me, I would burst into tears. […]. Everyone started being really kind to me. Because, otherwise, I would cry anyway. [Quote 19]

Interestingly, Long et al. (2015) conveyed that fear of mortality was associated with strong emotional responses. However, most participants stated they were not aware nor realized that their sibling could potentially pass away from this disease at the time.

Moreover, as mentioned in the literature, some siblings compared their emotional reactions to a roller-coaster of mood states and emotions (Long et al., 2015). To that regard, Participant 6 recalled a mix of emotions through the treatment and remission period, which varied from intense fatigue, confusion, extreme frustration, and sadness, feeling depleted by the odds of survival, to feeling grateful.

> I would say it's different during the treatments compared to the remission period. I couldn't pinpoint one specific feeling: it's a mix of emotions depending on the situation. During the treatments, it's a combination of fatigue, confusion, feeling extremely angry, and extremely sad. It's like fighting against odds that are not in your favor. And during remission, I would say it's incredibly grateful. You appreciate life much more, but at the same time, it's also very stressful because you know it could change at any moment. But ultimately, it's a feeling of gratitude. [Quote 20]

Interestingly, Participant 6 also recalled feeling a profound numbness through the disease; she said:

> You function on adrenaline, you don't question it, you have to go, you have to do it, you have to go to the hospital, the appointments. You don't really have a choice, so you operate on some kind of auto pilot, unconsciously, maybe I was already having (some anxiety), but consciously, it was only later. [...]. It was just like an automatic response, I don't know. [...]. I was like a robot. [Quote 21]

Symptoms of Anxiety. Previous studies identified anxiety symptoms and disorders as a potential impact of childhood cancer on siblings but established that only a small proportion of siblings fell into the clinical range for self-reported anxiety (Alderfer et al., 2003; Kaplan et al., 2013; Long et al., 2018). Congruently, two siblings recalled feeling anxious at the time of the disease and following the treatments. A participant reported not only feeling extremely anxious but also feeling misunderstood, as her feelings were constantly disregarded and invalidated.

> I was always seen as the weird one, the anxious one. I wasn't "childlike" enough, not relaxed enough, not fun enough, not living in the present moment enough. [Quote 22]

Similarly, another participant recalled being very anxious as a child, a consequence she attributed to her brother’s cancer. She mentioned spending most of her time with adults and evoked developing irrational fears when separated from her family.

> I was afraid of everything. I was scared that it would rain because I would get lost in the school. I was just scared. I was making weird connections that seemed impossible, but I still made them. [Quote 23]

Interestingly, the subsequent participant reported not experiencing any lingering anxious symptoms from the cancer experience, whereas the previous participant mentioned retaining a significant anxiety disorder. Two other participants expressed dealing with anxious disorder later in life but not at the time of the disease. Long-lasting anxiety disorders and symptoms in participating siblings will be discussed below. These findings are consistent with previous results (Alderfer et al., 2003) and contribute to the argument that a small subgroup of siblings of children with cancer is at increased risk for psychological maladjustment.

Witnessing the Ill Sibling's Suffering

One frequently mentioned yet often neglected aspect of childhood cancer is the direct link to the emotional impact experienced by siblings who witness their ill brother or sister undergoing cancer treatment and dealing with the side effects of medical procedures. Those findings are consistent with previous results that highlight the significance of the negative impact of being a bystander to the suffering and changes in the psychological and physical state of their sibling (Prchal & Landolt, 2012). Some sibling participants reported feeling sad for their sibling, but others reported feeling extremely uncomfortable and preferred to stay away from witnessing this pain, both reactions have previously been reported in the literature (Prchal & Landolt, 2012; Woodgate, 2006).

> I think that was the hardest part, was when he came home looking really beat and just kept vomiting. When he was in the hospital, it was one thing because I couldn't see him, but when he was right in front of me... Honestly, I would often try to escape. When he was there, I would mentally check out, go to my friends' places; I had a hard time seeing him like that. Especially on bad days, it seemed like I was more focused on avoiding the situation than anything else. [Quote 24]

As mentioned in Prchal and Landolt (2012), physical changes that were especially difficult for siblings to observe were the loss of hair, the drastic weight loss or gain, seeing them connected to medical equipment, and seeing them experience high levels of pain and discomfort. Participant 2 mentioned feeling powerless while witnessing the suffering and physical and psychological changes in her sister during the treatment and identified it as the worst part of the cancer experience. For him, observing the loss of his sister's hair was emotionally challenging, despite being aware that it is a widely recognized side effect of cancer treatment. In addition to hair loss, he also noticed significant changes in his sister's body, such as water retention in her face, which he believed should not be overlooked. He said:

> There are other bodily changes that, in my opinion, are just as difficult to witness as hair loss. Water retention, for instance, can be quite intense. The round head, like a soccer ball, it's a significant physical change to see on your six-year-old sister. [...] I would say the hard part is seeing my sister being different from how I knew her before. Especially during chemotherapy. [...] Cortisone really causes facial swelling. Hair loss is less stigmatized. Everyone knows that it happens. Of course, there are physical changes and also behavioral changes that we can’t overlook. I would say they are even worse than the physical changes. [Quote 25]

Additionally, Participant 6 recalled hearing her sister yell in pain, which was undoubtedly extremely troubling and is a memory that has haunted her for over fifteen years. Participant 2 also reported important and shocking behavioural changes in the ill child, which was also reported as very difficult to handle for siblings, as also previously suggested in Prchal and Landolt (2012). As a side effect of the medication, some ill children were often reported to be aggressive, moody, passive, unreasonable (Porteous et al., 2019; Prchal & Landolt, 2012), demanding, and prone to outbursts (Long et al., 2015).

> Yes, it does change the person's physical appearance, but it also affects their mental well-being. Not just chemotherapy, but other antibiotics and medications she had to take due to being immunosuppressed, like Decadron, really altered her personality. [...] It can lead to aggression,

> impulsivity, and some unique emotional food cravings. [...] Of course, the physical changes on my sister due to the side effects, that was something that made me feel sad, sad for her, for sure. [Quote 26]

Participant 2 mentioned knowing that these side effects were very common and to be expected with the treatment protocol his sister was undergoing. However, he still felt unsettled in witnessing those changes in his 6-year-old sister. As Long et al. (2015) stated, even with the knowledge and understanding that these behavioural changes were directly related to the treatments, it was very difficult for siblings to witness and deal with these fluctuations in behaviour. Similarly, Participant 3 reported observing changes in the mental and emotional state of her sister at different moments in the rounds of chemotherapy. Participant 5 also stated that her brother still lived with important long-term consequences of cancer and its treatment to this day, which she said were very difficult to witness.

> It's a lot of side effects. My brother underwent very intense radiotherapy at a very young age. It was a level of radiation that normally isn't given to a child because it was so strong. But it was the only way to target the tumor. They administered very strong treatments, but my brother experienced so many side effects from it, whether it's academic difficulties, balance issues, dizziness, or migraines. My brother lives with migraines every single day of his life. [Quote 27]

She conveyed that those side effects have a significant impact of not only his brother's life but also the rest of the family. Even if her brother is now an adult, he remains unable to fulfill some of his responsibilities and requires the help and support of his parents. She stated that those non-negligible long-term side effects are often misunderstood and overlooked. She described a persistent sense of helplessness that has endured throughout the years, up until this very day.

These findings contribute to further our knowledge that exposure to the physical and emotional pain of their ill brother or sister, and witnessing invasive and long-lasting cancer treatments might be associated with low adjustment, high emotional pain, and symptoms of traumatic stress in siblings of young people with cancer (Alderfer et al., 2003) and need to be further explored.

Changes in Roles and Responsibilities

As highlighted in the literature, an important shift in roles and responsibilities can often be observe as a family adapts to the challenges associated with having a child with cancer. One of the first noticeable outcomes of this adaptation in the family unit is observed as healthy siblings often take on some of the roles and responsibilities previously carried out by their parents (Long et al., 2015). Three siblings mentioned having to take over meal preparation, especially during adolescence.

> I learned to be independent at a young age. At 14, I had to cook my own food. It rapidly pushes you to be responsible and take care of yourself. [Quote 28]

Participant 2 also reported taking on responsibilities related to taking care of his younger brother during the time of his younger sister's cancer:

> I had to take the role of taking care of my brother sometimes. […] In the morning, either my mom or my dad, the one that spent the night at home would drive my brother to school and would leave for the hospital. But at night, I would pick him up at school and things like that. [Quote 29]

These findings are consistent with the literature on siblings of children with cancer, as increased roles and household duties have been commonly reported (Long & Marsland, 2011; Porteous et al., 2019; Prchal & Landolt, 2012). One participant reported that this increase in responsibilities naturally led to an increase in autonomy and independence, which he viewed as a positive consequence of childhood cancer.

Interestingly, it was returning to traditional roles that appeared to be most disruptive to the family system. Three siblings reported conflict associated with the parents returning to their *typical* role of caretakers, either following the remission or the passing of the ill child. One participant shared:

> Since I was 14, I've been independent in the sense that I could do what I want with my evenings, and stuff. I didn’t have to be accountable to anyone, and there was no curfew. But when I turned 16 and my brother's cancer treatments were over, I started living with my parents full-time again, and suddenly, my mom wanted to act like a mother. I remember telling her: *Don't start that now, you're not my mother anymore. It's been two and a half years since you stopped playing that role. And now you're telling me what time to come home, asking what I've eaten, if I've done my homework?* It didn't sit well with me. That's just how it was. Once I tasted my independence and they let go of that role, they couldn’t reclaim it. [Quote 30]

Three participants shared a similar experience after the cancer episode. They reported encountering conflict related to parental attention, discipline, and control, which had been redirected toward them after a period of independence. Consequently, it seems that the disruption in the family dynamic occurs twice for some families. The initial disruption which took place when the family received the cancer diagnosis, and healthy siblings assumed some responsibilities previously handled by their parents. However, during this time, siblings also experience a degree of newfound independence, particularly those in adolescence. The second disruption occurred after the cancer episode when parental attention shifted back to the healthy sibling. Naturally, parents seek to re-establish their parental role and regain some control over the daily lives of their healthy children, including curfews, nutrition, schoolwork, and social activities. This change in autonomy, gained during the illness, followed by its loss as routines return to normal, unsettled the family dynamic. The second disruption appeared to generate more conflicts than the first among family members, leading to frustration in siblings and significant tensions within the family unit.

Long-Term Impact of Cancer in Siblings of Young People with Cancer

General Emotional Well-being and Psychosocial Adjustment

As aforementioned, an umbrella definition, defined by Feller et al. (2018), was used to conceptualize the general emotional well-being and psychosocial adjustment of siblings. This definition includes different psychological dimensions, “including positive emotions and moods (e.g., happiness); the relative absence of negative emotions, moods, and states (e.g., stress, sadness, loneliness); life satisfaction; sense of meaning and purpose; quality of life; and satisfaction with other life domains (e.g., work satisfaction, satisfaction with relationships)” (Feller et al., 2018, p. 137).

The long-term consequences of pediatric cancer have already been addressed in the literature pertaining to childhood cancer (Alderfer et al., 2003). However, some studies identified salient long-term outcomes in siblings of children with cancer, including poorer quality of life (Houtzager, et al., 2004), anxiety, depression, posttraumatic symptoms of stress (Alderfer et al., 2003), and social and academic disruption (Lähteenmäki et al., 2004). Although most negative consequences of childhood cancer on siblings appear to occur in the early phases of the cancer experience (Gerhardt et al., 2015), it is believed that some experience long-lasting consequences. Therefore, it is crucial to deepen our understanding of the long-term impact of these experiences. By doing so, we can normalize the consequences siblings face, establish a standard of care that focuses on prevention, and provide improved support to siblings during and after the cancer experience. This approach aims to address the unique needs and challenges faced by siblings, ultimately enhancing their overall well-being and resilience.

The majority of siblings interviewed conveyed that their experience with cancer was generally more negative than positive. However, Participant 2 held a distinct perspective, expressing that he did not perceive any long-term negative consequences resulting from the illness. Instead, he identified several aspects of his family's encounter with cancer that had positive effects. Participant 2 specifically expressed feelings of gratitude towards their extended family and friends who rallied together to support him and his family during their time of need. Additionally, he expressed appreciation for the scientific advancements and professional assistance his sister received for her cancer treatment.

> I take away some positive! My family and friends of the family helped a lot. I still feel that even today. The fact that I gained for independence and autonomy quickly is a positive impact. […] I mostly feel grateful for the doctors, the nurses, and the treatment protocols developed by researchers. [Quote 31]

Similarly, Participant 5 conveyed some gratefulness when recalling the experience of her brother's childhood cancer.

> I would say that it brought a lot of positive things into my life. Many things happened because of my brother's illness, and it led to maturity, independence, and all these other things. [Quote 32]

Nevertheless, she also recalled important negative consequences of cancer on her life and her family's life. Participant 1 and 4 confessed to feeling more negative consequences regarding their experience with cancer. They both said that the negative outcomes are related to the impact of cancer on their current mental health and on their family dynamic. However, Participant 4 stated that one of the positive experiences she retained from living with an ill sibling is the importance of seeking professional mental health help when needed. Interestingly, Participant 4 mentioned that her experience with cancer helped her become more comfortable with hospital settings and the health care settings, whereas Participant 6 recalled a complete loss of trust in the healthcare setting due to the treatments her sister endured.

Anxiety Disorders

Three participants mentioned having a severe anxiety disorder, which developed through adolescence and young adulthood. A participant mentioned having been diagnosed with an eating disorder in her youth and severe anxiety disorder in adulthood, which she directly attributed to her sister's cancer and its subsequent consequences. She indicated being still very distraught with regards to the cancer experience of her and her family. She stated that she only started to properly cope with the cancer and the subsequent death of her sister in her twenties, decades after her passing. Another participant reported a general anxiety disorder which she attributed in part to her brother's cancer and other cancer occurrences in her loved ones. A third participant reported episodes of extreme distress and reported suffering from panic attacks and what appears to be a serious anxious disorder, even years after the cancer and death of her sister. She reported feeling extreme fatigue and burned out in all the dimensions of her life.

> I was burned out all around. It was not only school, but it was also an emotional generalised burn out. I hit a wall at some point, because whether you want it or not, in the following years (after the death of a sibling) you have to take care of your parents, you want to be the child that is doing okay. You try your best to go back to a somewhat normal life, but I burned out trying to do that. To this day, anxiety is a problem… especially panic attacks. [Quote 33]

All three participants mentioned seeking professional help on their own to help them cope with the emotional distress they were feeling in late adolescence and young adulthood. Additionally, they conveyed that it was challenging to find support tailored to their specific needs and therapists equipped to help them cope with the unique challenges of being the sibling of someone who has or had cancer during their youth. Moreover, a fourth participant mentioned feeling distressed at times and feeling unsupported in those emotions. This participant mentioned a desire to confide in loved ones but hesitated due to the belief that they were also grappling with their own challenging emotions related to the cancer experience. Consequently, she expressed a wish to have someone outside of her immediate family to whom she could openly share her emotions about her personal journey with cancer without burdening her loved ones with her emotions. One participant also mentioned further adverse consequences, including a profound difficulty in developing and maintaining relationships with others, a difficulty experiencing happiness, a refusal to take vacations, as well as some symptoms of posttraumatic of stress. She said:

> To this day, it's haunting me, because I would hear her scream in pain at night when she would be home. [Quote 34]

On the other hand, Participant 2 reported not feeling any emotional consequences of his sister's pediatric cancer. Those findings are consistent with the literature (Gerhardt et al., 2015), in that there is a wide spectrum of severity of long-term emotional consequences.

Bereaved siblings

It is important to mention that two of the participants experienced the loss of their sibling to cancer. Some studies highlight the differences in bereaved siblings of young people with cancer in terms of emotional well-being and long-term adjustment (Gerhardt et al., 2015). Bereaved siblings experienced more signs and symptoms of psychological distress, which was not only associated with the death of the child but also with the unfavorable prognosis, the difficult course of the illness, and the severity of their sibling's prognosis (Houtzager, Oort, et al., 2004). For both bereaved siblings interviewed, the end-of-life support appeared to be very ineffective and insufficient. One confessed having a very brief meeting with her sister's doctor only a few hours before her sister's passing:

> I had a ten-minute meeting with the palliative care doctor. It was the only meeting I had where he said, *Here's what's coming. Do you understand what it means?* But ironically, I had that meeting on Friday, and my sister passed away on Saturday morning. [Quote 35]

This lack of acknowledgment and preparation left her feeling left out and unimportant and made the grieving process extremely difficult as she did not get the chance to say goodbye. She reported feeling ripped off this extremely important grieving process which she believed would have been possible if the medical personnel had considered her grief in the process of the end-of-life care of her sister. Another sibling, who was considerably younger when her sister passed, mentioned not receiving any support prior, and following the death of her sister.

Impact of Cancer on Cancer-Stricken Families

Family Coping Strategies.

Sibling participants reported different family coping strategies and ways of dealing with the ill child's death. One participant described her family's coping process as extremely tenuous as they lost their child to cancer in her childhood. Even after 25 years, she confessed:

> Actually, we don't talk about it, no. We don't talk about it, there are no photos, we don't talk about it at all. I think it was a sense of pride when we had come out of it and we were still in good spirits. It wasn't in line with the image our family chose to portray, to be defeated by it. It was like, "No, we don't talk about it." [...] My parents never sought counseling, they never... For them, they are proud that we came out of it without help, but I don't think that was necessarily a good thing. I think, yes, in the moment, they couldn't do anything differently, but afterwards, there are things that could be done. [Quote 36]

Interestingly, she expressed different opinions about how her parents have managed the terrible situation of losing a child to cancer. She recalled:

> No, I think my father would want to talk about it all the time. My mother never wants to talk about it. As for me, I think I started bringing it up later on […]. Even today, when I bring it up to them, they still tell me that it wasn't that bad for me and that they did everything they could, and I shouldn't feel that way. But that's not my point. It's like whenever we try to talk about it, someone always feels frustrated. My father would want us to talk about it and have celebrations. My mother would prefer we never talk about it again, as if it never happened. My sister, she's like, *a sister I never knew, why are you talking about her.* It's like everyone, nobody is in a state of calm and acceptance. [Quote 37]

Likewise, another bereaved sibling participant, who lost her older sister to cancer recalled that her family dealt with the cancer diagnosis and subsequent death of their oldest child in a very private manner. Moreover, she recalled her father being extremely emotional in announcing her cancer relapse.

> All the details that are really specific to my sister, her state of mind, and everything. We kept it to ourselves. We are a very private family. We're not the kind of family that has active social media. We tend to keep things to ourselves. [Quote 38]

By contrast, another participant's family decided to start a *GoFundMe* page to collect some financial support and bring some awareness to their child's situation. Alternately, Participant 2 experienced a completely different family adaptation. His sister survived her childhood cancer and underwent treatments for about two years.

> Yes, since my sister has been doing well, we laugh about it. It's not a taboo subject in my family. [Quote 39]

Interestingly, he considered that this way of coping and addressing the distressing time with his family, using a humoristic approach, was the result of healthy coping mechanisms and appropriate family adjustment. Moreover, they consider themselves to be lucky overall. He said:

> I would say that within the family, the consensus is probably that we were fortunate in an unfortunate situation. We got *lucky* with an acute lymphoblastic leukemia, but with an established treatment protocol that has been around for years, and a relatively low mortality rate for those who respond well to chemotherapy. It becomes evident in the first few months who responds well. We felt that we were somewhat lucky in our misfortune. Of course, no one is fortunate to have cancer, but when it is curable, we consider ourselves lucky in that moment. [Quote 40]

Furthermore, Participant 4 recalled that her family also now uses a humoristic approach when discussing the cancer of her brother. However, she mentions that although cancer was already part of their family history, it became somehow *taboo* during her brother's treatment. She mentioned that it was perhaps a way for her parents to keep some sense of normalcy during the cancer experience.

As previously mentioned, it is important to view siblings within the context of the family unit rather than as independent individuals. These findings align with existing literature in two ways. Firstly, it acknowledges that every family has a unique experience when it comes to cancer, indicating that the impact on siblings can vary significantly across families (Long & Marsland, 2011). Secondly, it recognizes that certain families and individuals within them may experience difficulties in adapting to the challenges posed by a cancer diagnosis, potentially leading to impairment in family functioning (Long & Marsland, 2011). Consequently, the ability of a family to change and adapt in response to the challenges of a cancer diagnosis is crucial in promoting positive psychological outcomes for children, including siblings (Long & Marsland, 2011). By understanding and addressing the dynamics and functioning of the entire family system, interventions and support services can be tailored to enhance the overall well-being and adjustment of siblings within the context of their family's cancer experience.

The Impact of Cancer on Family Relationships

Participant 2 admitted that the cancer experience created stronger bonds between all the family members and increased the general family cohesion. A feeling also shared by Participant 3, who, although was still going through the cancer experience at the time of the survey, believed her family would grow closer as a result. However, one of the study's most surprising finding was the distinctive transformation in relationships within certain family units. For instance, several siblings acknowledged that the cancer experience had resulted in significant emotional distance among family members. Those strained relationships were, for some transient, for the time of the treatment; for others lasting for years after the cancer experience. A participant shared details about her family situation during the cancer of her sister as she had the opportunity to live with a friend of the family. She recalled having mixed feeling about moving out of the house because she felt isolated from her parents and brother, who got increasingly closer during the treatments.

> On the other hand, it had a negative impact because my parents became completely focused on my brother. I, on the other hand, felt like the outsider. [Quote 41]

For Participant 4, the family adaptation following the cancer experience appeared to be extremely challenging and created long-lasting strains in the family dynamics. Even years later, the participant vividly remembered that her family had to put in significant effort to rebuild and improve the quality of their relationships. On the other hand, Participant 5 shared that due to the need to sustain the family finances, her father had to work away from home for extended periods of time. As a result, he was mostly absent during the week and spent most of his free time at the hospital with their ill child. The participant revealed that this situation had a clear impact on her relationship with her father, which continued to be challenging even to this day. Her father's absence and focus on the ill child understandably had consequences on the connection and closeness between them. Similarly, another sibling shared that she had significantly different relationships with her mother and father. She remembered feeling unable to communicate openly and honestly with her father, starting from the time of the cancer diagnosis. Even to this day, the relationship with her father remained extremely difficult for her. Furthermore, this family endured the additional challenge of going through a divorce during the illness. This added stressor likely further complicated the family dynamics and had a lasting impact on the sibling's relationships with both parents. However, she recalled the divorce not being extremely disruptive as the family was already living separately due to the demands of the cancer treatments.

> To be honest, even though my parents hadn't officially divorced yet, it already felt like I was living in a shared custody situation. Because I no longer lived with my mother. Since the diagnosis, she was always at Sainte-Justine. It was just me and my father, and my sister and my mother, but we weren't really a cohesive family unit for a very long time. So, when the divorce happened, there wasn't much of a real difference, except that occasionally it would change where I slept. We were already divided as a family unit. It didn't change much. [Quote 42]

These accounts highlighted the significant strain that a cancer diagnosis can place on family dynamics, particularly the parent-child relationships. These long-lasting effects demonstrate the importance of addressing and repairing such strained relationships within the family unit, even after the immediate cancer experience has ended. It is clear that family relationships sustain an incredible number of challenges during a cancer experience. Most studies addressing the impact of cancer in young individuals on the family system typically address parental conflicts or sibling relationships but rarely discuss how the cancer experience can impact the relationships between healthy siblings and their parents.

Siblings' Relationships. The literature reported that siblings of young people with cancer had some difficulty maintaining their relationships with their other siblings and parents due to each other's psychological distress and reported that hospitalization periods were especially difficult on the siblings' relationships (Woodgate, 2006). Accordingly, some sibling participants felt like their relationship with their sibling was minimized and forgotten through the process of the cancer treatment. They stated that despite their relationship being extremely strong, they felt that little support was aimed at maintaining and utilizing this relationship during the treatments.

> I think the relationship between siblings is really important. My brother confides in me much more than he does with our parents. It's still the same. There are many things he won't tell our parents. [Quote 43]

One participant heartbreakingly described how she felt like she had been robbed off quality time with her sister. She expressed a poignant sentiment that she did not have a single moment of fun and joy to share alone with her sister, after the cancer diagnosis, despite their previously close relationship.

> My sister and I were extremely close. We never fought. We were like soul mates. Even today, I still consider my sister to be my soul mate. We didn't spend much time together. She was diagnosed in December, and we didn't have many moments just the two of us, having fun before she passed away. So, finding a way to make that time easier would be important to me. [Quote 44]

Nevertheless, some participants recalled great memories shared with their siblings at the hospital. For instance, Participant 5 recalls still having some joyful moments with her brother through the cancer treatments. Participant 1 similarly recalled:

> We were at Sainte-Justine, there were organized activities. It wasn't necessarily negative memories. It felt like we were spending quality time together, just like we would at home. [...] We also had the opportunity to experience the Make-A-Wish trip to Walt Disney with my sister. Those moments were incredibly powerful. They are truly beautiful memories. [Quote 45]

Impact of Cancer on Siblings' Life Perspectives

The presence of cancer in the lives of siblings of young people with the disease can have a profound impact on their overall perspective and outlook on life. Two main categories were identified pertaining to the general shift in sibling's vision of life: a loss of childhood innocence, and the impact of cancer on their career choices.

Loss of Childhood Innocence

A frequently overlooked aspect in the literature concerning siblings of young people with cancer is the loss of childhood innocence. Participant 1 said:

> It's for a kid, like I said, you stop believing in Santa Claus really quickly. There is no more Santa Claus. [Quote 46]

She recalled that she was quickly made aware of some topics of conversation that children are typically shielded from:

> We were discussing money, illness, and other very adult topics. It was like being push into adulthood at a rapid pace. [Quote 47]

This impression was openly shared by 4 of the siblings interviewed. They recounted how the cancer diagnosis and its effects on the family dynamic forced them to mature and grow up quickly. Accordingly, increased expectations of maturity and autonomy were the more potent outcomes of this premature loss of innocence. One participant, specifically mentioned embracing the increased maturity that resulted from the cancer experience, recognizing it as a catalyst for developing her entrepreneurial personality. However, she also expressed the challenges she faced during childhood, struggling to connect with peers due to the accelerated maturity imposed by her brother's cancer, which set her apart from her same-aged peers.

> But it was definitely difficult for a while to relate to other kids in a certain way because we weren't going through the same things and doing the same activities. We weren't growing up in the same way, that's for sure. [Quote 48]

Impact of Cancer on Career Choices

Three out of the six participants admitted that their career choices were influenced by the experience of their family with cancer. Interestingly, the rationale behind those choices varied. Participant 2 was not sure at first that the cancer of his sister had an impact on his occupational choices, but then admitted that it might have been an important event in shaping his interest, and through the conversation realized that his curiosity for research in oncology might be related to his experience in supporting his sister through cancer. Alternatively, a participant was adamant that her brother's cancer and the illnesses of other family members highly influenced her career decisions.

> Certainly, I believe that my career choice has been greatly influenced by all the illness in my family. Yes, I work in healthcare today because of it. [...] Because I have been immersed in the realm of helping others, healthcare, and illness my entire life, I shaped my career around it. Now, I realize that without that experience, maybe I would have chosen something else. I might have become a teacher or pursued a different path, but I have known nothing else but this. [Quote 49]

Despite expressing being very happy with her life decisions, she openly admitted to wondering whether those choices were truly made freely, considering the influence that cancer had on her career path. Likewise, Participant 6 reported being involved in a medical research project because she wanted to bring awareness to a medical cause she believed vastly needs research attention.

Support for Siblings of Young People with Cancer

One of the most sticking aspects of interviewing sibling participants was the obvious lack of support developed for and provided to siblings during, and after the cancer treatments. Only one participant recalled receiving an appropriate form of support during the cancer treatment. This participant received individual sessions of art therapy as a child through a non-profit organization directly aimed at helping cancer-stricken families. She believed this support was instrumental in adjusting to the long-lasting illness of her brother. However, she expressed that while the support she received was indeed helpful, it was only provided for a few months, despite living with a brother who had an incurable form of cancer. Moreover, this support was discontinued once her brother was no longer undergoing active treatment. All the other participants expressed either receiving inappropriate, short-term interventions (less than two sessions) or no emotional support at all. These findings are consistent with a previous large-scale studies assessing the emotional and instrumental support provided for siblings of hospitalized children across the United States and Canada. This study reported that only 48% of pediatric health care centers asserted to providing support for siblings (Newton et al., 2010). Consequently, more than half (52%) of those pediatric centers did not offer support for siblings. To our knowledge, no specific statistics on the access to support for siblings of cancer-stricken patients in Quebec healthcare centers have been published.

With that said, most of the interviewed siblings recalled having the chance to participate in specialized summer camps designed for families dealing with cancer. Interestingly, without any specific prompting about camp experiences, five out of the six participants openly mentioned their involvement in such summer camps. Moreover, all of the siblings who shared their experiences of attending these camps reported overwhelmingly positive outcomes. These camps were offered by a non-profit agency advocating and providing support and resources for families impacted by cancer. Attending a specialized camp appears to be a valuable way for children to meet and engage with other siblings, which they might feel more comfortable sharing their experience with cancer. However, it is worth noting that these specialized camps appear to currently be the primary and only widely accessible support available specifically for siblings of children and adolescents with cancer.

These findings contribute to the existing knowledge that therapeutic summer camps are an efficient way to support siblings and help them cope and adapt to the changes in their family life (Hancock, 2011; Packman et al., 2005; Sidhu et al., 2006). Therapeutic camps for siblings of children with cancer not only provide a supportive environment to discuss with peers but also improve medical knowledge, social confidence, self-esteem, as well as promote wellness, through well-ness education surrounding healthy eating and engaging in physical activity (Hancock, 2011). Nonetheless, Sidhu et al. (2006) highlighted the importance of establishing and evaluating clear intervention protocols and guidelines in order for the summer camp intervention targeting at improving the quality of life and mental status of siblings of children with cancer to be effective.

Overall, it was found that none of the participants received adequate age-appropriate, individualized, adapted, and family-oriented support during and after the cancer treatment, except for the opportunity to participate in specialized summer camps. The only organization that provided support to the interviewed participants was Leucan, a Quebec-based community organization dedicated to supporting children with cancer and their families. While the support offered by Leucan's camp for families affected by cancer was overwhelmingly well-received by the siblings, it is worth noting that this remained the primary form of support available to them. The lack of additional comprehensive support tailored to the unique needs of siblings throughout their cancer journey raises the importance of expanding and enhancing the range of supportive services provided to siblings and their families. It underscores the need for a more comprehensive and ongoing support system that addresses the emotional, social, and practical needs of siblings beyond the scope of specialized camps.

Discussion

Exploring the Needs of Siblings of Young People with Cancer

As previously stated, the first objective of this project was to highlight some of the needs of siblings of young people with cancer might face, particularly in the Quebec context. The purpose of this project was also to extend the literature on siblings' needs while contrasting the similarities and differences reported by Tasker and Stonebridge who presented a thorough portrait of needs expressed by sibling adolescents of children with cancer in British Columbia in an article published in 2016 in the Journal of Pediatric Nursing. They highlighted eight needs for siblings of children and adolescents with cancer to enhance our understanding and support siblings through their experience with a cancer-stricken brother or sister: 1) attention and acknowledgment; 2) honest and open family communication; 3) inclusion in the family during treatment; 4) knowing it is normal to have difficult emotions and uncomfortable thoughts; 5) emotional support; 6) instrumental support; 7) being a kid; 8) family humor, laughter, and light-heartedness.

In an effort to contribute to Tasker and Stonebridge work and provide a Quebec portrait of the needs of siblings, the findings of the previous study helped identify six needs pertaining to siblings' adjustment to childhood cancer. Although the findings presented here led to very similar conclusions in terms of needs, some important differences will be highlighted. Based on the results obtained from the interviews and using the thematic approach described above, six needs were identified as the most potent and commonly reported and are as follows: 1) need for attention and acknowledgment; 2) need for emotional support; 3) need for medical knowledge and preparatory information; 4) need for inclusion; 5) need to maintain family relationships; 6) need for instrumental support. Preliminary ideas on how these needs could be better met are discussed through the cumulative and circumflex model of family functioning lenses.

Need for Attention and Acknowledgement

The literature pertaining to siblings of young people with cancer almost unanimously mentions a decrease in attention, particularly parental attention, as an outcome of cancer in siblings (Murray, 2000; O'Shea et al., 2012; Patterson et al., 2014; Porteous et al., 2019; Prchal & Landolt, 2012; Tasker & Stonebridge, 2016; Woodgate, 2006). This decrease in attention perceived by siblings of young people with cancer has been widely documented, however, the consequences of such decrease in parental attention are not always discussed. Furthermore, it is commonly recognized that the decreased attention experienced by siblings during the cancer journey is often seen as a temporary outcome, with the consequences gradually subsiding once the cancer experience comes to an end. Nevertheless, the results presented in this study add to the evidence suggesting that various short- and long-term consequences are linked to a reduction in parental attention, as discussed in Woodgate (2016). The present findings distinctively highlight that some consequences of a decrease in parental attention can be chronic rather than transient in certain cases.

Parental Attention. The lack of parental attention was one of the most potent and commonly reported themes throughout the interviews and member-checking sessions with the sibling participants. The challenges in dealing with this specific need lie in some of the inevitable aspects of childhood cancer and the important strain parents feel through the cancer experience. It is without saying that going through a cancer experience with a child can be extremely overwhelming and distressing for a parent (Prchal & Landolt, 2012). Understandingly, their attention might be solely directed at their ill child. Numerous studies reported this shift in the family dynamic, leading to a decrease in parental attention following a cancer diagnosis (Long et al., 2017; O'Shea et al., 2012; Tasker & Stonebridge, 2016; Wilkins & Woodgate, 2005). As aforementioned, studies have reported that parents were not only emotionally unavailable to siblings, but they were also often physically absent from their home and spent an increasing amount of time with the ill child at the hospital (Prchal & Landolt, 2012). Moreover, it appears that inattentive parents might be less equipped to notice and care for distressed siblings (Long et al., 2013).

A great deal of consequences can come from a lack of parental attention as some of their needs might not be cared for, as reported by Woodgate (2016). As reported, sibling participants confessed hiding important information about their personal life, their well-being, and their medical health from their parents. Siblings felt like their feelings and needs were not as important as their parents' or siblings'. As a result of this perceived lack of attention, they felt left out, excluded, and forgotten by their loved ones. Those feelings went away for some, but not for others. Important and long-lasting consequences were reported by siblings, including health complications and negative impact on the family dynamics, which they attribute in part to this decrease in parental attention during the cancer episode.

The physical absence of both parents is unfortunately difficult to avoid in cancer-stricken families and is mostly caused by logistical demands. Most healthcare centers recommend that at least one parent be always at the hospital with their ill child. Numerous parents are forced to leave their work during the treatment of their child (Roser et al., 2019). A Canadian study reported that 40% of mothers and 11% of fathers of cancer-stricken families had to leave their job for an extended period of time to care for the ill child (Limburg et al., 2008). Cancer treatments, being usually extremely strenuous on both the ill child and the parents, typically leads to the highest-income parent keeping their job to maintain family incomes and the lowest-income parent assuming the care-taker position to stay at the hospital with the ill child (Chesler & Parry, 2001). This redistribution of parental roles and occupational changes is naturally centered around the needs of the ill child but often leaves out the healthy siblings, which are left to care for themselves at home.

Supporting Parents. While parents are certainly not at fault in this context, it is important that parents are made aware of this tendency and are given the tools to better attend to the needs of all their children. Family therapy or family-oriented intervention ought to be developed to keep in mind the needs of siblings and could be based on the circumflex model of family functioning developed by Olson, et al. (1979), which integrates two aspects of family functioning: family adjustment and family cohesion. However, longitudinal data indicated that while family adaptability may be beneficial in the short term, it can have adverse effects on siblings if it becomes a long-term or structural characteristic (Houtzager, Oort, et al., 2004). Although the cancer treatment in a child might be extremely unsettling for the family unit, parents might mistakenly assume that the changes in the family dynamic might only be transient. However, cancer treatment and its negative impact on family dynamics can last for months and years after the disease. Thus, it is crucial to develop and build programs that focus on family adaption and cohesion during the treatments and after the treatments, as opposed to providing support only after cancer treatments. Some barriers in providing support to facilitate family cohesion during the cancer treatment need to be further explored with cancer-stricken families.

Even if all siblings reported a decrease in parental attention, it is important to mention that not all siblings felt the long-term impact of this lack of parental attention. Some recalled feeling rejected or isolated during the treatment but reported that parental attention had regained some normalcy after the end of the treatment, and associated feelings had subsided. Thus, it is imperative to develop screening tools to identify families that might require support with regards to family adaptation and functioning, including parental attention and sibling emotional state, and help them cope with those unforeseen consequences of cancer.

Even though the lack of parental attention was reported as a major concern in both the result of this study and in previously published work (Porteous et al., 2019; Prchal & Landolt, 2012; Tasker & Stonebridge, 2016; Wilkins & Woodgate, 2005), the research directly pertaining to parental attention during the cancer of a child is very limited. Research attention should be directed at the impact of parental attention on siblings of young people with cancer and how to prevent and minimize the adverse consequences. Helping parents cope with the distress and burden that is associated with the diagnosis of cancer in children is a crucial step in helping siblings better recover and adapt from this experience.

Seeking Recognition for Emotional Distress and Loss. Parental attention was not the only type of attention sought by sibling participants, through and after their cancer experience. Medical personnel, family members, teachers and other's attention all seemed to be fully directed at the ill child and their parents. Some siblings reported being treated like the sibling of someone who is going through a difficult time rather than treated as someone who is going through a difficult time, as also reported by Tasker and Stonebridge (2016).

One of the salient aspects of this perceived lack of attention and acknowledgment was reported in their need to be acknowledged and supported through their emotional pain and loss. Thus, an important part of this general lack of perceived attention lies in the minimization of the pain and suffering lived by siblings of children with cancer. This approach to intervention and interaction with siblings of cancer patients, also reported Tasker and Stonebridge (2016) minimize and invalidates their needs and feelings toward the difficulty of having a sibling stricken with cancer.

> It's ironic because we talked about it and we actually argued about it. We revisited the topic and talked about it again. I mentioned that I had met with you and we discussed it. I just said that we talked about stress, and they were saying, *We never left you alone, we never....* I don't know how to express it. It's like it's too hard for them to admit that it was difficult for me, even if they did everything they could. It's true, they did everything, but one doesn't negate the other. I don't blame them at all for how they handled the situation back then, but I do hold some resentment towards their current actions. [...] I have a lot of respect. I have immense respect and admiration for my parents, but that doesn't mean I haven't experienced consequences...[Quote 50]

As previously mentioned, two of the six participants interviewed heartbrokenly lost their sibling to cancer. Both of them recalled feeling like their grief was minimized and not acknowledged properly. Those findings contribute to the argument that the grief of siblings is still often overlooked in the context of cancer in young individuals (Stroebe et al., 2001). Providing end-of-life information and preparation appears to be crucial in properly acknowledging and supporting the emotional loss of siblings, particularly those of young people who will die from the disease (Lövgren et al., 2016, 2018; Rosenberg et al., 2015). Positive communication, end-of-life preparation, and the opportunity to say goodbye might be important potential protective factors for bereaved siblings (Wallin et al., 2016). Despite the difficulty in addressing such issues, it appears to be crucial for the psychological adjustment of siblings (Tasker & Stonebridge, 2016).

Therefore, it appears that siblings of young people with cancer need to feel acknowledged in their emotions and their feelings need to be validated, as they are an important component of the family unit. Thus, providing supporting tools to parents and medical teams to better support the needs of siblings of young people with cancer appears to be tremendously important.

Need for Emotional Support

While inquiring about the siblings' experiences with cancer, a crucial element became evident and was succinctly expressed by Participant 6.

> It's difficult because each cancer is unique, and every family is different. There is no universal solution. [Quote 51]

Taking into consideration the unique nature of each family and sibling, several common aspects related to their emotional needs emerged from the conversations. These aspects include: 1) normalizing difficult emotions, 2) individualized and age-adapted emotional support, 3) varied length and timing of support, 4) family-oriented and prevention-based support.

Normalizing Difficult and Uncomfortable Emotions and Thoughts. Some participants wished they had been told that it was normal to feel unsettled and overwhelmed through the cancer experience. One of them recalled:

> I just wish there was more understanding, more information on how I might feel years later and how I may have unique personality traits that others don't have. [Quote 52]

They expressed that it would have been helpful for them and their parents to be aware of the difficult emotions, symptoms, or even potential complications in their mental and physical related to the traumatic elements of cancer. Some participants mentioned they did not feel like they had the tools to deal with these strong emotions because no one told them it was normal. Moreover, siblings felt like their parents, teachers or extended families were not properly equipped in identifying distress in siblings of young people with cancer and did not recognize the signs that they might require additional support to cope with their family situation.

> But at 15, 16 years old, when certain things were still there, the nightmares were still there, at some point, I feel like... I feel like someone should have realised that certain things needed to be addressed. [Quote 53]

These findings are consistent with Tasker and Stonebridge (2016) and emphasize the importance of emotional preparation and equipping siblings of pediatric cancer patients with coping mechanisms to navigate such challenging circumstances as they unfold. These findings contribute to the argument that siblings are forgotten from the cancer experience (Stroebe et al., 2001), especially when the cancer experience is considered to be over. Regardless of whether the ill youth survived, passed away, or continued to live with an incurable form of cancer, the emotional consequences and distress associated with a sibling's cancer can persist.

Accessible and Tailored Support: Individualized and Developmentally Appropriate Interventions. It is important to reiterate that there is no *one-size fits all* solution to supporting the emotional needs of siblings of young individuals with cancer. Emotional support might take different forms for different people. All siblings interviewed reported needing some emotional support at some point in the experience with dealing with their sibling's illness. However, multiple barriers appeared to prevent siblings from having the appropriate emotional support when needed. First, the support provided to siblings was not always developmentally appropriate or individualized. Some participants expressed their frustration when being offered art therapy as the only form of support available. One participant remembered:

> I was willing to do drawings, but it was a lot of drawings, a lot of them. But it didn't help... I don't know, they weren't like tools... There were moments of extreme distress, and it was like... those drawings wouldn't help me. [...]. It was like "draw your family, draw your house." In my mind, I thought, you could just ask me directly, and I would clearly tell you how I feel. [Quote 54]

Similarly, another participant also shared feeling infantilized and invalidated through the support offered:

> I was a teenager... For me, doing little crafts... their approach for siblings is very child-ish. I understand because Leucan focuses on treating pediatric cancers, so it's mainly for young children with cancer. But my sister was 15 years old... I was a teenager, so Leucan's approach was a total failure for me. I even tried again later on with an activity for grieving siblings, and that was also a complete flop. Making collages just doesn't work for me. [Quote 55]

Thereby, providing an age-appropriate and individualized approach might be extremely beneficial in providing siblings with the appropriate form of emotional support. Moreover, providing some choice in the intervention provided might be relevant, especially for adolescents who might need to gain some control over their life.

Duration and Timing of Support. As previously mentioned, despite cancer being viewed as a temporary event, the repercussions of having a sibling with cancer may extend beyond the immediate period and persist for a longer duration. Siblings of young people with cancer might require emotional support for a long period of time, even years after the end of the cancer experience, especially in bereaved siblings or siblings whose brother or sister have an incurable disease. Multiple sibling participants recalled seeking psychological or emotional support by themselves years after their experience with cancer.

> Because even today, I would say that support is still necessary as long as it's not completely over. That's what I found in the case of my brother. I believe it's always helpful. It seems that once things stabilize and there's no more treatment, we tend to drift apart a little bit. It's over, it's fine. But increasingly, as I go through it, I see that it still affects me. [...]. Of course, today, I no longer have follow-up or support for it. When I'm not doing well, it's tough because you're more inclined to lean on the people close to you, but those people are going through it as well. [Quote 56]

One extremely important aspect that was raised through the interviews is the notion that cancer is believed to be a transient event; thus, support provided, if any, will be transient. However, the findings of this study have led to a differing conclusion, where some siblings require support for a long period of time, especially bereaved siblings. This conclusion provides evidence to the argument that cancer and its psychosocial consequences should be considered as having chronic repercussions on the cancer-stricken individual and their family. The duration of potential support for siblings of young people with cancer is rarely addressed in the literature. Given the non-linear and intricate nature of the cancer experience, it is essential to conduct additional research focusing on the timing of needs in siblings. This can help gain a deeper understanding of when, why, and how to effectively provide support.

Promoting Family-Oriented Intervention and Support. Family-oriented intervention and support might be beneficial in dealing with difficult family dynamics and functioning. As previously mentioned, family adaptation might be one of the most prominent indicators and factors in the adjustment of siblings of young people with cancer (Houtzager, Oort, et al., 2004). Thus, it is important that emotional support aimed at siblings of children and adolescents with cancer focuses on maintaining family cohesion and adjustment through the cancer experience. Nevertheless, it appears that staff availability, funding, and lack of physical space to hold programs are commonly identified as barriers to providing appropriate support for siblings of hospitalized children (Newton et al., 2010). Moreover, the need for emotional support for siblings in hospital settings is undermined by the lack of evaluation tools. As shown in Newton et al.'s survey, hospitals that provided support for the siblings tend not to have the appropriate tools and procedures in place to evaluate, assess and adapt the support provided to siblings (Newton et al., 2010). It would be interesting to develop tools to better assess and address the barriers to providing such services in the province of Québec.

Need for Appropriate Preparatory Information and Medical Knowledge

The study initially explored the impact of medical knowledge on the psychological adjustment of siblings of young people with cancer. However, the findings revealed a distinction between medical knowledge and preparatory information. While providing age-appropriate medical knowledge (Long et al., 2015; Prchal & Landolt, 2009), and transparent communication with siblings of young people with cancer (Tasker & Stonebridge, 2016) are significant factors in their adjustment, it might not be sufficient to maintain their psychological well-being.

Medical Knowledge. Studies on the significance of age-appropriate medical information for siblings of children with cancer has been limited. According to Prchal & Landolt (2012) siblings reported how crucial it was for parents to discuss the medical treatment and prognosis with them. They emphasized the need for accurate medical information about their ill sibling's diagnosis, treatment, and prognosis (Long et al., 2015). Providing medical information and knowledge to siblings, parents, and healthcare professionals might alleviate some of the burden on siblings of having to figure out for themselves and might facilitate coping (Long et al., 2015). Additionally, siblings emphasized the value of having the medical terminology explained to them during discussions about the ill child's medical situation. This preparation empowers them to engage in medical conversations and ask questions to healthcare professionals more effectively (Long et al., 2015).

Preparatory Knowledge. Psychological preparation, or preparatory knowledge for patients has been defined as a "process of communicating accurate and developmentally appropriate information, identifying potential stressors, as well as planning and practicing coping strategies" (Fortunato, 2000, p. 18). Psychological preparation can also be described as a specific intervention received prior to a medical procedure to provide information and reduce anxiety, providing three types of information: (a) information about the procedure itself (including the steps that healthcare professionals will perform); (b) the sensations the patient can expect to feel (i.e., sharp scratch, numbness); and (c) about how to cope with the procedure (National Clinical Guideline Centre, UK, 2010). Nevertheless, it is important to note that these two definitions primarily focus on patients themselves and may not explicitly encompass the experiences and needs of their loved ones and family members. To our knowledge, no appropriate definition of the term psychological preparation has been developed in the context of families of cancer-stricken individuals. A working definition was developed for this analysis based on the definition provided by Fortunato (2000) and the National Clinical Guideline Centre (2010). Therefore, in the context of sibling's preparation in supporting their brother or sister through cancer, psychological preparation could be defined as providing accurate and developmentally appropriate information to siblings to provide them with a well-rounded preparation and might include; (1) medical information required to understand the disease and the treatments (including the impacts of side effects); (2) emotional preparations (including tools to dealing with changes in the family dynamic, and general emotional health); (3) preparation and tools to dealing with potential instrumental changes (i.e., changes in the routines, the impact of living with an immunocompromised sibling…), (4) preparation and tools to dealing with the potential long-term consequences of childhood cancer, (including what life looks like after cancer and preparation for end-of-life care).

This preparatory or educational knowledge undoubtedly needs to be thoroughly developed and provided by trained professionals, be developmentally and individually suited as well as be adapted to the medical condition of the ill child as well as the family's needs and desires. Preparatory knowledge support should be aimed at developing accurate expectations and reduce the stress associated with medical treatments and side effects, as well as reducing the feeling of being excluded and misunderstood (Ahlberg et al., 2003). Addressing the physical and emotional side effects of cancer treatment is crucial, as leaving them unaddressed can lead to siblings worrying about the prognosis and doubting the efficacy of treatments (Prchal & Landolt, 2012). Self-management strategies to better prepare siblings in coping with the unforeseen changes associated with being a sibling of a young person impacted with cancer should be prioritized. Further considerations ought to be explored on the importance of the sibling's age and developmental level when deciding on the appropriateness and implementation of interventions targeted at providing preparatory information (Flowers & Birnie, 2015). Individual needs and ability to cope must be considered, as not all siblings will require additional help in coping with the events associated with cancer.

Patient education or preparation in the field of oncology has been previously investigated regarding adult patients' anxiety and acceptance of cancer treatment and procedures (Ahlberg et al., 2003; Waller et al., 2015). For instance, Ahlberg et al. (2003) suggested that providing valid information to cancer patient about what to expect will increase the likelihood of them developing accurate expectations about the disease and the treatment, reducing stress from unexpected issues during treatments. Similarly, research has examined the importance of providing appropriate medical information to pediatric cancer patients (Chari et al., 2013; Flowers & Birnie, 2015; Li et al., 2016; Li & Lopez, 2008). For instance, Flowers and Birnie (2015) provided strong empirical evidence that contributed to the argument that children and adolescents undergoing important medical interventions should be provided with the appropriate preparatory information and psychological preparation. Findings suggest that different types of therapeutic play, including medial and preparatory play, can be used with young patients as a mean to prepare them to cope with the stressful situation associated with cancer treatment (Li et al., 2016), but ought to be explored in the context of siblings whose family has been impacted by cancer. Ahlberg et al. (2003) proposed an insightful hypothesis suggesting that patients who receive preparatory knowledge gain a significant advantage in preparing for unforeseen medical complications and developing effective self-management strategies. It is reasonable to extend a similar hypothesis to siblings of young people with cancer. Providing siblings with preparatory knowledge may empower them to better navigate the challenges that arise during their sibling's cancer journey and equip them with effective coping mechanisms.

Appropriate End-of-life Education and Preparation. Providing appropriate end-of-life education and preparation to children and adolescents for the passing of their ill sibling appears to be crucial for the positive psychological adjustment of siblings (Lövgren et al., 2016, 2018; Rosenberg et al., 2015; Tasker & Stonebridge, 2016; Wallin et al., 2016). The findings underscored the importance of providing appropriate and tailored support to siblings, regardless of their age, particularly in the context of end-of-life support. It was observed that these siblings often faced difficulties in their psychological adjustment following the loss, highlighting the need for targeted interventions and support services that address their specific needs and promote their well-being. Recognizing and addressing the unique challenges faced by bereaved siblings can contribute to their overall psychological adjustment and help them navigate the grieving process more effectively. Both sibling participants who lost their sibling to cancer reported experiencing significant long-term consequences from their cancer experience, and their interviews subjectively indicated the lowest emotional well-being compared to all six participants. Their lower psychological well-being and adaptation appears to be evident even after a decade of grieving their sibling's passing. It has been established that bereaved siblings undergo and endure a wide range of emotional and psychological difficulties following the death of their siblings in the context of childhood cancer (Alderfer & Hodges, 2010). That being said, it is crucial to further investigate the nature and extent of the support needed by bereaved siblings before, during, and after the loss of the ill sibling to cancer.

Need for Inclusion

Most of the studies on siblings of children or adolescents with cancer mention that siblings feel excluded from the family unit and hospital setting (Porteous et al., 2019; Prchal & Landolt, 2012; Tasker & Stonebridge, 2016). Despite the support received, the siblings interviewed expressed a lingering sense of exclusion in being the last ones to learn about their sibling's health condition and potential treatments. This feeling of being left out or not being fully included in important medical updates can contribute to a sense of isolation and frustration. When asked what the most difficult part of the cancer experience was, Participant 6 frankly said:

> To be the last one to know what was happening. [Quote 57]

Furthermore, when asked to give suggestions and recommendations to parents of children who just received a cancer diagnosis, a few of the sibling participants mentioned being transparent and disclosing the diagnosis to their other children as soon as possible. Waiting to tell the other children in the family, even for only a few days, appeared to be extremely painful for siblings as they felt this life-changing news was kept from them. Based on the interviews conducted, it appears that the way the cancer diagnosis was disclosed, and the amount of information provided did not seem to be impacting the healthy sibling as much as the timing in which parents decided to disclose the information. Therefore, it would be important to develop informative tools to help parents cope with the first few moments following the cancer diagnosis and provide them with tips on how and when to disclose the situation to their other children.

In contrast to the literature, which suggests that siblings often express the need to be included in medical decisions during cancer treatment (Porteous et al., 2019; Tasker & Stonebridge, 2016) most of the siblings interviewed in this study acknowledged that they were unable to be directly involved in the majority of medical decisions. They described several reasons that hindered their ability to be actively involved in the medical decisions of their cancer-stricken sibling. One key factor was the complexity and gravity of the medical decisions, which were often complicated and involved life-altering consequences. The medical professionals primarily engaged with the parents and the diagnosed child, leaving the siblings with a limited role in the decision-making discussions. Despite expressing their desire for inclusion, the siblings demonstrated a mature understanding of the complexities involved in medical decision-making, and they recognized the importance of deferring to medical experts and parents.

Another noteworthy observation from the study was that certain participants expressed a desire for direct involvement in their sibling's care. For instance, one participant mentioned wanting to be included in her sister's physiotherapy treatment. This sentiment aligns with findings from other studies such as Samson et al. (2016). Nevertheless, not all sibling participants shared the same desire to be involved in the medical aspect of their sibling's care. In fact, one sibling mentioned that excessive inclusion could lead to negative consequences, such as heightened anxiety and distress.

Need to Nurture Strong Relationships within the Family

One compelling need raised by the sibling participants is the need to maintain and nurture family relationships during and after the cancer treatments. It was reported by Woodgate (2006) that some siblings expressed important difficulties in maintaining their relationships with their ill siblings during the illness, which was also reported by some of the participants interviewed. It is interesting to consider that family functioning is believed to be one of the most important aspects of siblings' adaptation to childhood and adolescent cancer (Long & Marsland, 2011) and appears to be closely related to family cohesion (Houtzager, Oort, et al., 2004). As previously mentioned, in the Circumflex Model of family functioning, a moderate level of adjustment and cohesion is the most favourable for positive outcomes and balanced family life (Houtzager, Oort, et al., 2004). Thus, siblings with higher rates of psychological distress usually come from families with a more 'chaotic' system. It can be argued that to preserve an optimum level of family functioning, maintaining family cohesion is essential. Thereby, maintaining relationships among the members of the family unit might be highly relevant to avoid lower levels of family functioning, which in turn, could aid the coping of siblings. These findings are interesting to consider in light of other similar projects, notably the work of Tasker and Stonebridge (2016) and of Prchal and Landolt (2012) who mostly focused on communication within the family unit. However, the present findings suggest that open communication and transparency might not be sufficient to nurture cohesion and closeness amongst family members. Some families might require additional help in maintaining and improving those relationships to facilitate family cohesion. Nonetheless, when inquired about what kind of support siblings needed to help with family relationships during and after the cancer experience, siblings were unsure of how and when support was required.

Disruption of Roles. The findings emphasize the noteworthy disruptions in roles throughout and after the cancer experience. As previously mentioned, this disruption in the family dynamic appears to occur twice for certain families. The shift in autonomy gained during the illness, followed by its subsequent loss, as routines return to normal, unsettles the equilibrium within the family. This disruption seems to generate more frequent conflicts among family members, leading to frustration for the siblings and significant tensions within the family unit. In some families, these conflicts were left unresolved and had tremendous impacts on the family dynamics and impacted each individual relationships in the family unit. Thus, it would be important to provide siblings and parents whose families have been impacted by cancer some tools to not only preserve the relationships within the family unit during the cancer experience but also how to regain family cohesion once the crisis is over.

Need for Instrumental Support

All siblings reported receiving and needing some instrumental support through their cancer experience, which occurred in two main ways: 1) instrumental support from their support system; 2) instrumental support through school.

Instrumental support, referring to tangible assistance offered to individuals in need, such as transportation, meal preparation, and help with household chores (Schultz et al., 2022), is believed to be vital in enabling healthy siblings to alleviate feelings of loneliness (Tasker & Stonebridge, 2016), and ease the burden associated with household chores (Patterson et al., 2014). Accordingly, most siblings interviewed reported that they received considerable support from their extended families, particularly with providing meals and helping with childcare and household chores. This support relieved siblings from some tasks and provided a sense of feeling supported by their loved ones. In general, this seems like an excellent way to support and help a family going through a cancer experience and was generally well-received by siblings.

Practical support received through school was commonly mentioned by the sibling participants. Support received from school on the other hand, requires some improvement and has been highly variable among the siblings interviewed. As mentioned in the literature, the support described by siblings appeared to be highly inconsistent from school to school and teacher to teacher (Long et al., 2015). However, instrumental support provided by school workers and teachers is believed to significantly reduce attention problems, rule-breaking behaviours, and other behavioural problems (Alderfer & Hodges, 2010). While some participants reported being granted flexibility in deadlines and schoolwork, as well as the opportunity to attend school remotely, others expressed disappointment in not receiving any such accommodations or understanding from their schools during their sibling's cancer episode. Furthermore, emotional support received through school interventions did not seem to be well received by siblings as they believed the school personnel, including social workers, guidance counsellor or school psychologist, were unequipped and unable to help with their unique and uncommon reality and family situation.

Long et al. (2017) conveyed that siblings could rarely attended medical appointments and hospitalization, which in turn kept them away from crucial medical knowledge and medical decisions and limited their parents their knowledge of their emotional state. Such visits were often held during school time, which made it difficult for siblings to attend. Notably, some obstacles to maintaining sibling relationships appeared to be linked to the inflexibility of school attendance. Younger sibling participants, not yet of high school age during treatments, fondly remembered joyful moments with their siblings both inside and outside the hospital. In contrast, high school attending sibling participants recalled fewer positive memories with their sibling during treatments, unable to visit the hospital due to the rigid school routine. Promoting schools' flexibility and managing expectations during the cancer of a sibling could in turn provide some relief for siblings and aid in nurturing siblings' relationships. Schools could be an excellent source of relief and support both for instrumental needs and emotional needs. Nevertheless, more research on how the school system could support siblings of young people with cancer ought to be conducted to better understand the roles it can take in such journey.

In an effort to contribute to Tasker and Stonebridge's work and present a Quebec portrait of siblings' needs, this study's findings have identified six essential needs concerning siblings' adjustment to cancer. Although the conclusions drawn align with previous research, some notable differences emerged**.**

Critical Examination and Consideration of the Study.

Taking a comprehensive approach to the study findings, it is essential to address several pivotal aspects that call for careful consideration. These encompass the encountered limitations, recruitment challenges, and potential future directions for further research.

Study Limitations

Different limitations can be highlighted in the homogeneity of the sample. First, the sample was relatively small. Although data saturation was believed to be obtained through the interview, it would be interesting to consider a larger sample to provide a more generalized portrait of the situation. Moreover, most sibling participants were recruited through non-profit agencies, which advocate and provide resources for families impacted by childhood cancer, as participants either volunteer or had parents involved with this agency. Not all families of children with cancer will be approached and join those such agencies, which leads us to believe that sibling participants who agreed to participate in this type of study might have received more support through their affiliation with such agency aimed at providing them with resources, as previously noted by Porteous et al. (2019). Furthermore, the family composition of the participants was quite similar in terms of race, religion, language, socioeconomic status, and parental education. Support, needs, desires, and expectations might be extremely different for some families with other background. The role of culture and socioeconomic status might be important factors to consider in relation to medical conditions. Lastly, participants were recruited from different age cohorts. Thereby, there is a wide gap in time between the first diagnosis in 1995 and the last one in 2023. Support might be different now and might have evolved throughout this 30-year period. Nonetheless, the findings clearly highlighted that even if the support offered to siblings has highly improved since, a group of siblings, who are now young adults, are still suffering and still might need extra support to overcome the adverse events related to their sibling's cancer.

Recruitment Challenges

The initial scope of the study was to provide preliminary data on the experience of adolescents through having a sibling with cancer. However, it became evident during the recruitment phase that such a population has become increasingly difficult to reach. Multiple factors have been identified as the reasoning behind recruitment challenges, especially with members of families living with a child with cancer (Besani et al., 2018). Besani et al. (2018) have highlighted the need to conduct an analysis of barriers to participation in research about siblings of young people with cancer. Despite recurrent efforts, we were unable to recruit enough adolescent participants to conduct the initial project. We then decided to interview adults through a retrospective scope. As in Tasker and Stonebridge's (2016), a retrospective study method was selected to provide more self-aware, informed, and articulated data (Lehna, 1998; Pompeo, 2009), from the vantage point of adults who are not presently immersed in the cancer experience.

Thus, rich data was collected from the interviews with participants that offered a great retrospective-perspective on their cancer experience.

Future Directions and Recommendations

In light of our current research, we have identified four key areas for future investigation. These directions aim to address important gaps in knowledge and contribute to the advancement of support and care for families affected by childhood cancer. The four main directions for future research are as follows:

1. Investigating the barriers to participation of cancer-stricken families: this line of research seeks to understand the various challenges and obstacles that prevent families from fully engaging in cancer-related programs and services. By identifying these barriers, we can develop strategies and interventions to overcome them, ultimately improving access to and utilization of crucial support resources.
2. Developing and implementing an approach to treating siblings of young people with cancer that focuses on preparatory and medical knowledge: this direction emphasizes the development of effective interventions and programs specifically tailored to the needs of siblings. The focus will be on providing them with appropriate preparatory information and age-appropriate medical knowledge to enhance their understanding and coping abilities throughout the cancer journey.
3. Investigating the direct impacts of a decrease in parental attention on siblings of young people with cancer: this area of research aims to explore the specific effects of reduced parental attention on siblings' emotional well-being, adjustment, and overall quality of life. By gaining a deeper understanding of these impacts, we can develop targeted interventions and strategies to address the unique needs of siblings during the challenging period of their sibling's cancer treatment.

4. Developing and implementing interventions aimed at improving or maintaining family relationships and cohesion during and after the cancer episode: this direction recognizes the importance of family dynamics and relationships in supporting the well-being of all family members. Research in this area will focus on developing interventions that promote healthy communication, resilience, and cohesion within the family unit throughout the cancer journey and into the survivorship phase.

By pursuing these four main directions for future research, the aim is to contribute to the development of evidence-based practices that enhance support, well-being, and resilience for cancer-stricken families. These areas of investigation have the potential to make a significant positive impact on the lives of families and siblings affected by this challenging illness.

Conclusion

This current study provided preliminary qualitative data on the importance and the availability of medical knowledge in siblings of childhood cancer patients and its impact on psychological adjustment throughout and following the cancer experience. Moreover, this study highlighted the needs reported by siblings of children with cancer to later develop tools to minimize the impact of childhood cancer on siblings and aimed at providing a preliminary portrait of the Quebec situation. By documenting and better understanding the realities of siblings of young people with cancer, health care professional, school personnel, and parents can provide better-adapted support and be provided with accurate tools to help healthy siblings through the cancer experience of their brother or sister.

This project extended the literature on siblings' needs while contrasting the similarities and differences reported by Tasker and Stonebridge. Six needs were identified as the most potent and commonly reported and are as followed: 1) the need for attention and acknowledgement; 2) the need for emotional support; 3) the need for medical knowledge and preparatory information;

4) the need for inclusion; 5) the need to maintain family relationships; 6) the need for instrumental support. Preliminary suggestions were put forward, considering the cumulative and circumplex models of family functioning to address the needs of siblings and enhance the support they received within the family.

Our findings and analysis further pointed out an important nuance in the idea of providing medical knowledge to siblings. Indeed, providing siblings with preparatory information, rather than solely providing them with open communication and medical knowledge, appears to be the key element in facilitating adjustment in siblings. The provision of comprehensive and tailored preparatory or educational knowledge requires the expertise of trained professionals who can address the developmental and individual needs of each child. It is essential to adapt the information according to the specific medical condition of the ill child and align it with the desires and requirements of the entire family. This ensures that the educational support provided is well-developed and effectively meets the unique circumstances of the family and the child's medical condition. Preparatory knowledge support should aim at developing accurate expectations and reduce the stress associated with medical treatments and side effects, as well as reducing the feeling of being left out and misunderstood. Self-management strategies to better prepare the siblings to cope with the unforeseen changes associated with being a sibling of a young person impacted with cancer should be prioritized. The importance of providing age-appropriate medical knowledge and preparatory information to facilitate the psychological adjustment of siblings of young people with cancer deserve some serious research attention. It is crucial to further extend on the slim existing knowledge of the needs of siblings during a childhood cancer episode to develop an age-appropriate and individualized approach to childhood cancer in the context of sibling’s well-being.

Throughout this study, we adopted a lens of existing developmental psychopathology frameworks and theories, including the cumulative risk factor approach, while examining preliminary evidence of the support offered to siblings of children and adolescents with cancer in Quebec. One common critique of previous research on the impact of childhood cancer is the apparent disconnection of findings from prevailing developmental psychopathology frameworks and theories (Alderfer & Hodges, 2010; Long et al., 2015). Our aim was to bridge this gap by establishing connections between these frameworks and the socio-demographic context through thorough observations and analysis.

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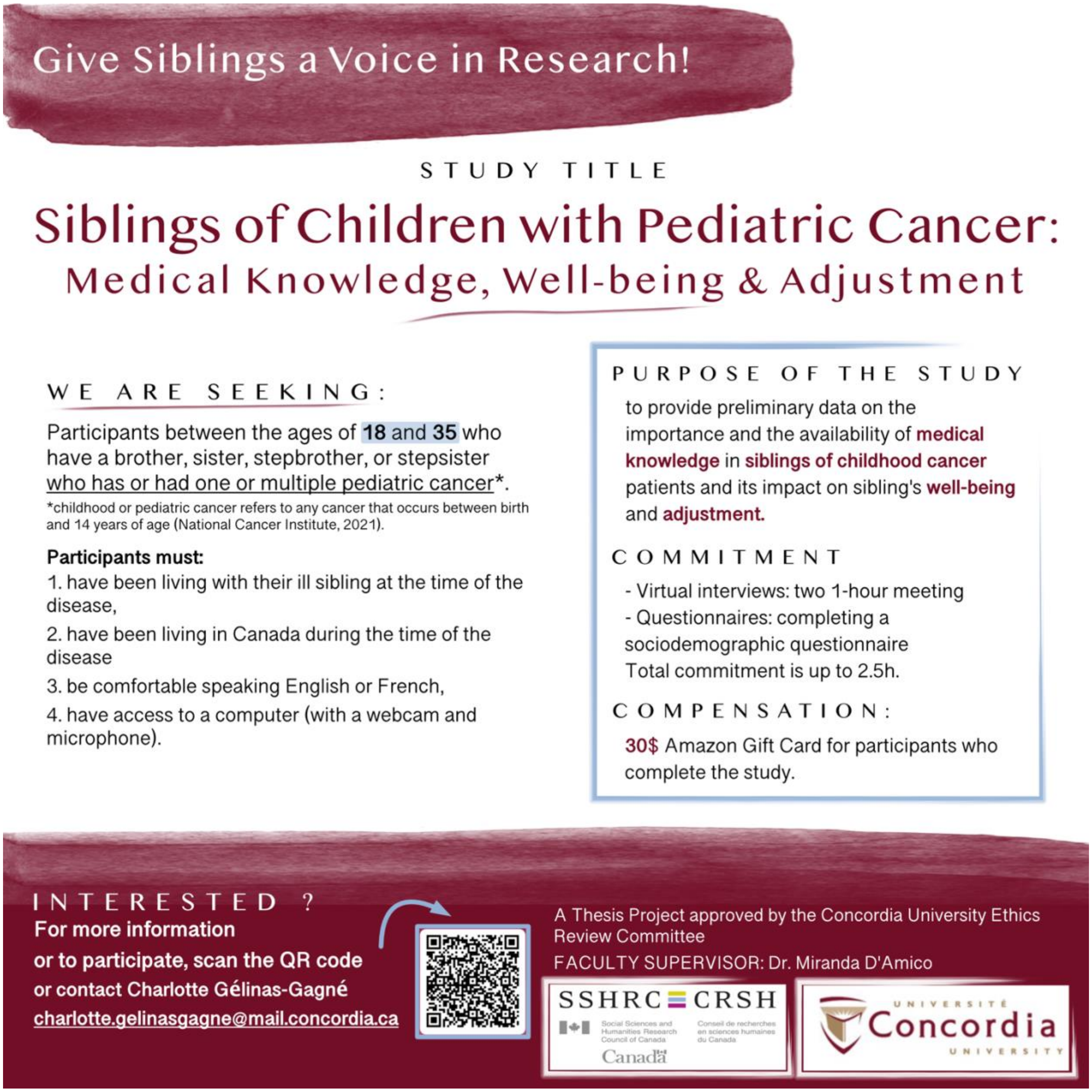
Appendices

Appendix A - Recruitment Poster



Give Siblings a Voice in Research!

STUDY TITLE

Siblings of Children with Pediatric Cancer:
Medical Knowledge, Well-being & Adjustment

WE ARE SEEKING:

Participants between the ages of 18 and 35 who have a brother, sister, stepbrother, or stepsister who has or had one or multiple pediatric cancer*.

*childhood or pediatric cancer refers to any cancer that occurs between birth and 14 years of age (National Cancer Institute, 2021).

Participants must:

1. have been living with their ill sibling at the time of the disease,
2. have been living in Canada during the time of the disease
3. be comfortable speaking English or French,
4. have access to a computer (with a webcam and microphone).

PURPOSE OF THE STUDY

to provide preliminary data on the importance and the availability of **medical knowledge** in **siblings of childhood cancer** patients and its impact on sibling's **well-being** and **adjustment.**

COMMITMENT

- Virtual interviews: two 1-hour meeting
- Questionnaires: completing a sociodemographic questionnaire

Total commitment is up to 2.5h.

COMPENSATION:

30$ Amazon Gift Card for participants who complete the study.

INTERESTED ?

For more information
or to participate, scan the QR code
or contact Charlotte Gélinas-Gagné
charlotte.gelinasgagne@mail.concordia.ca

A Thesis Project approved by the Concordia University Ethics Review Committee

FACULTY SUPERVISOR: Dr. Miranda D'Amico

SSHRC CRSH
Social Sciences and Humanities Research Council of Canada
Conseil de recherches en sciences humaines du Canada
Canada

Université Concordia University

Appendix B - Email Template for Participants

OBJECT: **Research Project: Siblings of Children with Pediatric Cancer: Medical Knowledge, Well-being and Adjustment**

Dear _____________,

First, I wish to thank you for your interest in this research project. This thesis project aims at providing preliminary qualitative data on the importance and the availability of medical knowledge for siblings of childhood cancer patients and its impact on the well-being and adjustment throughout and following the cancer experience.
We wish to learn more about the experience of sibling's of children with cancer to further our understanding of the impact of pediatric cancer on them.

Procedure:
If you wish to take part in this study, we will schedule two one-hour interview with you Zoom to discuss your experience during a semi-structure interview. You will be asked to fill in a sociodemographic and cancer-related questionnaire. This study should take no longer than 2.5h total.

Inclusion Criteria
To participate in this study, your child must:

1) be between the ages of 18 and 35 at the time of the study
2) have a brother, sister, stepbrother, or stepsister who has or had one or multiple pediatric cancer (childhood or pediatric cancer refers to any cancer that occurs between birth and 14 years of age (National Cancer Institute, 2021).
3) be living with the child who had/has cancer at the time of the treatments,
4) be comfortable speaking English or French,
5) live in Canada during the time of the disease,
6) have access to a computer with a webcam and microphone.

Throughout this project, our main objective is to allow siblings of children with cancer the opportunity to speak out about their experience with childhood cancer.

If you have any questions, please contact us.

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*This research has been approved by the Research Ethical Board of Concordia University

Appendix C - Participant Consent Form

FORMULAIRE D'INFORMATION ET DE CONSENTEMENT

Titre de l'étude : Frères et sœurs d'enfants atteints d'un cancer pédiatrique : Connaissances médicales, bien-être et adaptation

Chercheure : Charlotte Gélinas-Gagné
Coordonnées du chercheur : 514-771-2215, charlotte.gelinasgagne@mail.concordia.ca
Superviseur de la faculté : Dre Miranda D'Amico
Coordonnées de la superviseure de la faculté : 514-848-2424 poste 2040, miranda.damico@concordia.ca
Source de financement de l'étude : CRSH (Subvention du Conseil de recherches en sciences humaines du Canada)

Vous êtes invités à participer à l'étude de recherche mentionnée ci-dessus. Ce formulaire fournit des renseignements sur l'implication demandés afin de participer à cette étude. Veuillez lire ce document attentivement avant de décider si vous souhaitez participer ou non. S'il y a quelque chose que vous ne comprenez pas, ou si vous voulez plus d'informations, veuillez demander au chercheur.

A. OBJET

Le but de la recherche est de fournir des données qualitatives préliminaires sur l'importance et la disponibilité des connaissances médicales adaptées à l'âge chez les frères et sœurs de patients atteints de cancer infantile et leur impact sur l'ajustement psychologique tout au long et après l'expérience d'un cancer.

B. PROCÉDURES

Si vous décidez de participer à cette étude, nous vous poserons une série de questions au cours de deux entrevues d'une heure avec le chercheur principal sur Teams. Nous vous demanderons de remplir un questionnaire sociodémographique en lien au cancer de votre frère ou sœur, basé sur les variables identifiées dans la littérature.

Au total, la participation du parent et du participant à cette étude prendra environ 2,5 heures.

C.RISQUES ET AVANTAGES

Vous pourriez faire face à certains risques en participant à cette recherche. Il est possible que certains participants se sentent mal à l'aise et en détresse lors de l'entrevue, car discuter du cancer d'un frère ou d'une sœur est sans aucun doute un sujet sensible. Au cours du processus d'entrevue, nous rappellerons aux participants qu'ils peuvent s'abstenir de répondre à toute question qui les rend mal à l'aise. Il est possible que certains participants se sentent mal à l'aise et en détresse en répondant au questionnaire, car discuter de leur expérience du cancer d'un enfant est sans aucun doute un sujet sensible.

Avantages potentiels: cette recherche vise à fournir un environnement sûr pour les familles de verbaliser leur expérience dans l'espoir de mieux comprendre les mécanismes d'adaptation et les comportements. L'objectif du projet est d'accroître les connaissances générales relatives au bien-être et à l'adaptation psychologique et l'accès aux connaissances médicales chez les frères et sœurs d'enfants atteints de cancer.

D. CONFIDENTIALITÉ

Nous recueillerons les renseignements suivants dans le cadre de cette recherche : des renseignements qualitatifs sur l'expérience du frère ou de la sœur seront recueillis, y compris ses sentiments associés au cancer de son frère ou de sa sœur, ses connaissances médicales de la maladie et le soutien qu'il a reçu tout au long de son expérience. Nous recueillerons également les renseignements suivants dans le cadre de cette recherche : des renseignements sur la famille (y compris le nombre d'enfants, le lieu de résidence et d'autres données démographiques), les caractéristiques des parents (y compris le sexe, l'âge, le niveau de scolarité, l'emploi et l'état matrimonial) et les renseignements sur le cancer de votre enfant (y compris le moment du diagnostic, le type de cancer, le nombre de diagnostics de cancer). Nous ne permettrons à personne d'accéder à l'information, à l'exception des personnes directement impliquées dans la réalisation de la recherche. Nous n'utiliserons les informations qu'aux fins de la recherche décrite dans ce formulaire.

Les renseignements recueillis seront confidentiels. Cela signifie que l'équipe de recherche connaîtra votre véritable identité, mais qu'elle ne sera pas divulguée.

Nous protégerons les informations en stockant les fichiers numériques sous un compte protégé par mot de passe sur l'ordinateur personnel de l'enquêteur principal. Ce compte sera restreint par le chercheur principal. Tous les documents résultants seront numérisés et stockés sur le compte protégé par mot de passe et les copies papier seront immédiatement détruites.

Nous avons l'intention de publier les résultats de la recherche. Cependant, il ne sera pas possible de vous identifier dans les résultats publiés.

Nous détruirons l'information cinq ans après la fin de l'étude.

F. CONDITIONS DE PARTICIPATION

Vous n'avez pas à participer à cette recherche. La décision d'y participer vous revient entièrement. De plus, si vous participez, vous pouvez vous arrêter à tout moment. Vous pouvez également demander que les informations que vous avez fournies ne soient pas utilisées. Si vous décidez que vous ne voulez pas que nous utilisions vos informations, vous devez en informer le chercheur dans les quatre semaines suivant votre entretien.

Il n'y a pas de conséquences négatives si vous décidez de ne pas participer, ou d'arrêter durant le processus de collecte de donnée, ou si vous nous demandez de ne pas utiliser vos informations.

G. DÉCLARATION DU PARTICIPANT

J'ai lu et compris ce formulaire. J'ai eu l'occasion de poser des questions et toutes les questions ont reçu une réponse. J'accepte de participer à cette recherche dans les conditions décrites.

NOM (lettres moulées)____

SIGNATURE
____

DATE ____

Si vous avez des questions sur les aspects scientifiques ou scientifiques de cette recherche, veuillez communiquer avec le chercheur. Leurs coordonnées se trouvent à la page 1. Vous pouvez également communiquer avec le superviseur de leur faculté.

Si vous avez des préoccupations au sujet de questions éthiques dans cette recherche, veuillez communiquer avec le gestionnaire, Éthique de la recherche, Université Concordia, 514.848.2424, poste 7481, ou oor.ethics@concordia.ca.

Appendix D - Sociodemographic Questionnaire

FAMILY CHARACTERISTICS

1. **Please, fill-in the following table for all the members of your family (including your siblings, step-siblings, parents/caregivers/tutors and step-parents/caregivers/tutors. Make sure not to forget yourself and your sibling who had/has cancer.**

First name of the members	Year of birth	Gender	Please identify your relationship with this family member (parent/tutor/caregiver, step-parent/tutor/caregiver, brother, sister, step-brother, step-sister, you) *please identify the sibling who had cancer with the letter C*

If you need more rows to complete this section, please continue this table at the bottom of this section

2. **Where did you live at the time of the cancer treatment (neighbourhood, city)?**

   ____

3. **What was your postal code?**

   ____

4. **What language did you speak at home?**
   ☐ French
   ☐ English
   ☐ Prefer not to say
   ☐ Other: ____________________

CAREGIVERS CHARACTERISTICS

* answer this section with the best of your ability and with the information you know about your caregivers

**if you have/had more than 2 parent/caregiver, please choose the two caregiver/parent you spent the most time with during the time of the cancer treatment.

PARENT/CAREGIVER 1

1. **First name of the caregiver:** _________________________

2. **Gender of the caregiver**
   ☐ Male
   ☐ Female
   ☐ Nonbinary
   ☐ Prefer not to say

3. **What is the highest degree or level of education they completed?**
   ☐ Some High School
   ☐ High School Diploma
   ☐ College / CEGEP Diploma
   ☐ Bachelor’s Degree
   ☐ Master’s Degree
   ☐ Ph. D. or higher
   ☐ Trade School
   ☐ Prefer not to say

☐ Other: ______________________

4. **What was their employment status during the time of the cancer treatment?**

(select all that applied if their status changed during this period)

☐ Employed full-time
☐ Employer part-time
☐ Seeking opportunities
☐ Retired
☐ Staying at home
☐ On leave
☐ Prefer not to say

5. **What is their mother tongue?**

☐ French
☐ English
☐ Prefer not to say
☐ Other: __________________

6. **If applicable, please specify their religion**

☐ N/A
☐ Catholicism/Christianity
☐ Judaism
☐ Buddhism
☐ Islam
☐ Hinduism
☐ Prefer not to say
☐ Other: __________________

7. **What was their marital status at the time of the cancer treatment?**

☐ Single
☐ Married or domestic partnership
☐ Separated
☐ Divorced
☐ Prefer not to say
☐ Other: __________________

PARENT/CAREGIVER 2

1. **First name of the caregiver:** _________________________

2. **Gender of the caregiver**

☐ Male
☐ Female

☐ Nonbinary
☐ Prefer not to say

3. **What is the highest degree or level of education they completed?**

☐ Some High School
☐ High School Diploma
☐ College / CEGEP Diploma
☐ Bachelor's Degree
☐ Master's Degree
☐ Ph. D. or higher
☐ Trade School
☐ Prefer not to say
☐ Other: ______________________

4. **What was their employment status during the time of the cancer treatment?**

(select all that applied if their status changed during this period)

☐ Employed full-time
☐ Employer part-time
☐ Seeking opportunities
☐ Retired
☐ Staying at home
☐ On leave
☐ Prefer not to say

5. **What is their mother tongue?**

☐ French
☐ English
☐ Prefer not to say
☐ Other: __________________

6. **If applicable, please specify their religion**

☐ N/A
☐ Catholicism/Christianity
☐ Judaism
☐ Buddhism
☐ Islam
☐ Hinduism
☐ Prefer not to say
☐ Other: __________________

7. **What was their marital status at the time of the cancer treatment?**

☐ Single
☐ Married or domestic partnership
☐ Separated
☐ Divorced
☐ Prefer not to say
☐ Other: __________________

Cancer-related variables

1. **How many cancer diagnoses did your sibling have?**
   - ☐ 1
   - ☐ 2
   - ☐ More than 2 (same types of cancer)
   - ☐ More than 2 (different types of cancer

2. **When did they receive the cancer diagnosis?**

   ____

3. **How old was your sibling when you received the cancer diagnosis?**

   ____

4. **What is the type of cancer?**

5. **Did they have any other chronic illnesses?**

☐ No

☐ Yes, please specify: ___________________

Appendix E - Interview Script & Interview Questions

Introduction questions

Question 1: Can you tell me more about your family? Can you tell me more about your siblings? (religion at home, type of parenting, hobbies, family life…)

Question 2: Who do you lived with as a child? Where did you live?

Question 3: Can you tell me a little more about your sibling's illness?

Question 4: How old were you at the time of the diagnosis?

Question 5: How old was your sibling?

Cancer-related questions

Question 6: At the time of the disease, how did it make you feel? Do you feel the same way now or is it different?

Question 7: What did you do when you were feeling this way?

Question 8: Is there anyone you talked to when you are feeling this way or about your experience in general? Did you talk to your friends about your brother/sister's cancer?

Question 9: How often did you think about your brother/sister's illness during the treatment? How about now?

Question 10: Did you feel the cancer diagnosis affected your life? How?

Question 11: During the cancer treatment, was did you believe was the hardest part? Looking back, do you think this is still accurate and/or similar?

Medical Knowledge

Question 12: Do you know what type of cancer your brother/sister has/had? Can you tell me a little more about it?

Question 13: Can you tell me a little about what you know about cancer in general?

Question 14: Do you know what type of cancer treatment your brother/sister received? Where did they receive the majority of their treatments?

Question 15: What do you know about the cancer treatment your sibling received?

Question 16: Where did you learn all of this information? Did you learn this information at the time or did you gain this knowledge later on?

Question 17: When you had questions about cancer or the cancer treatment, did you look for the information on the Internet? Did you ask your parents? Did you ask professionals at the hospital?

Question 18: Did you find the medical personnel to be helpful when you had questions?

Question 19: Did you talk about the disease with your parents and siblings? Do you talk about the disease with them now?

Question 20: Did you feel like you could be completely honest with your parents about your concerns and questions about your sibling's illness? How about now?

Question 21: Did you feel like you could be completely honest with your friends about your concerns and questions about your sibling's illness? How about now? Is this life event something you share with people around you?

Question 22: How did your parents first tell you that your brother/sister had cancer? Some study suggests that individuals should be informed of their loved ones medical condition, do you agree with this?

Question 23: What did they tell you about the cancer diagnosis?

Question 24: Did you feel like you were always told everything about your brother/sister diagnosis?

Questions 25: When your parents went to medical appointments with your brother/sister, where you present with them? Did the doctors talk to you about the disease?

Question 26: Did you ever discuss the diagnosis with a doctor/nurse/psychologist/Child Life Specialist/or any other medical professional at the hospital?

Question 27: During those conversation, what sort of things would you like to know about the disease? (facts about the illness, how it affects the body, treatments…)

<u>Support to Siblings & Well-being</u>

Question 28: What kind of support did you receive after the diagnosis? What kind of support have you received following the cancer diagnosis (from friends, organizations, family members, school personnel, hospital personal…)?

Question 29: Was there anything they did that was helpful with dealing with your brother/sister's cancer? Why was this helpful for you?

Question 30: Was there anything they did that was unhelpful (people, friends, organizations, family members, school personnel, hospital personal…)? Why was this unhelpful for you?

Question 31: What could have made things easier/better for you?

Question 32: What would you suggest to parents of children going through a cancer diagnosis?

Question 33: Do you feel siblings of childhood cancer patients are supported?

Cumulative Factors

Question 36: Was there any other event or situation going on at the same time in your life (breakup, conflict with friends, parental dispute, financial hardship, mental health, physical health, geographic location…) that made dealing with your sibling's cancer more difficult?

Question 37: From what you remember, did you have a hard time dealing with academic demands? Social demands?

Question 38: From what you know, were your parents having financial difficulty, marital conflict, employment difficulties, conflicts with other members of your family?

Appendix F - Original Quotes

QUOTE 1

Tu sors de l'orbite... c'est comme si ta sœur ou ton frère, c'est le centre de cet univers. Tu as les parents, tu as les intervenants, tu as les gens qui orbitent autour de ce centre, mais toi, tranquillement, tu es expulsée de plus en plus loin du centre. Tu deviens juste comme un parasite qui tourne autour.

QUOTE 2

[…] même encore aujourd'hui, des fois, j'ai des gens qui m'écrivent, puis qui me demandent juste comme « Ah ton frère, comment ça va? » Ce n'est pas que ça me dérange, mais il y a comme autre chose autour de tout ça. […] Mais c'est difficile pour l'entourage aussi.

QUOTE 3

Je comprends qu'on est moins important que les parents, mais on fait partie de l'unité familiale.

QUOTE 4

C’est comme beaucoup de solitude

QUOTE 5

C'est sûr que pendant les trois, quatre premiers mois de l’hospitalisation, moi et mon frère, on se sentait un peu isolés parce que mes parents n'étaient jamais à la maison, ils étaient toujours à l'hôpital.

QUOTE 6

C'est sûr que j'ai vu comme une différence… c’est pas que mes parents s'occupaient moins de moi… mais… comme, oui un petit peu…

QUOTE 7

C'est comme un sentiment d'abandon quand même assez important

QUOTE 8

Moi, je passais plus de temps avec mes grands-parents, ma marraine, mon parrain. J'étais un peu partout en même temps. Je me suis sentie mise de côté.

QUOTE 9

Tu peux faire venir un membre de la famille pour s'occuper des enfants. Je pense que c'est le meilleur compromis à faire. Mais ultimement, ça ne remplacera pas la présence de la mère ou du père.

QUOTE 10

Donc moi, je souffrais de mon bord. Mais il ne fallait pas que ça paraisse. Mes parents, il leur restait juste un enfant qui allait bien. Je ne voulais pas être l'enfant qui allait mal aussi. Mais ça n'a pas aidé parce que c'est extrêmement douloureux.

QUOTE 11

Je ne me sentais même pas à l'aise d'aller déranger mes parents pour ça. Et pourtant, j'ai vraiment une famille ouverte […]. Mais comme dans ma tête, je ne voulais pas la déranger parce que moi, ce n'était pas important. […] Tu te fais petit, puis tu vas les voir quand tu as vraiment besoin.

QUOTE 12

Puis, d'un autre côté, moi, je pense que le plus gros 'impact à l'époque ou maintenant, c'est que moi, j'ai eu une tumeur par la suite aussi. Puis, je l'ai cachée de mes parents jusqu'à la fin parce que je me disais comme *encore un problème qu'il va falloir qu'ils gèrent*. On dirait que je ne l'ai pas rajouté encore […]. Je pense que dans ma vie personnelle aujourd'hui, c'est juste que je garde des choses vraiment pour moi. Quand il faut, je le dise, comme là, il fallait que je me fasse opérer, je leur ai dit… Quand il faut, il faut, mais moi sinon je ne le dis pas. Je ne veux pas rajouter comme d'anxiété à ma famille, de l'inquiétude, je ne veux pas être un autre cas

QUOTE 13

Au début […] je me cachais plus. Mais là, comme elle va mieux, donc j'ai plus besoin de me cacher […]. C'était déjà difficile pour tout le monde. Comme je ne voulais pas en rajouter non plus.

QUOTE 14

Je dirais que moi et mon frère, on se sentait isolés. Vu que c'était ma sœur, ça ne me dérangeait pas. Je savais qu'elle était malade

QUOTE 15

Je sais qu'une fois, j'ai fait une grosse crise et j'ai dit à mes parents *je sais que je n'ai pas le droit de dire ça, mais vous vous occupez plus de moi.*

QUOTE 16

Moi, je me suis sentie déboussolée. Je ne comprenais pas ce qui se passait

QUOTE 17

C'est sûr que j'étais quand même jeune, au début, je ne savais pas c'était quoi un cancer. À 12 ans, je ne comprenais pas trop l'implication.

QUOTE 18

C'est sûr qu'il y a eu de l'incompréhension. À trois ans, je pense que tu réalises pas tout ce qui se passe

QUOTE 19

C'est un jour là que j'ai pleuré en tarbarnouche. J'étais à l'école, j'ai juste pleuré, j'ai fait « Oh my God, mon frère a peut être le cancer. » Je suis pas allée en classe la journée. Je suis juste restée dans l’aire commune à pleurer ma vie avec mon chum du moment. Ils m'ont laissé la journée à pas aller dans la classe avec lui, puis juste pleurer. […] Pour de vrai quand même, au niveau émotionnel, je le gérais bien, je pense. Autre que j'étais vraiment émotive. Même mes profs ont vu la différence, comme j'étais en secondaire 3. Puis j'ai passé de la petite fille joyeuse à « je pleurais à rien ». Tu me froissais moindrement un peu, je me mettais à pleurer. […].Tout le monde s'est mis à vraiment être plus gentil avec moi. Parce que je pleurais de toute façon.

QUOTE 20

Je dirais que c'est différent durant les traitements versus durant les rémissions. Je ne pourrais pas dire que c'était un sentiment particulier, c'est un amalgame d'émotions, dépendamment de la situation. Durant les traitements, c'est un mélange de fatigue, de confusion, d'être extrêmement fâché, extrêmement triste. Juste sentir que tu te bats contre des chiffres qui ne sont pas de ton côté. Et durant la rémission, je dirais incroyablement reconnaissant. Tu apprécies la vie beaucoup plus, mais en même temps aussi très stressant parce que tu sais que ça pourrait changer à tout moment. Mais ultimement reconnaissante.

QUOTE 21

Tu fonctionnes sur l'adrénaline, tu ne te poses pas de questions, il faut que tu y ailles, il faut que tu le fasses, il faut que tu ailles à l'hôpital, les rendez-vous. Tu n'as pas vraiment le choix, donc tu fonctionnes sur une espèce d'automatisme, inconsciemment, probablement que j'en faisais (de l’anxiété), mais consciemment, seulement plus tard. […]. C'était juste comme un automatisme, je ne sais pas. […]. J'étais un robot.

QUOTE 22

[…] c'était toujours moi qui étais perçue comme étant weird, étant anxieuse. Je n'étais pas assez comme un enfant, je n'étais pas assez relax, je n'étais pas assez fun, je n'étais pas assez dans le moment présent

QUOTE 23

J'avais peur de tout. J'avais peur qu'il pleuve parce que j'allais me perdre dans l'école. J'avais peur. J'avais des liens qui étaient impossibles que je faisais quand même.

QUOTE 24

Je pense que ça, c'était difficile ou justement quand il revenait en maison vraiment amoché, et qu'il faisait juste vomir. Quand il est à l'hôpital, c'est une chose parce que je le voyais pas, mais quand il était devant moi, comme je... Pour vrai, j'essayais souvent de m'enfuir. Quand il était là, dans le fond, j'allais ailleurs, j'allais chez des amis, j'avais de la misère à le voir comme ça. Surtout quand ce n’était pas une bonne journée, on dirait que je faisais de l'évitement plus qu'autre chose.

QUOTE 25

Mais il y a d’autres changements corporels aussi qui sont, selon moi, aussi pire que la perte de cheveux. La rétention d’eau, c’est quand même assez intense. La tête ronde comme un ballon de soccer’. C'est un gros changement physique à avoir sur sa petite sœur qui a six ans. […] Je dirai’ c'est de voir ma sœur être différente de ce que je la connaissais avant. Surtout la chimiothérapie. […] La cortisone, ça fait vraiment gonfler le visage. La perte de cheveux, c'est moins stigmatisé. Tout le monde sait que ça arrive. C'est sûr qu'il y a des changements physiques, puis des changements comportementaux aussi, qu’il ne faut pas oubliés. Ils sont pires, je dirais, que les changements physiques.

QUOTE 26

Oui, ça change le physique de la personne, mais ça change l'aspect mental aussi. Pas juste la chimiothérapie, d'autres antibiotiques, tout ce qu'il y avait a prendre justement parce qu'elle était immunosupprimée, le décadrons, ça change vraiment la personnalité. […] Agressivité, impulsivité, des cravings de bouffe d'émotion assez spéciales. […] mais les changements physiques sur ma sœur à cause des effets secondaires, ça, c'était quand même quelque chose que je dirais j'étais triste, triste pour elle, c'est sûr.

QUOTE 27

C'est beaucoup d'effets secondaires. Mon frère a eu de la radiothérapie très forte à un âge vraiment jeune. C'est de la radiothérapie qu'on ne donne pas à un enfant normalement, tellement c'était fort. Mais c'était comme la seule façon de faire contact avec la tumeur. Ils donnaient des traitements très forts, sauf que mon frère a tellement d'effets secondaires reliés à ça, que ce soit académique, que ce soit son équilibre, des étourdissements, des migraines. Mon frère vit avec des migraines tous les jours de l'année.

QUOTE 28

J'ai appris à être autonome, vraiment jeune, comme à 14 ans, je faisais ma bouffe... Ça te force à devenir responsable de toi même vraiment rapidement.

QUOTE 29

C'est sûr qu'il y avait ce rôle-là, un peu d'occuper de mon frère […]. Le matin, je m'en occupais moins. Il y a toujours mon père ou ma mère qui dormait à la maison et qui allait porter mon frère à l'école, puis après qui repartent à l'hôpital. Mais le soir, c'était plus comme des fois, j'allais chercher à l'école ou des choses comme ça.

QUOTE 30

[…] ça fait depuis que j'ai 14 ans que je suis autonome, dans le sens que je fais ce que je veux de mes soirées, je n'ai pas à rendre de comptes à personne, je n'ai pas d'heure à quelle je dois rentrer. Puis, à mes 16 ans, les traitements pour le cancer de mon frère étaient terminés, je suis retournée vraiment vivre à temps plein chez mes parents, puis tout d'un coup, elle voulait être ma mère. Je me souviens, je lui ai dit « ne commence pas ça, tu n'es plus ma mère. Ça fait deux ans et demi que tu ne joues plus ton rôle de mère. Tout d'un coup, tu me dis à quelle heure rentrer, tu me demandes qu'est-ce que tu as mangé, est-ce que tu as fait tes devoirs ?» Moi, ça ne passait plus. C'était comme ça. Comme j'ai goûté à mon indépendance, puis de comme lâcher ce rôle, tu ne le reprends pas.

QUOTE 31

Oui, je retiens des éléments positifs. Des exemples, ma famille, les amis de mes parents s'entraident et nous aident. C'était un élément positif que je retiens encore. Le fait d'avoir été plus autonome, je trouve aussi que plus rapidement, c'est un élément positif. […] Je suis surtout reconnaissant pour les médecins, les infirmières, et des protocoles de traitement qui a été établi par des chercheurs.

QUOTE 32

Je te dirais que ça m'a amené vraiment beaucoup de positif dans la vie. Il y a plusieurs choses qui se sont passées comme ça, parce que mon frère était malade justement, puis la maturité, l'autonomie, toutes ces choses-là

QUOTE 33

J'étais en état de burn-out à tous les niveaux. Ce n'était pas juste un burn-out à l'école. J'étais vraiment burn-out émotionnel, généralisé. J'ai comme frappé un mur, parce que veut veut pas, les années qui suivent (après le décès), il faut que tu t'occupes de tes parents, tu vas être l'enfant qui va bien. Tu essaies de retrouver un semblable du normal, mais en fait, je me suis épuisée à faire ça. À ce jour, l'anxiété est encore un problème…les attaques de panique surtout.

QUOTE 34

[…] encore aujourd'hui, ça me hante parce que même quand je dormais, je l'entendais hurler de douleur quand on était à la maison."

QUOTE 35

J'ai eu droit à une rencontre de dix minutes avec le médecin qui était en charge de soin palliatif. Ça a été la seule rencontre que j'ai où il m'a dit « Voici ce qui s'en vient. Comprends-tu ce que ça représente? Mais ironiquement, j'ai eu cette rencontre le vendredi, puis ma sœur est décédée le samedi matin.

QUOTE 36

On n'en parle pas en fait, non. On ne parle pas, il n'y a pas de photo, on en parle pas du tout […]. Je pense que la fierté, c'était quand on s'en était sortis, puis qu'on était full de bonne humeur quand même. C'était pas dans le...C'était pas dans la ligne de partie qu'on avait choisi comme famille de parler de ça. C'était comme « non, on en parle pas. […]. Mes parents sont jamais allés consulter, mes parents sont jamais... Pour eux, ils sont fiers de qu'on est sorti sans aide, alors que ça je pense pas que c'était une si bonne chose que ça. Je pense que c'est sûr, que sur le moment, ils ne peuvent rien faire différemment, mais après, oui, il y a des choses qui peuvent être faites.

QUOTE 37

Non, je pense que mon père voudrait en parler tout le temps. Ma mère ne veut jamais en parler. Moi, je pense que je me suis mis à en parler plus tard […]. Encore aujourd'hui, quand je leur en parle, ils me disent encore que ce n'était pas si pire pour moi, puis qu’ils ont tout fait, que je ne devrais pas me sentir comme ça. Alors que mon message, c’est pas ça, c'est comme si dès qu'on essaie d'en parler, il y a toujours quelqu'un qui a un sentiment de frustration. Mon père voudrait qu'on en parle, qu'on fasse des célébrations. Ma mère voudrait qu'on en parle plus jamais, comme si c'est jamais arrivé. Ma sœur, elle est comme « C'est une sœur que j'ai jamais connue, pourquoi vous en parlez? C'est comme tout le monde, personne n’est dans le calme et l'acceptation.

QUOTE 38

Tous les détails sont vraiment spécifiques à ma sœur, son état d'esprit, tout ça. On a gardé ça pour nous. On est une famille qui est extrêmement privée. On n'est pas le genre de famille qui a des réseaux sociaux actifs. On a tendance à garder ça pour nous.

QUOTE 39

Oui, depuis que ma sœur va bien, on en rit. Ce n'est pas tabou, comme sujet dans ma famille”

QUOTE 40

Je dirais que dans la famille, le consensus, c'est probablement qu'on a été chanceux, on a eu *de la chance* d'avoir une leucémie lymphoblastique aiguë avec un protocole qui est déjà établi depuis des années, que le taux de mortalité est relativement bas pour ceux qui réagissent bien à la chimiothérapie. Et puis ça se voit tout de suite ceux qui réagissent bien dans les premiers mois. On se disait qu'on était un peu chanceux dans notre malchance. C'est sûr que personne n'est chanceux d'avoir un cancer, mais quand ça se guérit, on se trouve chanceux à ce moment-là.

QUOTE 41

Ça a été néfaste d'un autre côté parce que mes parents sont devenus une bulle avec mon frère. Moi, j'étais vraiment « the outsider ».

QUOTE 42

Pour être bien franche, même si mes parents n'avaient pas encore divorcé, tu vis déjà la garde partagée. Parce que moi, je ne vivais plus avec ma mère. Depuis le diagnostic, elle était tout le temps à Sainte-Justine. C'était moi, puis mon père, ma sœur et ma mère. On n'était plus une unité familiale depuis extrêmement longtemps. Donc quand le divorce est arrivé, il n'y a pas de réelle différence à part que de temps en temps, je changeais de place pour dormir. On était déjà divisés en tant qu'unité familiale. Ça n'a pas changé grand-chose.

QUOTE 43

Je pense que c'est vraiment important la relation entre les deux. Mon frère se confie beaucoup plus à moi qu'il pouvait se confier à mes parents. C'est encore comme ça. Il y a plein de choses qu'il ne dira pas à mes parents.

QUOTE 44

Moi, ma sœur, on était extrêmement proches. On ne s'est jamais chicané. On était comme des âmes de sœur. Moi, je considère encore aujourd’hui que ma sœur, c'était mon âme de sœur. J'ai passé aucun temps avec elle. Elle a été diagnostiquée en décembre. On n'a passé aucun moment ensemble, vraiment juste nous deux, avant son décès. À juste avoir du fun. Donc trouver une façon de faciliter ce temps-là.

QUOTE 45

Nous, on était à Saint Justine, et il y avait des trucs d'organisés. C'était pas nécessairement des souvenirs négatifs. C'était comme on passait vraiment du temps ensemble, comme on passerait à la maison. […]. On a aussi eu Rêve d'Enfant à Walt Disney avec ma sœur. Ces moments-là, c'est des moments vraiment, vraiment forts. C'est vraiment des beaux souvenirs.

QUOTE 46

C'est beaucoup, je trouve pour un enfant, comme je disais, tu ne crois plus au père Noël pas mal vite. Il n'y en a plus de père Noël.

QUOTE 47

On parlait d'argent, on parlait de maladie, on parlait de... C'était comme des sujets adultes, très adultes. C'était comme devenir très adulte, rapidement.

QUOTE 48

Mais c'est sûr que ça a été difficile pendant un moment de rejoindre les autres enfants sur certains points de vue, parce qu'on ne vivait pas la même chose, on ne faisait pas les mêmes activités. On ne grandissait pas de la même manière, ça, c'est sûr.

QUOTE 49

Certainement, je pense que mon choix de carrière a été quand même grandement influencé par toute la maladie dans ma famille. Mais oui, je travaille en santé aujourd'hui à cause de ça. […]. Parce que j'ai baigné dans la relation d'aide, puis dans la santé, puis dans la maladie toute ma vie, que j'ai fait ma carrière autour de ça. Aujourd'hui, je réalise que sans ça, peut être que j'aurais choisi autre chose. J'aurais peut-être été enseignante, j'aurais peut-être fait autre chose, mais je n'ai tellement rien connu d'autre que c'est là-dedans.

QUOTE 50

C'est drôle parce qu'on en a parlé, et on s'est vraiment chicané. On en a reparlé, on parlait de... J'ai dit que je t'avais rencontré, puis on parlait de ça. J'ai juste dit qu'on avait parlé de stress, puis eux, ils disaient « on ne t'a jamais laissé tout seul, on ne t'a jamais... ». Je ne sais pas comment l'exprimer. C'est comme trop dur pour eux d'admettre que ça a été difficile pour moi, parce qu'eux, ils ont tout fait. C'est vrai qu'ils ont tout fait, mais un n'empêche pas l'autre. Je leur en veux pas du tout pour la façon dont ils ont géré la situation à l'époque, mais je leur en veux de dire ça maintenant. Je leur en veux un peu de leur action maintenant. […] J'ai beaucoup de respect. J'ai énormément de respect et d'admiration pour mes parents, mais ça n'empêche pas que j'ai quand même eu des conséquences...

QUOTE 51

C'est difficile parce que chaque cancer est du cas par cas, chaque famille est différente. Il n'y a pas de solution universelle.

QUOTE 52

J'aurais juste aimé qu'il y ait plus de compréhension, d'information sur comment moi, je peux me sentir comme des années plus tard, puis comment j'ai des traits de personnalité qui peuvent être particuliers, que d'autres gens n'ont pas.

QUOTE 53

Mais comme à 15, 16 ans, quand certaines choses étaient là, les cauchemars étaient encore là, à un moment donné, c'était comme ... j'ai l'impression que quelqu'un, que quelqu'un qui aurait dû expliquer que certaines choses devraient être adressées

QUOTE 54

Je veux bien faire des dessins, mais c'était beaucoup de dessins, beaucoup de dessins. Mais ça n'a pas aidé à... Je ne sais pas, ce n'était pas comme des outils... Mais il y avait des moments de détresse extrême, c'était comme...ce n'était pas des dessins qui allaient m'aider […]. C'était comme dessine ta famille, tu dessines ta maison. Moi, dans ma tête, je me suis disait que tu peux juste me le demander, je vais te répondre vraiment clairement comment je me sens.

QUOTE 55

J'étais ado... Moi, d'aller faire des petits bricolages […] l'approche qu'ils ont pour les frères et sœurs est très juvénile. Je comprends parce que Leucan, c'est pour les traites, surtout les cancers pédiatriques, donc les jeunes enfants qui ont des cancers, mais toutes leurs approches tournent autour des enfants de ces âges-là. Mais comme moi, ma sœur avait 15 ans […] moi, j'étais une adolescente, donc l'approche de Leucan, ça a été un échec total. Et j'ai même réessayé par après, il y avait une activité pour frères et sœurs endeuillés qui avait été aussi un flop total. Moi, faire des collages, ça ne marche pas.

QUOTE 56

Parce que même aujourd'hui, je te dirais, je pense que l'aide est toujours nécessaire tant que c'est pas fini en tant que tel. C'est ce que j'avais fini dans le cas de mon frère. Je pense que c'est toujours utile. On dirait que dès que c'est stable, il y a plus de traitement, on tombe un petit peu à part. C'est fini, c'est correct. Mais de plus en plus, j'y vais, je vois que ça atteint encore. […]. C'est sûr que moi, aujourd'hui, je n'en ai plus de suivi, puis je n'ai plus d'aide pour ça. Quand je vais moins bien, c'est dur parce que tu es plus tentée à aller vers les gens qui sont proches de toi, mais les gens qui sont proches de toi le vivent aussi.

QUOTE 57

D'être la dernière à savoir ce qui se passait.