SIBLINGS' EXPERIENCES WITH PSYCHOSOCIAL SUPPORT THROUGHOUT THE PEDIATRIC CANCER TRAJECTORY

SIBLINGS’ EXPERIENCES WITH PSYCHOSOCIAL SUPPORT THROUGHOUT THE PEDIATRIC CANCER TRAJECTORY

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Abstract

Siblings of children with cancer are exposed to significant stress and experience challenges in many aspects of their lives throughout the pediatric cancer trajectory. As a result, siblings are at risk for acute and long-term psychosocial consequences and must be provided with appropriate supportive services during and after cancer treatment. At this time, there are no evidence-based standards to guide the supportive care of siblings of children with cancer. The purpose of this study was to explore and develop an understanding of the different ways in which siblings of children with cancer perceive their psychosocial needs are addressed from formal and informal sources.

A qualitative interpretive descriptive methodology was used in the study design. Data were collected from a sample of ten siblings in Ontario whose siblings were diagnosed and treated for pediatric cancer within the past ten years. The data collection methods included semi-structured individual interviews, socio-demographic questionnaires, field notes, and the researcher's reflexivity journal. A reflexive thematic and inductive approach was used for the analysis of the collected data.

The study findings highlight that there are significant gaps in the psychosocial support provided to siblings of children with cancer. Four overarching issues were identified, including: (1) siblings' isolation from the pediatric cancer experience, (2) limited parental awareness of siblings' psychosocial needs, (3) needs for consistent academic and school support, and (4) needs for standardized psychosocial support from healthcare professionals and hospital systems.

The study findings provide several implications for clinical practice, policy, education, and research for nurses and other healthcare professionals working in pediatric oncology settings. Recommendations include: (1) integration of psychosocial care for siblings into clinical

practice, (2) development of evidence-based standards and guidelines for the psychosocial support of siblings, (3) ongoing education and training for healthcare professionals related to siblings' psychosocial healthcare needs, and (4) additional research on standardized screening tools and interventions for siblings.

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List of Abbreviations

CDI	Children’s Depression Inventory
CPSS	Child Post-traumatic Stress Disorder Symptom Scale
HiREB	Hamilton Integrated Research Ethics Board
OONSV	Ontario Oncology Nurse School Visitation Program
OPACC	Ontario Parents Advocating for Children with Cancer
PAT	Psychosocial Assessment Tool
PI-ED	Pediatric Index of Emotional Distress
PHAC	Public Health Agency of Canada
POGO	Pediatric Oncology Group of Ontario
PTSD	Post-traumatic Stress Disorder
STAIC	State-Trait-Anxiety Inventory for Children

Declaration of Academic Achievement

I, Reenu Chhokar, declare that this work is my own and, if not, I have acknowledged the original source according to APA guidelines.

Date: March 24, 2023

Graduate Thesis: An interpretive description of siblings' experiences with psychosocial support throughout the pediatric cancer trajectory

Signature:

CHAPTER 1: INTRODUCTION

Introduction

The diagnosis and treatment of pediatric cancer is a life-changing experience for children and their families. Frequent prolonged hospital admissions, financial hardships, changes in family functioning, and uncertainty of prognosis are just a few of the significant challenges that families must cope with during a child's cancer treatment (Gerhardt et al., 2015). Siblings of children with cancer are at an increased risk for long-term psychosocial consequences as they experience tremendous changes in their lives throughout the illness trajectory (Alderfer et al., 2010). Healthy siblings often must learn to adapt quickly to changing circumstances with limited psychosocial support from family, friends or other professionals, including those in healthcare, education, or social services (Gerhardt et al., 2015).

There is extensive literature that examines the impact of pediatric cancer on patients and their parents with respect to their psychosocial needs; however, there is minimal research that explores the experiences of siblings of children with cancer, including their perceived needs for or access to psychosocial support (Erker et al., 2018). Due to the significant impact of pediatric cancer on families, it is critical to understand sibling experiences throughout the cancer trajectory in order to inform development of family-centred, evidence-based standards for psychosocial support. The purpose of this qualitative study is to explore the varied and perceived experiences of siblings of children with cancer with receiving psychosocial support. Throughout this thesis, the study participants will be identified as "siblings" which refers to siblings of children that have been diagnosed with and treated for pediatric cancer.

Background

Pediatric cancer is the most common disease-related cause of death among children in Canada. Each year, there is an average of 880 new cases of pediatric cancer and approximately 150 children die from this disease (Public Health Agency of Canada [PHAC], 2012). Among Canadian children, the most common type of cancer is leukemia (33%), followed by brain and central nervous system cancers (20%), and lymphomas (11%) (PHAC, 2012). The treatment of pediatric cancer is intensive and can last from several months to years as a combination of different treatments are often used such as chemotherapy, radiation, surgery, and stem cell transplant (National Cancer Institute, 2019). The survival rates for pediatric cancer have improved significantly over the past 30 years due to ongoing advancements in cancer research and treatments. As a result, approximately 83% of children diagnosed with pediatric cancer will survive at least five years after diagnosis (PHAC, 2012). While survival rates have increased for several types of pediatric cancers, more than 75% of children will experience long-term effects related to cancer treatment including cardiopulmonary, endocrine, renal or hepatic dysfunction, reproductive difficulties, neurocognitive impairment, psychosocial difficulties, and the development of subsequent cancers (PHAC, 2012).

Siblings of children with cancer are exposed to significant stressors throughout the trajectory of the illness including concerns about the child with cancer, disruptions in family functioning and daily routines, decreased physical and emotional availability of parents, and additional demands for caregiving or other responsibilities in the home (Gerhardt et al., 2015). These challenges can lead to serious emotional, behavioural, and social consequences for siblings especially if they are not provided with adequate psychosocial support (Gerhardt et al., 2015). During cancer diagnosis and treatment, parents and caregivers typically focus their time and attention on providing care for the ill child which may lead to siblings feeling isolated and neglected (Weiner & Woodley, 2018). Similarly, in hospital settings, nurses, and other healthcare professionals acknowledge the importance and prioritize providing family-centred care for children with cancer and their parents while often disregarding the psychosocial healthcare needs of siblings (MacKay & Gregory, 2011). As a result, siblings of children with cancer are at an increased risk of receiving limited psychosocial support from social and professional sources (Long et al., 2018). Given the impact that childhood cancer has on siblings, it is important to understand their experiences with receiving psychosocial support to inform caregivers and healthcare professionals of their needs and to develop interventions that reduce distress and promote adjustment throughout the illness trajectory and beyond.

Context

The diagnosis and treatment of pediatric cancer requires highly specialized care which typically occurs in urban, tertiary pediatric centres throughout Canada’s publicly funded universal healthcare system (Mitra et al., 2015). Children with cancer require close observation, frequent hospitalizations, and follow-up to receive intensive treatments such as chemotherapy, radiation, surgery, and stem cell transplants (National Cancer Institute, 2019). As a result, many families must relocate from their homes for extended periods during cancer treatment to be close to a hospital, specifically those living in rural or remote areas. Ultimately, pediatric cancer treatment often places a significant burden on families due to multiple factors including financial challenges, loss of employment, and separation from other children (Gerhardt et al., 2015).

The majority of pediatric cancer centres within Canada commit to providing family-centred care. Family-centred care is an approach to the planning, delivery and evaluation of healthcare that recognizes the central role of the family in a child’s life and highlights the importance of the partnership among healthcare providers, patients, and families that is developed through core values such as respect, empowerment, communication, collaboration, and support (MacKay & Gregory, 2010). While the provision of family-centred care is recognized as a priority in pediatric oncology, nurses and other healthcare professionals experience challenges when implementing this approach to care in clinical practice (MacKay & Gregory, 2010). Some of the barriers that pediatric oncology nurses experience include limitations in the required knowledge, skills, and system-based supports needed to implement family-centred care into clinical practice (Gerhardt et al., 2015). As a result, siblings often report having unmet psychosocial needs and may be at an increased risk for receiving limited psychosocial support throughout the cancer trajectory (Gerhardt et al., 2015).

Research Purpose

Siblings of children with cancer are exposed to significant stress and experience challenges in several aspects of their lives throughout the cancer trajectory. As a result, siblings are at risk for acute and long-term psychosocial challenges and must be provided with appropriate supportive services during and after cancer treatment (Gerhart et al., 2015). Currently, there are no evidence-based standards to guide the supportive care of siblings of children with cancer and there is limited access and availability of resources to provide psychosocial support to them (Gerhardt et al., 2015; van Warmerdam et al., 2020). Furthermore, while the provision of family-centred care promotes positive health outcomes for siblings, pediatric oncology nurses experience challenges in providing them with appropriate psychosocial support due to a lack of understanding of their healthcare needs and limited access to standardized psychosocial screening tools and interventions (Gerhardt et al., 2015; MacKay & Gregory, 2011).

The purpose of this study is to explore and develop an understanding of the different ways in which siblings perceive their psychosocial needs are addressed. The findings of this study will highlight siblings' experiences with receiving psychosocial support which may allow nurses and other healthcare professionals to identify the potential gaps in the care that is currently provided. In addition, the findings from this study may be used to improve psychosocial support for siblings of children with cancer through the development of standardized and evidence-based assessments and interventions that can be individualized to siblings. Overall, the findings of this study may inform how nurses provide family-centred care for siblings of children with cancer, inform the development of assessments and interventions that promote psychosocial support, and provide a foundation for future research.

Reflexive Statement

As a pediatric oncology nurse and the sibling of a child that was diagnosed with a terminal brain tumour, I have always been interested in exploring the experiences of siblings impacted by pediatric cancer. At the age of nine, my sister was diagnosed with glioblastoma, an aggressive form of brain cancer: I was five years old at that time. My family spent more than a year in the hospital as my sister underwent several surgeries and received intense cycles of radiation and chemotherapy. My sister passed away 20 years ago but my family continues to experience immense grief and trauma related to this experience. Informed by my personal experiences, I hold the belief for myself, that being a sibling of a child with cancer was one of the most difficult experiences that I have had to endure. As a sibling, it was my experience that I lost my parents' attention, often at times when I needed it most. During this period of time, I received vague explanations about my sister's diagnosis and treatment and my life completely changed in an instant. My personal experiences have underpinned my motivations and actions as a registered nurse to ensure that other siblings impacted by pediatric cancer feel understood and receive the psychosocial support that they require to cope with challenging circumstances. While my experiences have allowed me to empathize and build rapport with the participants in this study, it is important to acknowledge that each sibling's experiences with pediatric cancer is unique, individualized and may vary based on a multitude of complex factors.

Furthermore, my professional experiences as a pediatric oncology nurse at The Hospital for Sick Children over the past four years have provided me with further insights into the experiences of siblings of children with cancer. An important value in my nursing practice is providing family-centred care, which recognizes that the entire family is impacted when a child is hospitalized and emphasizes that healthcare professionals must collaborate with families to ensure that they are involved and supported in all aspects of care. While providing family-centred care is a core value in my clinical practice, I often do not place a major emphasis on incorporating siblings in my nursing care due to various reasons including heavy workloads, patient acuity, lack of sibling presence in the hospital and limited availability of psychosocial assessments and interventions for siblings. Overall, my personal and professional experiences have informed my current knowledge about the psychosocial impact of pediatric cancer on siblings and influenced my interest in exploring siblings' experiences to enhance family-centred care in the future.

CHAPTER 2: LITERATURE REVIEW

Search Strategy

The purpose of this literature review is to provide an overview of the existing research related to the impact of pediatric cancer on siblings and the psychosocial support that they receive from social and professional sources throughout the cancer trajectory. A search of the literature was conducted on databases including CINAHL, PubMed, Medline, Embase and Google Scholar (see Appendix A). The following key terms were used in various combinations in the literature search: sibling*, pediatric cancer*, childhood cancer*, psychosocial, support*, experience* and impact*. Given the significant advancements in pediatric cancer care, survival, and research over the past several years, the literature search was limited to studies published in English from the year 2000 to the present date to ensure relevance. Studies were excluded if they did not focus on siblings of children with cancer as participants or the sibling experience. A total of 174 citations were initially screened from the literature search and irrelevant articles were excluded. From this search, 27 studies were selected for the literature review and were critically appraised using checklists from the Critical Appraisal Skills Programme (2012).

There is a growing body of knowledge about the impact of childhood cancer on healthy siblings. The literature review includes nine qualitative studies, seven quantitative studies, one mixed method study, six systematic reviews, and four integrative reviews. The studies included in the literature review were conducted in the United States, Canada, United Kingdom, Sweden, Switzerland, New Zealand, Belgium, and the Netherlands. Several of the studies included in this literature review were conducted with participants while their sibling was undergoing cancer treatment; however, 10 of the studies were retrospective in nature, and data were collected from sibling participants up to 20 years after cancer treatment. The majority of participants in the selected studies were siblings of children with cancer, between the ages of 8 and 18 years; parents and healthcare providers were also included. The sample sizes across studies varied significantly ranging between 7 to 94 participants in qualitative studies and 56 to 7897 participants in quantitative studies. The literature was reviewed and will be summarized in the following sections with a focus on the impact of pediatric cancer on siblings and the psychosocial support provided to them (see Appendix B).

Impact of Pediatric Cancer on Siblings

Siblings of children with cancer are exposed to significant stress and they experience changes in all aspects of their lives throughout the cancer trajectory (Gerhardt et al., 2015; Weiner & Woodley, 2018). Many studies, identified that siblings are at risk for acute and long-term emotional, behavioural and psychosocial challenges. This includes symptoms of anxiety, depression and posttraumatic stress, lower quality of life and healthcare utilization, and disruption to academic and social functioning (Gerhardt et al., 2015; Weiner & Woodley, 2018). Overall, the diagnosis and treatment of pediatric cancer have shown to be a significant influence on five major aspects of siblings' lives including: (a) emotional changes, (b) psychosocial adjustment, (c) family functioning, (d) academic performance, and (e) social relationships (Prchal & Landolt, 2012; Weiner & Woodley, 2018).

Emotional Changes

All of the studies included in this review highlight a range of emotional changes that healthy siblings of children with cancer experience throughout the illness trajectory and beyond. A systematic review by Alderfer et al. (2010) included 65 qualitative, quantitative, and mixed methods publications to establish a broader understanding of the psychosocial impact of pediatric cancer on siblings. In this review, key findings include that siblings report experiencing feelings of loss, anxiety, grief, shock, disbelief, helplessness, insecurity, loneliness, abandonment, jealousy, anger, and guilt (Alderfer et al., 2010). At the initial cancer diagnosis, siblings often report experiencing feelings of shock, uncertainty, fear, anger, and sadness (D'Urso et al., 2017). As treatment progresses, siblings continue to experience significant emotional distress which adds to stressors that may already be present in their daily lives (D'Urso et al., 2017). Many siblings express feelings of jealousy because the child with cancer receives more attention from parents, family members, and healthcare professionals (O'Shea et al., 2012). Feelings of uncertainty are common among siblings as parents and healthcare professionals often do not share adequate and age-appropriate information about their brother or sister's cancer diagnosis and treatment or openly discuss the impact of cancer on their lives (Toft et al., 2019). Siblings also report feeling isolated and distant from the cancer experience because they are typically not provided the opportunity to be actively involved in their brother or sister's cancer treatment (D'Urso et al., 2017).

Furthermore, many siblings express feelings of guilt, sadness, and grief throughout cancer treatment. These emotions are experienced by siblings as they realize that their brother or sister has a potentially terminal disease and loses the ability to engage in normal childhood activities, while they can continue with their daily routines (Weiner & Woodley, 2018). As treatment progresses, these feelings persist because siblings witness their brother or sister undergo significant physical changes and experience side effects related to aggressive treatments (Prchal & Landolt, 2012). Although many studies emphasize the negative emotions described by siblings, some also identify that siblings express an optimistic outlook on the cancer experience especially after treatment has been completed (Alderfer et al., 2010; Weiner & Woodley, 2018). Many siblings report personal growth from the cancer experience, including increased confidence, independence, maturity, resilience and empathy, and a greater appreciation for life (Alderfer et al., 2010).

Psychosocial Adjustment

Several studies included reports of a profound psychosocial impact on siblings of children with cancer (Woodley & Weiner, 2018). An integrative review by Gerhardt et al. (2015) examined the psychosocial impact of pediatric cancer on siblings and included a total of 125 primarily descriptive studies. This review concluded that siblings are at risk for emotional and behavioural challenges, including anxiety, depression, post-traumatic stress symptoms, academic and social disruptions, poor quality of life, and lower healthcare utilization. It also outlined that siblings' psychosocial challenges tend to be more common in the early phases of the illness and improve over the first year after cancer diagnosis (Gerhardt et al., 2015). Alderfer et al. (2003) recruited 78 adolescent siblings of pediatric cancer survivors who completed self-reported measures of anxiety, post-traumatic stress, and perceptions of the cancer experience. Study findings indicate that approximately half (49%) of the sample reported mild post-traumatic stress and one-third (32%) indicated moderate to severe levels of post-traumatic stress between 1 to 10 years after cancer treatment (Alderfer et al., 2003).

Similarly, Kaplan et al. (2013) measured symptoms of post-traumatic stress disorder (PTSD) using the Child PTSD Symptom Scale (CPSS) among 125 siblings between the ages of 8 and 17 years with a brother or sister diagnosed with cancer in the past 4 to 38 months. The results of this study outline that one-fifth (22%) of siblings met the full criteria for PTSD based on their self-reported responses, and an additional one-third (34%) of siblings exhibited some of the symptoms associated with a diagnosis of PTSD. Finally, a recent case-control study by van Warmerdam et al. (2020) identified 7897 siblings from a provincial childhood cancer registry in

Ontario to determine the long-term impact of pediatric cancer on their mental health. Specifically, the study examined the rate of mental health-related outpatient visits and the incidence of severe psychiatric events. The findings of the study demonstrate that siblings of children with cancer experience an elevated and prolonged risk for mental health and substance use disorders for up to 20 years after initial diagnosis (van Warmerdam et al., 2020).

Siblings' psychosocial adjustment to pediatric cancer remains poorly understood due to mixed study findings and the complex nature of this phenomenon (Long et al., 2018). An integrative review by Zegaczewski et al. (2016) included 12 non-experimental and quasi-experimental studies to identify factors related to the psychosocial adjustment of siblings between 1 and 19 years of age. Within this review, three significant factors were identified that are associated with siblings' psychosocial adjustment, including: (a) personal characteristics of the sibling, (b) social support from family, peers and professionals, and (c) contextual factors. Regarding the personal characteristics of the sibling, research indicates that age and gender play a significant role in psychosocial adjustment. In particular, female siblings often exhibit more behavioural problems, anxiety, and decreased quality of life in comparison to male siblings ($P \leq .05$). Moreover, younger siblings typically exhibit psychosocial distress during play activities whereas older children tend to internalize their feelings, become withdrawn, and experience challenges with academics (Zegaczewski et al., 2016).

The amount and quality of support provided to siblings of children with cancer by family, peers, and professionals has also been associated with sibling psychosocial adjustment and functioning throughout the cancer experience (Erker et al., 2018). A study by Barrera et al. (2004) examined the role of emotional and social support in the psychosocial adjustment of 72 siblings of children with pediatric cancer between 6 to 18 years of age. Siblings completed measures of depression, anxiety, behaviour and emotional social support using validated scales such as the Children’s Depression Inventory (CDI) and State-Trait-Anxiety Inventory for Children (STAIC). The findings indicated that perceived social support had a negative correlation with symptoms of depression ($P \leq .05$), anxiety ($P \leq .01$), and behavioural problems ($P \leq .05$). Thus, siblings who reported more social support had significantly fewer symptoms of depression, anxiety, and fewer behaviour problems than siblings who reported lower social support (Barrera et al., 2004). Finally, several contextual factors impacted siblings’ psychosocial adjustment including illness-related factors and hospitalizations, home environment, socioeconomic status, family adaptability, and role overload (Zegaczewski et al., 2016). A systematic review by Long et al. (2018) included 102 studies with quantitative, qualitative, and mixed methods designs to examine siblings’ psychosocial adjustment to childhood cancer. The review outlined that risk factors for poor sibling psychosocial adjustment include lower social support, impaired family functioning, lower income, non-White race, and shorter time since diagnosis (Long et al., 2018).

Family Functioning

Changes in family functioning during treatment are extensively reported in qualitative literature and have a significant impact on siblings of children with cancer throughout the illness trajectory. The most common findings reported in the literature included siblings’ disrupted sense of normalcy and loss of parental attention (Alderfer et al., 2010; Weiner & Woodley, 2018). Siblings described that they spent less time with their ill brother or sister and parents, had an increased number of responsibilities in the home, felt forgotten and isolated within their family, and experienced significant changes in their daily routines and activities (Alderfer et al., 2010; Gerhardt et al., 2015; Weiner & Woodley, 2018). A longitudinal mixed methods study by

Woodgate (2006) explored 30 siblings' experiences during the childhood cancer trajectory through observations and interviews. The findings outline that changes in family functioning cause significant distress for siblings and the cancer experience is often viewed as a "different way of being in the family" (Woodgate, 2006). In particular, siblings reported experiencing disruptions in how they and their family members related to each other and functioned together, as well as a loss of their sense of self within the family unit (Woodgate, 2006).

From a parental perspective, a systematic review of 65 studies conducted by Alderfer et al. (2010) found that parents experience challenges attending to the needs of both their sick and healthy children throughout the cancer trajectory. Parents express that they must prioritize their child's cancer treatment which may make them physically and emotionally unavailable for their other child(ren). A study by Sidhu et al. (2005) included focus group interviews with 9 parents of children with cancer, and parents frequently expressed feeling guilty for not being physically and emotionally present for their other child(ren) and worried about the potential long-term consequences it would have on them. While the literature outlines several challenges that families experience during the cancer experience, there are also several positive outcomes reported by siblings including a greater sense of family cohesion, closeness, and strengthening bonds (Long et al., 2018). Specifically, siblings report having more valuable and closer relationships with their brother or sister and parents after going through a difficult and life-changing experience together (Weiner & Woodley, 2018).

Academic Performance and Social Relationships

Siblings of children with cancer may also experience difficulties with academics, especially within the first 6 months after diagnosis (Alderfer et al., 2015). The primary themes documented within this body of literature were disruptions in school performance, behaviour changes, as well as a perceived need to be more responsible for independently completing their school work (Alderfer et al., 2010). A qualitative study by Prchal and Landolt (2012) described the experiences of 7 siblings in the first 6 months after cancer diagnosis through semi-structured interviews. The study outlines that siblings of children with cancer may miss significant amounts of school and fall behind academically in comparison to their peers. Siblings reported feeling that they are expected to continue with their daily lives as normally as possible, but find this task difficult due to competing priorities, increased stress, and distractions related to cancer treatment (Long et al., 2018).

Furthermore, a case-control study by Alderfer et al. (2015) examined social functioning among 87 siblings and compared them to 256 demographically matched peers. This study concludes that siblings' relationships with their peers were similar to those of their classmates. However, siblings experience a decrease in involvement in social and extracurricular activities after their brother or sister's cancer diagnosis. Although siblings experience challenges with school attendance, academic performance, and activity participation throughout the illness trajectory, supportive peer relationships are cited as a valued resource for siblings in the literature as it provides them with distraction, opportunities to socialize, and express their feelings in an open and non-judgemental environment (Long et al., 2018).

Psychosocial Support for Siblings

Siblings of children with cancer are exposed to significant stress and experience unique challenges that increase their risk for acute and long-term emotional, behavioural, and social issues (Gerhardt et al., 2015). As a result, siblings of children with cancer should be provided with appropriate psychosocial support beginning at diagnosis and continuing beyond the illness trajectory (Gerhardt et al., 2015). Psychosocial support for siblings has a major impact on their adjustment to the cancer diagnosis and can mitigate potential negative emotional and behavioural consequences (Zegaczewski et al., 2016). This support allows siblings to express their thoughts and feelings, promotes positive coping mechanisms, and facilitates open communication (Zegaczewski et al., 2016).

Forms of Psychosocial Support

Psychosocial support has been broadly defined as “the provision of assistance, comfort or resources to individuals to help them cope with stressors” (Wawrzynski et al., 2021). Supportive care for siblings can take many forms but is generally comprised of formal and informal support. Formal support consists of programs, services or resources that are provided by hospital systems or community organizations, while informal support is often received by family, friends, peers, teachers, and others (Wawrzynski et al., 2021). The literature highlights that a combination of both formal and informal psychosocial support is necessary to improve outcomes for siblings throughout the cancer trajectory (Wawrzynski et al., 2021).

A scoping review by Wawrzynski et al. (2021) categorizes psychosocial support for siblings into several specific types, including: (a) emotional, (b) instrumental, (c) informational, (d) companionship, and (e) validation. Emotional support is described as verbal and nonverbal expressions of caring, compassion, and empathy towards siblings (Wawrzynski et al., 2021). An example of emotional support for siblings may include creating a safe space where siblings are encouraged to share their feelings and are provided with reassurance and validation. Next, instrumental supports are defined as tangible items or services provided to siblings throughout the cancer trajectory such as transportation to extracurricular activities or assistance with completing homework and household chores (Wawrzynski et al., 2021). In addition, informational support is the provision of knowledge and education about pediatric cancer including the diagnosis and treatment, as well as the resources and supports available for siblings (Wawrzynski et al., 2021). Companionship involves the presence and availability of family, friends, and peers for social engagement and spending quality time together (Wawrzynski et al., 2021). Finally, validation support allows siblings to feel “seen” and is described as a sense of belonging and acknowledgement for their achievements and contributions throughout the cancer trajectory (Wawrzynski et al., 2021).

Current State of Psychosocial Support

Siblings need access to timely screening and supportive care; however, these services are often limited throughout the pediatric cancer trajectory (Mooney-Doyle et al., 2021). Currently, there are no evidence-based standards for the initiation, or delivery in providing supportive services and psychosocial care for siblings within the healthcare system (Barrera et al., 2020; Gerhardt et al., 2015). Therefore, the provision of psychosocial support for siblings is often not implemented from a healthcare perspective and siblings report having unmet needs related to social and emotional support, cancer-related information, and involvement in cancer treatment (Long et al., 2018; Gerhardt et al., 2015).

A national survey study from three major pediatric oncology organizations in the United States identified that only 25% of healthcare professionals report that they provide psychosocial services to siblings of children with cancer (Gerhardt et al., 2015). In addition to this, van Warmerdam et al. (2020) outlines that while targeted resources focused on supporting the mental health of siblings are limited during cancer treatment, they are often completely non-existent once treatment is completed. Thus, siblings may not receive any formal psychosocial support after the patient’s treatment is completed despite the literature emphasizing the long-term risk for poor psychosocial outcomes including cancer-related post-traumatic stress, academic challenges, and risky health behaviours (Brosnan et al., 2022).

In the field of pediatric oncology, the importance of developing evidence-based standards of care for siblings of children with cancer including systematic assessments of their psychosocial healthcare needs and appropriate supportive interventions has been highlighted (Gerhardt et al., 2015; Kazak et al., 2015). At this time, there is limited evidence related to effective assessments, resources, and interventions that can be implemented by families and healthcare professionals to provide psychosocial support for siblings comprehensively and consistently (Gerhardt et al., 2015).

A study was conducted by Selove et al. (2011) to examine the proportion of families of recently diagnosed pediatric cancer patients that are offered psychosocial services at Children's Oncology Group institutions, which is a collaboration of over 200 hospitals in North America, Australia, New Zealand, the Netherlands, and Switzerland. The findings indicate that only 9% of the organizations surveyed used evidence-based psychosocial evaluations and less than 11% implemented empirically-based interventions for families impacted by pediatric cancer (Kazak et al., 2015). As a result, further research is required to explore siblings' psychosocial healthcare needs and develop evidence-based assessments and interventions that can inform parents and healthcare professionals and be implemented routinely for all siblings (Gerhardt et al., 2015).

Psychosocial Assessments and Interventions

To implement sustainable, standardized, and comprehensive psychosocial care for siblings of children with cancer, it is important to understand and evaluate which assessments and interventions are most effective in supporting psychosocial health (Brosnan et al., 2022). A first step in providing appropriate support to siblings is to implement a systematic and universal approach to assess and evaluate their psychosocial healthcare needs at multiple intervals after a cancer diagnosis. A second step is to provide appropriate supportive services to siblings based on their age and developmental stage, as well as their level of psychosocial risk and individualized needs (Brosnan et al., 2022).

Psychosocial Assessments and Screening

While the literature describes that many siblings experience distress after their brother or sister's cancer diagnosis, their psychosocial functioning is rarely assessed in clinical pediatric oncology settings (Long et al., 2018). A major barrier to systematic psychosocial screening is the lack of a validated, sibling-specific screening tool. A study by Long et al. (2018) developed and evaluated a sibling-specific psychosocial screening instrument among 29 parents of children with cancer. The sibling-specific Psychosocial Assessment Tool (PAT) is a brief parent-reported screening instrument that identifies psychosocial risk in siblings of children with cancer, whereby risk scores are used to inform the delivery of care by matching supportive services to the siblings' needs. The screening tool was developed to assess siblings' psychosocial risk immediately at diagnosis and several months after diagnosis. Barriers to implementing this screening tool included the absence of siblings from healthcare settings, and parents' limited knowledge of siblings' adjustment during cancer diagnosis and treatment (Long et al., 2018). While the proposed screening tool had several areas for improvement related to format, developmental sensitivity, and content, the study highlights the importance of psychosocial screening. Comprehensive psychosocial assessments may allow healthcare providers to identify siblings with higher psychosocial risk who can be referred for more intensive assessment and care, as well as increase awareness of siblings needs for support (Long et al., 2018).

Psychosocial Support Interventions

Effective, sustainable, and meaningful interventions must be grounded in or formally developed through rigorous research that explores siblings’ needs for psychosocial support and evaluates the effectiveness of proposed interventions (Mooney-Doyle et al., 2021). Much of the published literature describes that sibling support groups and camps are the primary resources offered to siblings of children with cancer for psychosocial support throughout the illness trajectory (Gerhardt et al., 2015; Sidhu et al., 2006). In an integrative review of 29 studies conducted by Hancock (2011), it is noted that camp programs for siblings are developed with a focus on facilitating discussions with peers and healthcare professionals, addressing emotional concerns, providing reassurance and validation, bolstering self-esteem, and improving knowledge about cancer and treatment.

Similarly, a systematic review by Kelada et al. (2020) included 19 studies and summarized the impact of camps for families as a form of psychosocial support. In the review, several positive outcomes of camps for children with cancer and their families including social support, fun and respite, and reconnecting as a family are outlined (Kelada et al., 2020). Many families reported that the social support they received from other families who have been through similar experiences is a major benefit of camps, as these families understood what they were experiencing. As a result, families did not feel that they had to explain or justify their emotions and behaviours. In addition, camp allows families to spend quality time together and reconnect away from the stress and distractions of daily life (Kelada et al., 2020).

A recent study by Gregory et al. (2022) explored the lived experiences of 10 siblings of children with cancer between the ages of 8 and 16 years who attended a peer support camp through individual semi-structured interviews. In the study findings, it was reported that attending camp has a positive influence on siblings' quality of life and social support. Four themes were developed, including: (a) social connection through expressing feelings, building relationships, and mentorship, (b) personal growth, (c) identity, and (d) freedom to have fun and relax (Gregory et al., 2022). Establishing a social connection was the most prevalent theme and all siblings perceived that connecting with others who understood what they were going through and did not judge them for their thoughts and feelings was meaningful and instrumental in developing close and positive relationships (Gregory et al., 2022).

Furthermore, siblings reported personal growth from attending the peer support camp, including learning life lessons, taking on new responsibilities, and developing new coping skills (Gregory et al., 2022). Identity is also an important theme in this study as the literature often describes siblings as feeling isolated and invisible throughout the cancer trajectory. Siblings expressed that the attention they received at camp made them feel special and contributed to an enhanced sense of identity (Gregory et al., 2022). Finally, siblings shared that attending a camp provided the freedom to have fun and relax, as it was a safe environment with a focus on recreational activities (Gregory et al., 2022). Overall, the literature highlights several benefits and positive outcomes of camps as a form of psychosocial support for siblings of children with cancer. However, it is unclear if there are any long-term impacts of attending camp and this form of support is often limited as it is only offered at particular times of the year and for a short period after cancer treatment is completed. Therefore, additional research is needed research to determine the outcomes and effectiveness of this type of intervention (Gregory et al., 2022; Hancock, 2011; Kelada et al., 2020).

Sibling support groups with multiple sessions are another common form of psychosocial support offered to siblings of children with cancer. A systematic review of 20 studies conducted by Mooney-Doyle et al. (2021) explored the core components and effectiveness of these interventions by evaluating outcomes including depression, anxiety, health-related quality of life, post-traumatic stress symptoms, and problem behaviour. The majority of sibling support groups have two components, including: (a) a psychoeducational component that was directed toward increasing siblings' knowledge about cancer and treatment and (b) a psychosocial support component where siblings could interact with peers, openly discuss their concerns and emotions, learn effective coping strategies, and receive support from peers and professionals. These sibling support groups were typically facilitated by trained clinicians such as child life specialists, social workers, and psychologists (Mooney-Doyle et al., 2021). The study findings demonstrate that the sibling support groups did not universally produce a statistically significant change in the outcomes that were tested; however, there was a beneficial impact of being part of a group with others who share the life-changing experience of having a brother or sister with cancer. Many siblings acknowledged the benefit of participating in group sessions and became more comfortable with sharing their emotions and concerns over time (Mooney-Doyle et al., 2021). A consistent barrier to accessing sibling support groups is that they are typically based in clinical settings and less often in community-based settings which may be more accessible to siblings who spend more time in community settings such as their home and school (Mooney-Doyle et al., 2021).

Another psychosocial support intervention that may be effective for siblings of children with cancer is a school visit by a nurse who provides education about pediatric cancer to peers and teachers. A study by Sjoberg et al. (2018) examined the impact of the Ontario Oncology Nurse School Visitation Program (OONSV) on the well-being and school adjustment of siblings. The OONSV program is designed to provide accurate information and correct misconceptions that children may have about pediatric cancer. This intervention is delivered by a Registered Nurse, who provides a 20 to 60-minute age-appropriate presentation for the sibling's class followed by a period where students are allowed to ask questions and have a discussion about pediatric cancer (Sjoberg et al., 2018). The study found an improvement in school attendance among siblings after the nursing visit, but there was no statistically significant improvement in siblings' quality of life. Siblings also described that the nurse visit helped their peers better understand the complex situation that they were experiencing and avoided them having to answer uncomfortable questions about cancer. Ultimately, this increase in knowledge and awareness resulted in siblings feeling that there was more acceptance, kindness, and support from their peers at school (Sjoberg et al., 2018).

A randomized controlled trial of 30 siblings between the ages of 6 and 17 years conducted by Prchal et al. (2012) evaluated the effectiveness of a two-session 50-minute psychological intervention for siblings of newly diagnosed children with cancer at two hospitals in Switzerland. The intervention was provided within the first two months after diagnosis and included medical information, promotion of coping skills, and psychoeducation for parents. In comparison, siblings in the control group received standard psychosocial care which consisted of meetings with a psycho-oncologist, who was primarily responsible for the patient and the parents but would meet with siblings if necessary. The researchers found that the intervention group exhibited better psychological well-being, had better medical knowledge, and reported receiving social support from more people (Prchal et al., 2012).

Finally, a randomized controlled trial by Barrera et al. (2020) recruited 122 families to evaluate whether providing psychosocial risk information to their primary treatment team would result in decreased depression and anxiety symptoms among children diagnosed with cancer, caregivers and family members, and siblings. In the study, siblings completed the Pediatric Index of Emotional Distress (PI-ED), a self-reported measures of depression and anxiety, at 1 and 6 months after cancer diagnosis. For families allocated to the intervention group, a summary of their psychosocial risk results were shared with the treatment team. In comparison, psychosocial risk results were not shared with the treatment team for families in the control group (Barrera et al., 2020). While the study findings were inconclusive due to the low statistical power, the study highlights that there was a significant decline in anxiety scores among all siblings over time. This supports previous reports that the psychosocial risk and impact of pediatric cancer on siblings is the strongest near diagnosis (Barrera et al., 2020).

Siblings' Perceived Needs for Support

While the literature on siblings' experiences and perceived needs for psychosocial support remains limited, there has been an increase in research in this area in recent years. A scoping review of 57 studies by Wawryznski et al. (2021) examined the experiences and perceived needs of siblings and describes that a common theme reported by siblings is a change in social support during cancer diagnosis and treatment. Many siblings report receiving less instrumental support (e.g., reduced support in getting to activities and doing schoolwork), as well as being expected to provide more instrumental support for the family (e.g., increased responsibilities such as caring for other siblings or chores). Siblings also experience a decreased amount of emotional support from family which results in emotional strain related to fear, uncertainty, jealousy, and worry about their brother or sister and parents. This is often compounded by receiving limited informational support about their brother or sister's diagnosis and treatment (Wawryznski et al., 2021).

Siblings consistently reported a need for instrumental support including distractions from the cancer experience, fostering a sense of normalcy, and support in maintaining their activities, schoolwork, and friendships (Wawryznski et al., 2021). Siblings also highlighted a need for increased emotional support which includes having someone to talk to whether that be family, friends, healthcare providers, or a professional counselor. Many siblings share feelings of worry and isolation when they did not understand what was happening with their brother or sister and a need for more informational support through open and honest communication with their parents about cancer and involvement in treatment (Wawryznski et al., 2021). Many studies have shown that an increase in knowledge about cancer including its causes and treatment can decrease anxiety and promote positive coping among siblings (Long et al., 2018). Furthermore, siblings value companionship support through physical affection and spending time with their parents and siblings. Finally, siblings conveyed the need for appraisal support and validation through acknowledgement of their achievements and contributions during the cancer trajectory (Wawryznski et al., 2021).

Parental Perspectives on Psychosocial Support

The parental perspective on siblings' psychosocial functioning and needs for support is essential as parents are typically the primary providers of support for siblings throughout the cancer experience and beyond. The literature highlights that siblings and parents often describe siblings' psychosocial functioning and needs differently, which may reflect parental unawareness of siblings' adjustment to cancer and increase the risk for negative sibling outcomes (Pariseau et al., 2020). Siblings may be resistant to seeking psychosocial support from parents throughout the cancer trajectory because they perceive parents as emotionally unavailable or they want to protect their parents from the additional burden. A qualitative study by Pariseau et al. (2020)

recruited 13 families to examine parental awareness of sibling adjustment and needs for psychosocial support. In the study, parents and siblings between the ages of 8 and 17 years completed in-depth individual interviews regarding siblings' psychosocial adjustment to cancer. Siblings and parents reported that parents were often unaware of the presence, severity, or content of siblings' cancer-related feelings. This may lead to parents feeling that siblings do not require psychosocial support from a formal or informal perspective which ultimately may result in them receiving a lack of support throughout the cancer trajectory (Pariseau et al., 2020).

Parental awareness of siblings' psychosocial needs is influenced by several factors including: (a) siblings' communication of cancer-related emotions to parents, (b) parents' observation of siblings' behaviour and affect, and (c) parents' interpretation of siblings' psychosocial functioning (Pariseau et al., 2020). First, siblings and parents report that it is often challenging for siblings to clearly and directly communicate their cancer-related emotions and concerns with parents. Many parents focus on remaining positive and limit their expression of negative emotions when they are around their children which may hinder siblings' emotional expression (Pariseau et al., 2020). Parents also indicate that conversations about siblings' emotions often require parent-initiation because siblings rarely seek out parents to discuss cancer-related emotions. This highlights the importance of parents consistently initiating conversations about cancer and encouraging open and honest communication from the time of diagnosis onwards (Pariseau et al., 2020).

Moreover, parents report that they spent less time with siblings during the cancer experience which results in fewer opportunities to observe siblings' behaviour and affect, identify challenges in their psychosocial functioning, and provide or seek out appropriate support for siblings (Pariseau et al., 2020). Finally, parents' interpretation of siblings' psychosocial functioning is often based on their own cancer-related emotions. Many parents report that with the emotional and practical demands associated with cancer, they felt unable to handle any additional stressors which result in higher expectations for siblings, less tolerance of siblings' negative emotions, and difficulty recognizing siblings' cancer-related adjustment issues (Pariseau et al., 2020). Finally, a scoping review of 57 studies by Wawryznski et al. (2021) outlines that a majority of parents reported little to no formalized support for siblings throughout cancer diagnosis and treatment. Parents also reported receiving less informational and psychological support than they needed which ultimately makes it difficult for them to access support for siblings or even address difficult subjects with siblings such as prognosis (Wawryznski et al. (2021).

Healthcare Providers' Perspectives on Psychosocial Support

Healthcare providers are well-positioned to provide psychosocial support for siblings of children with cancer by assessing their psychosocial needs, implementing supportive interventions, assisting with family communication, and advocating for additional resources (Gerhardt et al., 2015). While healthcare providers acknowledge the importance of supporting siblings throughout the cancer trajectory, several barriers existed in providing supportive care for siblings. A systematic review by Gerhardt et al. (2015) included 125 studies and examined current psychosocial standards of care for siblings of children with cancer. The results of the review outline that healthcare providers experience several challenges in providing psychosocial support to siblings due to limitations in: (a) availability of trained psychosocial staff and community resources, (b) knowledge of issues experienced by siblings, (c) access to standardized screening tools to assess sibling distress and psychosocial needs, (d) interactions and communication with siblings, and (e) interventions to inform evidence-based care (Gerhardt et al., 2015).

Similarly, Brosnan et al. (2022) conducted a study in which 27 healthcare providers were interviewed to evaluate the barriers that they experience in supporting siblings of children with cancer. Identified barriers included those arising from the (a) healthcare system, (b) oncology centre, and (c) family-level. Barriers within the broader healthcare system include a lack of integration between medical care and mental health services which often leads to siblings being overlooked and not receiving the support that they need. At the level of the oncology centres, barriers include a lack of funding for sibling programs, inadequate physical space to deliver supportive services, and limited number and availability of trained staff. The providers also outlined family-level barriers to providing siblings with support including limited attention focused to siblings, as well as limited awareness of and difficulty with identifying siblings' psychosocial needs (Brosnan et al., 2022).

Synthesis of the Literature

Overall, there has been an increase in published literature over the past decade about siblings' experience of pediatric cancer and the consequences it may have on their own emotional, behavioural, and psychosocial functioning (Long et al., 2018). The literature also begins to examine siblings' needs for psychosocial support and assessments and interventions that may be implemented to support siblings (Mooney-Doyle et al., 2021). This growing body of literature identifies the unique stressors and challenges that siblings of children with cancer experience throughout the illness trajectory and beyond, as well as the need for standardized and comprehensive psychosocial screening and supportive care for siblings. Despite improvements in the literature in recent years, there continues to be significant gaps and further research is needed to improve psychosocial care for siblings of children with cancer in the future (Long et al., 2018; Weiner & Woodley, 2018).

The reviewed literature has several methodological limitations that may impact the external validity and generalizability of findings. For instance, many of the studies include small and non-diverse samples of participants with limited heterogeneity in important characteristics such as sibling age, gender, developmental level, ethnicity, and socioeconomic status. In addition, there are limited prospective, longitudinal study designs which have resulted in a poor understanding of the long-term outcomes for siblings of children with cancer (Long et al., 2018; Weiner & Woodley, 2018). Furthermore, the literature indicates that there is a lack of standardized approaches to care to support siblings' psychosocial healthcare needs. Importantly, studies related to psychosocial support for siblings reflect the perspectives of parents and healthcare professionals and not siblings themselves. Future interventions aimed to optimize sibling psychosocial support must be informed by sibling perspectives and experiences with current initiatives. Therefore, further research is needed that evaluates the impact and experiences of siblings' receiving psychosocial support from a social and professional perspective, throughout the illness trajectory. The knowledge and insights developed from this research may inform parents and healthcare professionals of siblings' psychosocial healthcare needs and experiences. In addition, this research may guide the development of assessments and interventions that aim to reduce distress and promote positive psychosocial adjustment for siblings of children with cancer (Long et al., 2018).

CHAPTER 3: RESEARCH METHODS

Chapter Overview

Siblings' experiences with receiving psychosocial support were explored using interpretive description qualitative methodology. This chapter will begin with a description of the research question that was posed for this study. Next, an outline of interpretive description methodology and the rationale for its selection for the study design will be provided. This will be followed by an explanation of sampling, participant characteristics, and recruitment strategies used in this study. Data collection methods and approaches for data management and analysis will be discussed. Finally, this chapter will present and describe the criteria used to promote trustworthiness and rigour, as well as ethical considerations for the study.

Research Question

The purpose of this qualitative interpretive description study is to develop a deeper understanding of the different ways in which siblings of children diagnosed with pediatric cancer describe their experiences with receiving psychosocial support. Therefore, the following research question was posed and guided this study:

Among siblings of children diagnosed with pediatric cancer, what are the ways in which their psychosocial needs are addressed by social and professional supports?

Study Design

Interpretive description was used to explore the psychosocial support experiences of siblings when their brother or sister was undergoing pediatric cancer therapy. As a methodology, interpretive description was developed in response to a need for a qualitative approach that could address complex healthcare challenges that are relevant to nursing and other applied health disciplines, and that are not adequately answered by traditional qualitative methodologies developed in the humanities and social sciences that result in theoretical, rather than applied, findings (Thorne et al., 1997). The purpose of interpretive description is to generate knowledge about the range and varied patterns of health and illness experiences and to provide clinically relevant applications that can directly inform nursing practice (Thorne, 2013). Interpretive description was selected to address the research question because it allowed for the description and interpretation of siblings' shared experiences of the phenomenon. The study also aimed to generate findings that can be applied by nurses and other healthcare professionals in clinical practice; this aligns with interpretive description methodology (Thorne, 2013).

Several key attributes of interpretive description support it as the most appropriate qualitative approach to address the research question. These characteristics include: (a) flexibility in the research design, (b) use of the researcher's clinical expertise to guide the design of the study, (c) co-construction of findings by the researcher and participants, and (d) development of knowledge that can be applied by nurses in clinical practice (Hunt, 2009; Teodoro et al., 2018; Thorne, 2013). Interpretive description does not imply any fixed design elements, which permits researchers to use a combination of methods from other qualitative approaches that are most suitable for each specific study (Thorne, 2013). The flexibility of the research design in interpretive description was essential in this study as it allowed for the application of different research techniques that were deemed appropriate for the study design (Thorne, 2013).

Furthermore, interpretive description methodology acknowledges the researcher's theoretical and practical knowledge of the phenomenon to be a platform on which to orient the study, establish anticipated boundaries, and identify assumptions, biases and preconceptions that guide the study design decisions (Thorne et al., 1997). Thus, the existing knowledge about the phenomenon from formal research and clinical interpretation was used to scaffold this study (Thorne, 2014). In particular, clinical expertise is identified as an essential foundational forestructure for orienting the research, especially when the phenomenon of interest has not been evaluated comprehensively (Hunt, 2009). My clinical knowledge and expertise as a pediatric oncology nurse was essential in guiding the design elements and applications of the study.

The philosophical assumptions of interpretive description are based on the perspective that objective knowledge is not attainable through empirical analysis (Hunt, 2009). Instead, understandings of reality are subjective and created as the researcher and participants interact to influence one another (Hunt, 2009). As a pediatric oncology nurse with vast experience in providing care for children with cancer and their siblings, I have valuable insight into siblings' experiences and the provision of psychosocial support from nurses and other healthcare professionals. Thus, I was able to collaborate with participants to co-construct a comprehensive understanding of their experiences (Hunt, 2009).

Moreover, the goal of interpretive description research is to generate knowledge that will improve nurses' understanding of complex healthcare challenges and provide recommendations about how the findings can be applied in clinical practice (Thorne, 2013). The findings of this study are intended to provide nurses with a better understanding of siblings' psychosocial healthcare needs and inform the development of comprehensive assessments and interventions to establish evidence-based standards and promote family-centred care. Finally, the study was completed over a 12-month period, which aligned with other interpretive description studies and provided an appropriate amount of time to conduct each aspect of the study comprehensively.

Sampling

The sample of participants in the study consisted of siblings of children previously diagnosed with and treated for pediatric cancer in Canada. Siblings that met the following inclusion criteria were eligible for enrollment in the study: (a) able to speak English, (b) able to provide in-depth descriptions of their experiences with receiving psychosocial support, (c) at least 16 years of age at the time of the study, and (d) were between the ages of 4 and 18 years during their sibling's cancer diagnosis and treatment. In addition, patients must have been diagnosed with pediatric cancer between the ages of 0 and 18 years and the diagnosis of cancer must have occurred within the past 10 years for their siblings to be eligible for the study.

Interpretive description does not require a single approach for sampling, allowing researchers to utilize techniques that best align with the nature of the clinical phenomenon (Thorne, 2013). Thorne (2014) suggests that a combination of purposive and theoretical sampling makes a useful contribution to the design of interpretive description for nursing knowledge development. Purposive sampling relies on the judgment of the researcher to identify participants that will be able to provide rich comprehensive descriptions of the phenomenon of interest based on their knowledge and experiences (Patton, 1990). Theoretical sampling focuses on sampling for maximal variation in which specific participants are recruited to further explore patterns and themes that have emerged from the initial phases of data collection and analysis (Thorne, 2014).

In this study, criterion sampling initially facilitated the selection of participants based on the requirements that were outlined in the inclusion criteria. Principles of maximum variation sampling were also applied to select participants based on variations in personal, demographic, and cancer-related factors including age, location of residence, ethnicity, type of cancer, and length of treatment. This ultimately allowed me to gather data from participants that had a comprehensive range of experiences and perspectives. Once data were collected and analyzed from each participant, theoretical sampling was utilized to identify additional participants that would be able to provide in-depth insight into experiences and perspectives that emerged and required further exploration (Hunt, 2009).

Emergent analysis of interview data from initial participants suggested that siblings often felt isolated and distanced from the cancer experience and received minimal psychosocial support in healthcare settings. The participants also reported that psychosocial support was mainly provided by family, friends, camps, and community-based pediatric cancer support organizations. Thus, during ongoing recruitment, siblings that received support from camps and pediatric cancer support organizations were sought to further explore their experiences with receiving these types of psychosocial support. Furthermore, it was identified that majority of the initial participants identified their ethnicity as White and as a result, there was a focus on recruiting additional participants of other ethnicities. This method of sampling occurred continuously throughout the study to fill knowledge gaps, clarify uncertainties and test interpretations (Thorne, 2013).

Sample sizes in interpretive description should align with the nature of the clinical phenomenon and the purpose of the study (Teodoro et al., 2018). In this study, the sample included a total of 10 participants which is consistent with the sample sizes in previous qualitative studies that explored the experiences of siblings of children with cancer. This sample size was small enough to facilitate intensive contact between me and the participants, which resulted in an in-depth and comprehensive exploration of siblings’ experiences with receiving psychosocial support (Teodoro et al., 2018). At the same time, the sample size was large enough to identify key variations among siblings' experiences and ensure that confident claims could be made about commonalities and differences across all of the variables within the phenomenon (Thorne et al., 1997).

Participant Recruitment

Participants were recruited to the study through the following three sources: (a) pediatric oncology and family support organizations (e.g., Pediatric Oncology Group of Ontario and Ontario Parents Advocating for Children with Cancer), (b) advertisements on social media (e.g., Twitter, Instagram and Facebook), and (c) word-of-mouth. Initially, recruitment was focused on approaching several pediatric oncology and family support organizations across Canada. I reached out to key contacts at each of the organizations through email to outline the background and purpose of the study and to request that the recruitment poster is shared on their respective websites and social media. I also inquired about any sibling-focused meetings or groups where details of the study could be shared.

Three major pediatric oncology and family support organizations agreed to support recruitment for this study including Ontario Parents Advocating for Children with Cancer (OPACC), Pediatric Oncology Group of Ontario (POGO), and the Canadian Retinoblastoma Society. These organizations supported recruitment throughout the study by sharing the recruitment poster on their website, social media, and biweekly newsletters. These organizations also emailed the study details and recruitment posters to all of their active members. The majority of the participants included in this study were enrolled through this method of recruitment.

Another main source of recruiting participants was advertisements using several different social media channels. Individualized accounts dedicated to the research study were created on major social media platforms including Facebook, Instagram, and Twitter. Posters and images were developed and shared frequently on these accounts to outline details of the study, as well as the researcher's contact information (see Appendix C). Members of the research committee and the School of Nursing at McMaster University also shared the recruitment poster for the study on their respective social media accounts.

Additionally, snowball sampling was also used, where participants enrolled in the study and their families facilitated further recruitment of participants. All participants in the study were asked if they were aware of any other siblings that would potentially be interested in participating in the study. At the end of the interviews, I shared the recruitment poster with participants through email and requested for it to be shared with other siblings of children with cancer that would be eligible and interested in participating in the study. All eligible participants that were interested in the study were contacted by telephone to provide further information about the study, answer any questions, and obtain informed consent (see Appendix D).

Data Collection

Data collection using interpretive description can draw on multiple and diverse approaches (Teodoro et al., 2018). This allows the researcher to select the most appropriate data collection strategies to achieve a comprehensive understanding of the phenomenon without relying on the inherent limits of any single approach (Thorne, 2014). Semi-structured interviews were the primary source of data in the study which allowed me to gain an in-depth understanding of siblings' experiences with receiving psychosocial support throughout the pediatric cancer trajectory. This source of data collection was further supported with a questionnaire to obtain relevant demographic and cancer-related data from participants.

Interviews are a primary data source in interpretive description as participants with lived experiences are often the best source to provide expert knowledge and insight into a phenomenon (Hunt, 2009). In this study, one individual, semi-structured interview was conducted with each participant. The length of the interviews ranged between one to two hours. The interviews occurred at times that were mutually agreeable to me and the participants and were conducted through video calls on a secure virtual platform (Zoom). The interviews were conducted between December 2021 and May 2022. The interviews were exploratory, guided by a semi-structured interview guide and the insights, concepts, and themes that emerged throughout the discussions (Teodoro et al., 2018). I conducted all interviews with the participants to ensure consistency in the delivery of the interviews. Field notes were recorded during and after each interview to document key observations and provide additional context to the data. Each interview was audio-recorded and subsequently transcribed by me for data analysis.

Before the interview, a short questionnaire was shared through email and completed by the participants. The questionnaire collected socio-demographic and cancer-related data including age, ethnicity, educational attainment, location of residence, type of cancer, length of cancer treatment, ages of the patient and participant at diagnosis, and time since completion of treatment (see Appendix E). I reviewed each participant's completed questionnaire prior to the interviews. The interviews were semi-structured using an interview guide with open-ended questions that were informed by the literature review and my clinical experience as a pediatric oncology nurse. The initial question was a grand tour question: "Can you tell me what it was like for you to have a sibling go through cancer treatment?" The subsequent questions in the interview were guided by the participant's initial answer and were related to the following topics: (a) emotional impact, (b) family functioning, (c) social relationships, (d) school performance, (e) hospital experience, and (f) psychosocial support (see Appendix F). Overall, these questions facilitated the exploration of siblings' experiences during the cancer trajectory, how it impacted different aspects of their lives, and the psychosocial support received from a social and professional perspective.

The interview guide was piloted initially with one nursing colleague from The Hospital for Sick Children to evaluate the relevance and phrasing of the questions, which was then revised appropriately based on her feedback. At the end of each interview, I summarized the interview and participants had the opportunity to confirm, clarify, and provide feedback on the data as a method of member checking. A hallmark of interpretive description is the concurrent collection and analysis of data (Thorne, 2016). In the study, the process of data collection and analysis occurred iteratively which facilitated the exploration of themes and perspectives that emerged as the interviews progressed. As a result, all interviews were transcribed and initial analysis was conducted before completing the next interview with a new participant.

Additional participants were recruited and interviews were completed until it was determined that I had an in-depth understanding of siblings' experiences with psychosocial support and no new significant themes emerged from the interviews. Finally, I engaged in reflexive journaling on an ongoing basis throughout data collection and analysis. This allowed me to become aware of personal values, beliefs, and assumptions that may have impacted the study. It also helped capture my clinical insights and interpretations throughout the process (Thorne, 2016).

Data Analysis

Data analysis in interpretive description is an inductive analytic process in which data collection takes place concurrently and iteratively with data analysis (Thorne, 2013). Data analysis in interpretive description encourages the researcher to begin with what is known about the phenomenon and remain open to new ways of understanding to expand disciplinary knowledge (Thorne et al., 2004). Reflexive thematic analysis was used for data analysis in this study as it is a rigorous yet flexible approach for identifying, organizing, describing, and reporting themes identified within a data set and is an appropriate method for data analysis in interpretive description (Braun & Clarke, 2006; Campbell et al., 2021). A practical and effective procedure for conducting reflexive thematic analysis was employed including: (a) data familiarization, (b) generating initial codes, (c) searching for themes, (d) reviewing and revising themes, (e) defining and naming themes, and (f) producing the report (Nowell et al., 2017).

Initial data analysis began immediately after each interview to ensure that new insights and themes identified during early interviews could be further explored and developed during ongoing data collection (Teodoro et al., 2019). All audio-recorded interviews were transcribed approximately one week after the interview. This allowed me to listen back to the interview and identify participant experiences and perspectives that required further exploration in future interviews. The field notes that were written to capture observations during interviews were also used to contextualize data during analysis. I became immersed in the data by reading the transcribed interviews in detail multiple times to understand the depth and breadth of the content (Nowell et al., 2017). During this data familiarization phase, colour-coded “sticky notes” and highlighters were used to emphasize important experiences and perspectives throughout the interview transcripts. Relevant quotes from participants and initial connections and patterns were documented in a separate file alongside transcription (Thorne, 2014).

The second phase of data analysis began once I was familiar with the data and involved the initial production of codes (Nowell et al., 2017). This phase began throughout data collection and continued once data collection was completed. Coding is a process in which researchers work systematically through the data to identify important sections of text and organize them into meaningful groups of data that represent the phenomenon of interest (Nowell et al., 2017). The data in the transcripts were sorted and organized into various groups or codes. Following the initial code generation phase, all of the relevant coded data was sorted and collated into overarching themes. Themes are abstract entities that bring meaning and identity to a recurrent experience, capture the nature of an experience, and are generally broader than codes (DeStantis & Ugarriza, 2000). The themes may be generated inductively from the raw data or deductively from previous research related to the phenomenon (Nowell et al., 2017). During this phase, I also developed visual representations including diagrams to demonstrate relationships and interactions between the initial themes that emerged, as well as identifying themes that may not fit (Braun & Clarke, 2006; Campbell et al., 2021).

The next step in the thematic analysis process included refinement of the set of themes that were initially developed. Each theme was reviewed to determine whether they form a coherent pattern and accurately reflect the meanings of participants' experiences that were evident in the data set (Nowell et al., 2017). During this stage, various changes were made to the themes to ensure that they were useful and accurate representations of the data. For example, I identified relevant experiences in the data that may have not been adequately represented by an existing theme and there may have been specific themes that did not have enough data to support them (Nowell et al., 2017). Furthermore, the fifth phase in the analysis process allowed me to define themes by providing a detailed description and analysis of each theme. The thematic analysis process was conducted by me and supported by my research supervisor to enhance credibility and determine congruence between the themes that were identified (Nowell et al., 2017).

The final step in the thematic analysis process began once the themes were fully established and I was prepared to produce the report of the findings. The final report communicates the logical processes by which the findings were developed and includes direct quotes from participants to enhance understanding of the themes and interpretations that are presented (Nowell et al., 2017). The findings of a study using interpretive description should include a conceptual description that outlines thematic patterns and commonalities that characterize the phenomenon, along with individual variations within them (Thorne et al., 2004). The study findings also include applications that can be used directly by nurses and other healthcare professionals in clinical practice including recommendations for potential assessments and interventions that promote family-centred care and psychosocial support for siblings (Thorne et al., 2004).

Trustworthiness and Rigour

Thorne (2014) proposes the following criteria to promote the credibility and rigor of an interpretive description study: (a) epistemological integrity, (b) representative credibility, (c) analytic logic, (d) interpretive authority, (e) moral defensibility, (f) pragmatic obligation, (g) contextual awareness, and (h) probable truth. In this study, several strategies were implemented into the research design to ensure epistemological integrity, representative credibility, interpretive authority and moral defensibility. Epistemological integrity refers to the congruence between the epistemological positioning, research question, study design, and findings (Thorne, 2014). This study demonstrates epistemological integrity as the research question and study design align with interpretive description and adhere to the principles of the approach.

Furthermore, representative credibility ensures that the theoretical claims made by the researcher are consistent with the methodological and sampling decisions in the study (Thorne, 2014). In this study, the sample consisted of 10 participants and the participants were sampled using techniques including purposive and theoretical sampling, which are consistent with the research design of interpretive description.

Moreover, interpretive authority confirms that the findings of the study truly represent the phenomenon of interest and are not adversely influenced by the researcher's own biases and preconceptions (Thorne, 2014). Interpretive authority was confirmed in the study using several strategies including ongoing reflexive analysis, recording of field notes, and member checking. First, I engaged in reflexive analysis during the development of the study protocol and continued this process throughout the study to identify pre-existing assumptions and biases that may influence the study findings. In addition, field notes were recorded during interviews with participants to capture observations and provide context to the collected data. Member checking was utilized by sharing and confirming the study findings with two participants to confirm the credibility and accuracy of their experiences (Birt et al., 2016). Finally, moral defensibility ensures that the knowledge developed about the phenomenon under study is necessary and will be applicable in clinical practice to address complex health and illness challenges (Thorne, 2014). Currently, there is an identified need for research that explores siblings' experiences with receiving psychosocial support and the development of evidence-based standards for providing siblings with psychosocial support throughout the cancer trajectory. Thus, the findings of this study aim to inform nurses and other healthcare professionals of siblings' experiences and needs to ultimately improve psychosocial support and promote positive health outcomes.

Ethical Considerations

The study was approved by the Hamilton Integrated Research Ethics Board (HiREB) on November 9, 2021 under project number 14122 (see Appendix G). This approval ensured that the study meets the appropriate ethical requirements and protects the welfare of study participants. During recruitment for this study, informed consent was obtained electronically from participants. The consent form consisted of the following components: (a) description of the study, (b) potential risks and benefits, (c) confidentiality, (d) dissemination of findings, and (e) contact information of the researcher (see Appendix H). Participants were emailed a copy of the consent form and asked to review the form and provide an electronic signature to be enrolled in the study. Informed verbal consent was also obtained at the beginning of each interview throughout the study to ensure that participation was voluntary and participants were aware that they may withdraw from the study at any point. Furthermore, I ensured that confidentiality was maintained for participants throughout the study. All data collected from participants is stored in locked files on my password-protected computer. The data will be securely stored for five years after the completion of the study with content from participants.

Moreover, there are ethical considerations that must be addressed when conducting research related to sensitive topics with adolescents and young adults. First, there is potential for misrepresentation of the findings in the study due to perceived power differences between adolescents and adults (Bell, 2008). For example, participants may not feel comfortable sharing their thoughts, feelings, and experiences during cancer treatment with an adult researcher and may modify their responses based on what they think would be the most appropriate or correct answer. In this study, I made all efforts to mitigate this potential challenge throughout the recruitment and data collection processes by developing rapport and trust with participants, creating a safe and open environment, and validating participants' thoughts and feelings.

Furthermore, there is an increasing awareness of the impact of conducting qualitative research on sensitive topics for both study participants and researchers (Orr et al., 2021). Due to the epistemological nature of interpretive description studies, findings were co-created by the researcher and study participants. Thus, there was potential for raising emotions and distress for both study participants and myself which was carefully considered and appropriately addressed throughout the study. A distress protocol was developed and utilized as a guide during interviews in case a participant exhibited acute distress or safety concerns. First, if a participant's distress reflected an emotional response reflective of what would be expected in an interview about a sensitive topic, I offered support and validated the participant's thoughts and feelings and provided the option to either stop the interview, regroup, or continue (Drauker et al., 2009). On the other hand, if a participant displayed a high level of emotional distress or a safety concern beyond what would be expected in an interview about a sensitive topic, the following actions would have been taken: (a) stop the interview, (b) offer support, validation, and allow the participant to regroup, (c) ask the participant if they have experienced these emotions before and what resources and/or coping strategies were used to manage the distress, and (d) provide additional relevant resources and supports available in the community to provide support (e.g., sibling peer support groups).

In the study, many of the participants became emotional and tearful at certain points of the interview as they reflected on difficult experiences throughout the pediatric cancer trajectory. In all of these instances, I paused the interview and provided appropriate emotional support and reassurance to the participants. When I gave participants the option to stop, reschedule or continue the interview, all participants decided to continue with the interview. None of the participants in the study displayed a high level of emotional distress or safety concerns beyond what would be expected in an interview about a sensitive topic. Thus, additional actions and support were not needed.

As a graduate student and researcher, I also developed a debriefing plan and strategies for myself, in collaboration with my committee, to mitigate and address potential emotional distress that could have arisen during interviews (Orr et al., 2021). First, after each interview, I engaged in reflexive journaling which allowed me to reflect on my reactions, insights, thoughts, and feelings. I also ensured that all interviews were scheduled at least one to two weeks apart to allow for appropriate breaks between interviews, as well as the opportunity to debrief and reflect with the research committee if needed. Finally, there was a plan to schedule a meeting with one of the three members of the research team when appropriate to debrief any potential issues or emotions that arose during interviews. Overall, these strategies to manage potential distress among participants and I were effective throughout the study.

CHAPTER 4: FINDINGS

Chapter Overview

The study provided insights into the experiences and perceptions of siblings of children with cancer with respect to the different ways in which they received psychosocial support from social and professional sources. The study also detailed their perceived needs for psychosocial support throughout the pediatric cancer trajectory, as well as how this support can potentially be improved in the future. This chapter begins with an overview of the participants' demographic characteristics and details about their siblings' cancer diagnoses and treatments. Following that, the participants' emotions and experiences throughout the pediatric cancer trajectory will be discussed. The types of psychosocial support that they received from social and professional sources, as well as their perceived needs for support will be highlighted. Finally, this chapter will conclude with a summary of the findings.

Participant Characteristics

The study included ten female siblings of individuals that were diagnosed with and treated for pediatric cancer. At the time of the interviews, the average age of the participants was 19.4 years with a range of 16 to 23 years. All of the participants in the study resided in Ontario with a majority living in the Greater Toronto Area throughout their brother or sister's cancer treatment. One participant lived in Ontario for the first few months of her sister's cancer treatment but moved to British Columbia for post-secondary education while her family remained in Ontario. The majority of the participants identified their ethnicity as White (n=7); however, two participants were South Asian and one participant was Middle Eastern.

Regarding the type of cancer diagnosis, three of the children with cancer were diagnosed with leukemia, three were diagnosed with lymphoma, three were diagnosed with solid tumours and one was diagnosed with a brain tumour. These children received several different treatments including chemotherapy, radiation, surgery, and stem cell transplants. Nine study participants reported that their brother or sister successfully completed cancer treatment and is currently alive, while one of the participants in the study was bereaved. The length of their siblings' cancer treatments ranged from 4 months to 3.5 years, which was primarily based on the type of cancer. The average age of the children with cancer at diagnosis was 12 years with a range of 2 to 17 years. Similarly, the average age of the siblings participating in the study at diagnosis was 12.6 years with a range of 4 to 18 years. Finally, at the time of the interviews, the average time since completion of cancer treatment was 6 years, with a range of 1 to 10 years (see Appendix I).

The Cancer Experience

All siblings participating in the study reflected on their brother or sister's diagnosis and treatment of pediatric cancer as a life-changing and overwhelming experience that has impacted them and their families significantly in all aspects of their lives. While some of the participants' siblings completed cancer treatment several years ago, this experience continues to affect them and their families in many different ways. The study participants shared a multitude of negative emotions and challenges that they experienced throughout the cancer trajectory; however, they also discussed some of the positive moments and outcomes of pediatric cancer. The following section will further explore both the difficult and positive emotions and experiences that were described by the siblings participating in the study.

Difficult Emotions and Experiences

The siblings participating in the study described several difficult emotions, thoughts, and experiences throughout the pediatric cancer trajectory, including: (a) seeing their brother or sister unwell, (b) isolation from the cancer experience, (c) disruption to normal life, (d) limited understanding of their brother or sister’s diagnosis and treatment, (e) changes in relationships with their family, (f) loss of control, (g) jealousy and guilt, (h) fear and uncertainty, and (i) hiding their thoughts and feelings. The difficult aspects of the pediatric cancer experience from the perspective of the study participants will be further explored in the following sections.

Seeing Their Sibling Unwell

All of the siblings participating in the study described that seeing their brother or sister unwell throughout cancer treatment caused them significant emotional distress and was the most difficult aspect of the entire cancer experience. Many of the participants became emotional and tearful as they remembered and reflected on the pain and suffering that their siblings endured from their cancer symptoms and the side effects from aggressive treatments. In particular, their siblings’ changing appearances and behaviours were challenging for participants to witness and deal with throughout the cancer trajectory. They described at length how difficult it was to see their brothers or sisters connected to complex medical equipment, lose their hair abruptly, become pale and lethargic, experience changes in their mobility, and constantly have significant nausea, vomiting, and pain. One participant shared: “…for me seeing [my brother] not well all the time was really hard and even when he was home from the hospital, he wasn’t willing to play or do the things I wanted to do with him.” Another participant expressed the following sentiment about the significant changes in her teenage sister’s appearance during cancer treatment:

> The hair loss was the hardest thing for me but I didn’t want to make it a big thing because I know that was a really hard thing for her to go through like her hair was the worst thing that happened. I think she was self-conscious without her hair so I didn’t want to point it out or anything but it was hard for me to see her like that.

Furthermore, many of the participants in the study described that it was like their ill siblings became strangers to them and changed completely throughout cancer treatment due to all of the physical, mental, emotional, and behavioural changes that they experienced. A participant shared that:

> …a part of me was reminding myself that this is still my brother but there were times where he was just lying there, lethargic, and basically the same colour as the sheets. He didn't look super alive and he definitely didn't look like my brother.

The participants reflected on how challenging it was to witness their siblings' entire lives change abruptly once they were diagnosed with cancer. The majority of these children went from being healthy and leading "normal" lives to suddenly having a life-threatening illness, spending most of their time in the hospital, and putting their lives on hold. One participant shared the following about her teenage sister that just begun college in hopes to become a nurse but had to drop out shortly after being diagnosed with pediatric cancer:

> Before she got cancer, she was going to college for her nursing degree and she was really excited and then she got diagnosed so she had to stop. I'll never say this to her but I felt really bad when I'd see her in bed and she couldn't walk because I know nurses have to be really active. It was very hard for that to happen and I felt really bad for her when I saw she was bedridden and losing her dream.

All in all, the study participants reflected on several experiences throughout the interviews that highlighted the significant and long-lasting emotional impact of witnessing their siblings become ill and unwell throughout the cancer trajectory.

Isolation from the Cancer Experience

Isolation from the cancer experience was described at length by nine of the participants during the interviews. Many of them described feeling lonely, left out, and distant from their sibling's cancer treatment. One participant shared: "I think people tend to overlook us a bit because we are the ones that are always fine, and I think that us being always fine is their justification to ignore us." The participants reported multiple factors that contributed to their feelings of isolation throughout the cancer trajectory, including: (a) not being physically present in the hospital, (b) receiving minimal information about their sibling's cancer diagnosis and treatment, and (c) being expected to continue with their daily lives as normal. First, several of the participants shared that they were not physically present with their family for most of their sibling's cancer treatment. In most situations, the participants and their families lived in suburban areas with distances ranging from one to three hours away from their sibling's treatment hospital, most usually located in a large urban centre. As a result, their sibling and parents spent a significant amount of time away from home as they were in the hospital for treatments, symptom management, and follow-up. Some of these families even had to completely move away from their homes to be closer to the hospital for the duration of the cancer treatment.

At the same time, all participants reported that they continued to live at home or with extended family members throughout cancer treatment so they could continue with school and their daily activities and routines. They also shared that there were strict visitor restrictions in the hospital that limited their ability to spend time with their sibling and parents throughout cancer treatment. Ultimately, the participants' physical distance and separation from the hospital resulted in them spending minimal time with their siblings and parents and significantly contributed to their feelings of isolation throughout the cancer experience. One participant emphasized her distance from her sister's cancer treatment when she shared that she "...never went to even one of [her sister's] radiation treatments and never saw any of her chemotherapy treatments in-person." Another participant shared that it felt like she "...was on the periphery of the entire cancer experience and there was no way of getting in."

Moreover, the study participants described that they felt isolated from the pediatric cancer experience because they were given minimal information and updates about their sibling’s cancer diagnosis, treatment, and prognosis from their parents and the healthcare team. The participants often associated the lack of information about their sibling’s cancer with their parents’ intention to protect them and avoid causing additional emotional distress. Some participants also felt that their parents were not mentally and emotionally prepared and genuinely did not know how to share cancer-related information with them in a sensitive and age-appropriate manner. A participant shared the following thoughts related to the limited information she received from her parents:

> I wish [my parents] told us a little more about what was happening at the hospital with her treatment but then again I also feel like my mom was really nervous to tell us because she didn’t want to scare us.

Similarly, another participant shared the following sentiment about her lack of knowledge about and involvement in her sister’s cancer treatment:

> When she was doing her treatment I just kind of wanted to know what was happening so to not be involved in any of it was really stressful. It kind of felt isolating especially since I felt like I couldn’t talk to her or my parents about it.

In addition, nine of the study participants described that they received minimal information and had limited interactions with their sibling’s healthcare team. In the study, only two teenage participants reported that they were given information about their siblings’ cancer diagnoses and treatments by the healthcare team. In both situations, the participants received information about their siblings’ cancer from a physician with their entire family present in a formal meeting shortly after diagnosis. After this initial discussion, participants shared that no additional information or updates were shared with them from their sibling’s healthcare team. All in all, the lack of involvement and information provided by the participants’ parents and the healthcare team was a major contributing factor to their feelings of isolation throughout the cancer trajectory.

Finally, all participants in the study described that they felt distanced and left out from the cancer experience because they perceived that the expectation was that they continue with their daily lives including school, part-time jobs, extracurricular activities, and household chores. While some of the participants thought that continuing with their daily routines and responsibilities provided a sense of normalcy and a distraction from the stressors related to pediatric cancer, more than half of the participants expressed that this caused additional stress and anxiety for them, and they wished that they could have focused more on supporting their sibling and parents during this difficult experience. One participant described the following regarding the challenges she experienced with attending school during her brother's cancer treatment:

> It was pretty scary for me when he was at the hospital, and I had to be at school and act like everything was normal like my mind was just not there. My mind was wherever he was, so I was scared the whole time because I was wondering what was happening while he was in the hospital and I was at school. I wish I could have been more present.

Overall, all of the siblings participating in the study reflected on their feelings of isolation throughout their brother or sister's cancer treatment as a negative experience. The participants desired more information about their siblings' cancer diagnoses and treatments and ultimately wanted the opportunity to be more present and involved in the experience alongside their family.

Disruption to Normal Life

All of the siblings participating in the study expressed that their brother or sister's shocking cancer diagnosis and demanding treatment caused significant disruption to their normal lives and changes to their daily routines and activities. This disrupted sense of normalcy was primarily associated with the prolonged physical separation of the participants from their ill siblings and parents throughout cancer treatment. Before their brother or sister was diagnosed with cancer, all of the participants described that they were accustomed to their family living together at home and being very involved in each other’s day-to-day routines and functioning. However, after the cancer diagnosis, their ill sibling and parents immediately had to shift their entire focus and attention to treatment which lasted anywhere from a few months to years. As a result, significant changes and alternate arrangements had to be made for the participants so that they could continue with their daily lives and routines. This often meant that the participants had to live with extended family members and their parents were not present for important daily routines and activities such as helping with homework, transportation to school or extracurricular activities, and having meals together. A teenage participant shared the following statement that highlighted the impact of the physical separation from her parents throughout cancer treatment on her daily life and routines:

> My parents spent a lot of time in the hospital with [my sister] so I would go to school and it would usually be my cousin or aunt picking me up from school and I would only see my parents two to three times per week. That was difficult because we spent a lot of time together prior to that. My mom works from home and my dad worked a shift where he would be home by the time we were done school and we would have dinner together so it was just like a disruption to routine which I found very challenging.

The disrupted sense of normalcy was a challenge for all participants to adjust to and cope with throughout cancer treatment as they relied on their siblings and parents for their presence and support in their daily lives in many different ways. Many of the participants expressed that they “just wanted life to go back to normal” but also knew that this was not possible until after their sibling’s cancer treatment was completed. The participants shared that in addition to their lives changing significantly in a short period, they also felt that they were expected to continue with their daily routines, activities, and responsibilities as normally as possible. This was difficult for several of the participants as they were often less focused and engaged in school, lacked interest in extracurricular activities, and were not willing to spend time with friends due to the stressors associated with pediatric cancer and its impact on their daily lives. Overall, the sudden and long-term disruption to the participants' normal lives and functioning had a major impact on them throughout the cancer trajectory and was outlined as a negative aspect of the experience by all participants in the study.

Limited Understanding of Sibling's Diagnosis and Treatment

Many of the participants in the study shared that they had a limited understanding of their sibling's cancer diagnosis, treatment, and prognosis. This was particularly common among participants that were younger during their brother or sister's cancer treatment between the ages of 4 and 14 years. All participants shared that they wanted to have more knowledge and information about their sibling's cancer and a better understanding of what was happening to them such as the type of cancer they had, treatments they were receiving, and side effects that they would experience. Participants felt that having this knowledge could have eased many of their fears and uncertainties, made them feel more mentally and emotionally prepared, and potentially correct any misconceptions that they may have had about cancer.

Multiple factors contributed to the participants' feelings of having a limited understanding of their sibling's diagnosis and treatment, including: (a) the complexity of pediatric cancer, (b) parents sharing minimal information, (c) limited interactions with their sibling's healthcare team, and (d) lack of time spent in the hospital throughout cancer treatment. First, pediatric cancer can be difficult and complex for children to understand as it involves several complicated procedures and treatments, and many aspects of the illness trajectory can be unpredictable. Due to the complex nature of pediatric cancer, several participants shared that they never fully understood their sibling's diagnosis and treatment until years after it was completed and they were older. One participant expressed the following regarding her limited understanding of her sister's chemotherapy treatments:

> I knew my sister was getting something called chemo but I didn't really understand it or know what it was at the time. Sometimes right when she started chemo she would like get upset from the side effects and I didn't really understand that so I'd be angry with her. I understand it now but I definitely didn't before.

In addition, many of the participants felt that they had a limited understanding of their sibling's cancer because their parents withheld this information from them. Participants expressed that this was challenging for them because they relied on their parents to keep them involved in the cancer experience and share important information with them. The study participants assumed that the lack of information provided to them was associated with their parents trying to protect them and avoid causing additional stress and they potentially did not know how to discuss such a sensitive and difficult topic in an age-appropriate way. One participant expressed the following about her limited understanding of her sibling's cancer:

> To be honest no one explained anything to me. They just told me what type of cancer it was and they told me to not talk to my sister about cancer so I felt very awkward asking her questions about it too. My parents would go out of their way repeatedly to tell me not to ask her.

While participants wished that they were provided with more information and updates about their sibling's cancer, they also empathized with their parents and understood how difficult it would have been for them to have these discussions with their children especially when they already have so much to stress and worry about.

Another reason that the participants felt that they had limited knowledge about their sibling's cancer was their limited involvement and interactions with the healthcare team. Many participants shared that the healthcare team treating their sibling provided in-depth explanations and frequent updates about the cancer diagnosis and treatment to their brother or sister and parents; however, the participants were rarely involved in these conversations and felt ignored by the healthcare team. When the participants were present for these discussions, they often felt overwhelmed and confused with the medical jargon that was used by the healthcare team and were not given the opportunity to ask questions or receive more age-appropriate explanations. A participant shared the following about her experience with receiving minimal information about her sister's cancer treatment and prognosis:

> I didn't fully understand how well her treatment was going or what her outlook was or any of those things. I don't know if it's just because I was never a part of those discussions or if it was a bad outlook at the beginning and they didn't want me to be part of that knowledge or anything. She was very sick at one point like unresponsive in the ICU and in those times I just fully came to the terms with the fact that I was going to lose her like I started to mentally prepare for it and luckily she's totally fine now but I wish I understood more.

Ultimately, many of the participants described that they expected their parents and sibling's healthcare team to understand their need for information about the cancer diagnosis and treatment and felt disappointed by the limited information shared with them.

Finally, participants felt that they did not understand their sibling's cancer diagnosis and treatment because of their lack of involvement throughout the cancer experience. Many of the participants expressed that they were not able to get a true understanding of the situation because they spent minimal time in the hospital with their sibling and parents. Due to the limited involvement and information that was shared with the participants, several of them sought this knowledge on the internet which often provided overwhelming and misleading medical information and specifically focused on statistics related to prognosis and death. One participant shared that her "…best bet for information was the internet and even then I didn't really know what to search." All in all, there were multiple reasons why the participants felt that they did not understand their sibling's pediatric cancer diagnosis which contributed to their stress throughout the experience.

Change in Relationships with their Family

Changes in relationships with family members were reported by all the siblings participating in the study and were outlined as a negative experience throughout the cancer trajectory. Eight of the participants described having a close relationship with their ill siblings and parents before this experience; however, these relationships completely and abruptly changed once their sibling was diagnosed with cancer. When participants reflected on their relationships with their siblings with cancer, they shared that they felt distanced from them throughout cancer treatment as their brothers or sisters spent a significant amount of time away from home due to prolonged hospital admissions and frequent follow-up appointments. In addition to this, when their siblings were at home, they were often tired or feeling unwell and spent most of their time resting and recovering from their cancer treatments. Participants also experienced challenges in navigating their relationships with their siblings. They felt that they had to act and treat their siblings differently because they were sick. Ultimately, these circumstances resulted in participants not being able to talk, interact, and play with their siblings as they typically would and the changes in their relationships with their brothers or sisters caused them significant emotional distress throughout the cancer trajectory.

Many of the participants shared experiences that highlighted the impact of the changes in their relationships with their siblings. One participant shared the following about her relationship with her sister while she was dying:

> I was very close with my sister before she had cancer but at the end of her life, she only saw me as being the source of constant annoyance so there was a lot of time where I literally couldn’t be involved because it would upset her if I was. She didn’t want to be around me and I just wanted to be with her before she left but I couldn’t.

Another sister expressed the following about the changes in her relationship with her brother during his cancer treatment:

> I think we were always close but during his treatment, I feel like it definitely pushed us away from each other, not in terms of like we just didn't talk to each other or anything like that. It was just because I was at school or he was sleeping, you know? It wasn't on purpose or anything. It was just because he didn't have the energy to like keep up with me and I obviously didn't want to push him and like on the days I would because I just wanted that interaction with him, he would obviously get mad.

These statements highlighted the challenges and losses that the participants experienced throughout the cancer trajectory stemming from changes in their relationships with their siblings.

Furthermore, participants reflected on the significant changes in their relationships with their parents throughout the cancer trajectory. Participants noted that their parents were often absent from the home as they spent most of their time in the hospital with their ill child. In addition to this, when their parents were at home, it was evident to the participants that they were exhausted, stressed, and withdrawn. As a result, many of the study participants described that they felt very distanced from their parents and completely lost their attention. These changed relationships between participants and their parents were particularly challenging as many identified their parents as their "support system" but they were not able to receive their support, attention, and companionship when they needed it the most. For example, parents were often not able to be present for significant milestones and events in their lives during this period such as the first days of school, dance recitals, graduations, and birthdays. Participants also expressed that their relationship with their parents changed because they suddenly felt that could not be open and honest with them about their thoughts and feelings for fear of causing additional stress or being a burden on their parents.

Study participants shared several thoughts and feelings related to the challenges they experienced with the changes in their relationships with their parents specifically associated with the loss of attention. One participant explained:

> I feel like a pretty common feeling is just like kind of feeling neglected in a weird way like not like I don't think my parents love me anymore or like not that I don't think [my brother] deserves the attention that he's getting because of what he's going through but just kind of like not having your parents there for like big moments and stuff.

Similarly, another participant described the change in her relationship with her mother:

> I'm very close to my mom and I was not happy with her at all because obviously all of her attention was devoted to [my brother] and then if she wasn't with him she was researching things for him so I wasn't very pleased with that. I don't feel like our relationship was rocky because she was still always there for me but it was different like it was very distant and weird at that point.

These statements emphasized how difficult it was for the participants to experience and navigate the loss of attention and distance from their parents among all the other stressors that they had throughout the cancer trajectory.

While all the participants acknowledged the challenges in their relationships with their sibling and parents throughout cancer treatment, they also noted that this experience ultimately strengthened their bonds with their family. Many participants shared that they had a greater appreciation for their siblings and parents due to the hardships that they experienced throughout cancer treatment. One participant shared the following sentiment that outlined the positive impact that the cancer experience had on her relationship with her sister:

> It definitely brought us a lot closer together because I think we both knew this could have also ended really badly. Thank god it didn't but I think it was a real eye-opener for both of us because I could have lost her. The childish like arguments just needed to go away. I would say our bond was definitely a lot stronger after her treatment and now is definitely a lot stronger too.

Loss of Control

A sense of loss of control was reported by many of the participants throughout the pediatric cancer trajectory. This feeling was common among participants that were teenagers when their sibling was diagnosed with cancer and particularly those that were older than their sibling with cancer. The participants described that the feeling of having a lack of control was often associated with not being able to make their sibling feel better or fix the situation that their family was in. Many siblings expressed that they wanted nothing more than for their lives to go back to normal, but they quickly realized that they had no control over the cancer trajectory and how it impacted their lives. Older participants also described feeling a need to protect their younger siblings which was not possible throughout this experience especially when they felt so distanced and isolated from their family. One participant expressed the following about her feelings of having a loss of control during her sibling's cancer treatment:

> I think there might have been a feeling of lack of control because I couldn't do anything to fix it and I knew that. There was definitely an aspect of like I can't control this and that's bothering me because the best thing I could do was be nice to him but it felt weird to be overly nice because I wasn't usually.

Similarly, another participant shared her experience with feeling a lack of control:

> I'm like the older sister so I feel like I kind of had that need to protect him but I couldn't and I knew that wasn't right. It made me really uncomfortable because I had a feeling that he was dying but I don't really think I fully knew.

Overall, the lack of control that participants experienced throughout the cancer trajectory was a significant challenge and many of the participants consequently felt that they needed to have more control over other aspects of their lives such as getting good grades in school or succeeding in extracurricular activities.

Jealousy and Guilt

Jealousy and guilt were common feelings reported by all of the siblings participating in the study. The participants outlined that their siblings with cancer received constant attention, gifts, and support from their parents, family, friends, community members, and staff in the hospital. At the same time, the participants were forgotten and felt lonely and isolated since their sibling was everyone's primary focus throughout the cancer trajectory. As a result, all participants expressed having feelings of jealousy towards their ill siblings during this experience and shared thoughtful reflections on these feelings. For example, one participant expressed the following regarding her feelings of jealousy throughout her brother's cancer treatment:

> I didn't fully understand but like he would get all these toys on his birthday or like even not on his birthday. All these people would see him and they'd light up. I'd kind of be in the background because nobody knew who I was so there was sort of like a bit of jealousy which sounds really bad but there's no point in leaving it out because it's a big part of the experience.

Similarly, another participant shared her thoughts about the jealousy that she felt throughout her sister's cancer treatment:

> She was getting all these gifts from everyone around her for doing so well and I was really confused about the entire thing. I was like well why didn't I get anything for going through this?

Finally, a participant shared the following experience throughout her sister's cancer treatment:

> My mom especially like catered a lot to her needs and then if I had something to say she would always put it into the perspective of 'oh, your sister is in this position and you're not' and it was hard for me to grasp at that time because like I was a lot younger so yeah I did feel like a sense of jealousy because of the attention that she was getting.

While all the participants shared that they felt jealous throughout their siblings' cancer treatments, they also acknowledged there was guilt that was associated with these feelings. The participants described that they understood the importance of their sibling receiving constant attention and gifts, but at the same time, they could not control their feelings of jealousy because they felt unimportant and forgotten. Many participants also shared that they felt guilty for enjoying themselves, being happy, and continuing with their daily routines during their sibling's cancer treatment. They felt guilty about this because they knew that their ill siblings were not able to participate in these activities while being in the hospital and receiving intensive cancer treatments. A participant explained the following about the guilt that she experienced during her brother's cancer treatment:

> I knew he should be getting the attention, but I also needed attention because I was struggling but I didn't want to take away from what he needs. I also almost felt like I felt guilty for ever like feeling really happy because like there's shitty things happening and everyone else is upset so like I shouldn't be happy either.

Similarly, another participant shared the following perspective on her feelings of guilt during her sister's cancer treatment:

> I felt guilty for feeling [jealous] when I did because she was going through all of this and was getting all the attention. At some point, I was like what about me? My graduation was around this time, and we didn't do anything for it and I was sad about that. I felt guilty for feeling that way because she was going through way more than me.

All in all, the jealousy and associated guilt that the participants experienced during their sibling's cancer treatment had a significant impact on them. This was particularly challenging as they could not openly express these feelings because it was uncomfortable, and they assumed that nobody would understand why they felt this way.

Fear and Uncertainty

Fear and uncertainty are feelings that were described by all of the siblings participating in the study. Many of the participants felt uncertain of their sibling's prognosis and feared that they would not survive their cancer diagnosis. When describing these feelings of fear and uncertainty, many of the participants became emotional as they shared that they truly did not know if their sibling would survive. Some participants even shared that they began mentally preparing for their sibling's death. The feelings of fear and uncertainty stemmed from multiple factors, including: (a) their limited understanding of the cancer diagnosis, prognosis, and treatment, (b) isolation from the cancer experience, and (c) witnessing their sibling unwell and suffering.

First, the majority (n=7) of the participants explained that a large part of their understanding of cancer was from what they have seen in the media. In the media, cancer is often portrayed as an incurable illness that is typically associated with death and 'success stories' are rarely shared. In addition to this, the participants were often isolated from their sibling's cancer treatment, they received a limited explanation of their sibling's cancer diagnosis, prognosis, and treatment, and their parents were reluctant to have open communication about cancer. Consequently, participants were left with significant fear and uncertainty about their sibling's survival and well-being throughout the cancer trajectory. A participant shared the following regarding the fear and uncertainty she experienced throughout her sister's cancer treatment:

> Seeing her in the hospital for me was very scary. She looked so ill in the hospital bed. I think maybe I was so scared because I didn't understand it and I definitely didn't have the knowledge that family did. I think because my mom was always so like stressed and scared all the time though it made me not want to ask about it either.

Another sibling expressed the following regarding her experience throughout her sister's cancer treatment which contributed to her fear and uncertainty:

> There was just a lot of uncertainty because her surgery date kept getting pushed back and she was spending a longer time in the hospital than expected. I just thought it was a lot more serious just because I never had a family member that was in the hospital for so many consecutive days and just seeing like what she was going through like her symptoms. She was throwing up every day and it wasn't normal and just seeing the amount of weight she lost was very concerning because she was already very petite and then watching her go through that as well was very difficult.

For many of the participants in the study, this fear and uncertainty continued throughout their sibling's entire treatment. They also identified that they wished that actions were taken by their family or hospital staff to provide reassurance and validation such as allowing them to be more involved or providing them with information about their sibling's cancer treatment.

Hiding Thoughts and Feelings

The previous sections outline several of the challenges that participants experienced throughout the pediatric cancer trajectory. In addition to all these stressors, many participants in the study shared that they felt that they had to hide their thoughts and feelings during this time. Participants shared that they could not openly share their thoughts and feelings with their parents and other family members for several reasons. First, many of participants described that they did not fully understand what they were thinking and how they were feeling or know how to articulate them at the time. They also did not want to cause additional stress for their parents and thought that their feelings were not a priority among all of the other challenges that their family was experiencing during this period. Finally, many participants explained that they did not want their families to be upset at them for having negative emotions throughout cancer treatment especially because they were healthy and able to continue with their daily lives. A participant shared the following about her experience with hiding her emotions throughout cancer treatment:

> Part of me tried to hide it because I didn’t want people thinking I was attention-seeking. I was like the background kid. I didn’t talk about it. I didn’t want to. Well, I think I wanted to but I was scared. I just pushed it down and ignored it until I couldn’t handle it anymore which was pretty recent.

Overall, many of the participants did not feel comfortable sharing the difficult emotions and experiences they had throughout the cancer trajectory. Some of the participants described that this has continued even multiple years after cancer treatment has ended and they still have not shared their thoughts and feelings about cancer treatment with anyone. A couple of the participants even described that completing this interview was the first time they discussed many of their difficult experiences.

Positive Emotions and Experiences

While the siblings participating in the study highlighted several difficult experiences throughout the cancer trajectory, they also highlighted some positive emotions and experiences. These included: (a) increased independence and responsibility, (b) increased maturity and empathy for others, (c) spending time with family, (d) seeing their sibling get better, and (e) new experiences and connecting with other families. The positive aspects of the pediatric cancer experience from the perspective of the study participants will be further explored in the following sections.

Independence and Responsibility

The increased independence and responsibility that siblings received was highlighted as a positive outcome of the pediatric cancer experience, particularly among participants that were in their teenage years during cancer treatment. For many of the participants, this life-changing experience allowed them to gain independence and take on new responsibilities to support their families in a way that they never needed to before. Participants associated their increased independence and responsibility with their parents being absent from the home and focusing their attention on their sibling's cancer treatment. Many of the participants shared that they felt that they were able to help their families through this difficult experience by becoming more independent and taking on additional responsibilities which allowed their siblings and parents to focus on the cancer treatment. Examples of responsibilities that participants assumed included cooking meals, taking care of younger siblings, and completing household chores.

Furthermore, participants shared that the increased independence and responsibility that resulted from this experience positively impacted them long-term in other aspects of their lives such as managing school and work and living on their own. Many of the participants that were teenagers during their sibling's cancer treatment shared their experiences with gaining independence and responsibility. One participant shared the following thoughts during her brother's cancer treatment:

> I was ready to take more responsibility and gain more independence like I enjoyed it. I liked getting things ready and making sure everything was where it needed to be and just like taking care of things and doing what I could to help because like my parents like someone had to be with [my brother] all the time. Doing the kind of behind the scenes things that I knew would be helpful to my family.

Similarly, another participant shared the following about her experience with taking on more responsibility throughout her sister's cancer treatment:

> When my parents weren't home like my dad was at work and my mom was at the hospital I took care of my little sister. I had to make sure she ate lunch and breakfast and she did her school work. I felt like I really had to be on top of her because my parents weren't there so like I always wanted to make sure she was okay.

Overall, the participants reflected on this increased independence and responsibility as a positive experience as it allowed them to contribute and help their family, especially in a situation where they often felt isolated and had limited control.

Maturity and Empathy for Others

Maturity and empathy for others were also identified as positive outcomes of the pediatric cancer experience by all siblings participating in the study. The participants described that dealing with a difficult experience like pediatric cancer at a young age helped them understand complex concepts and feelings such as illness, death, and grief. As a result, the participants perceived themselves to be more mature and empathetic towards others . In particular, many of the participants shared that they "had to grow up faster" and felt more mature than their peers because of the significant stressors and challenges that they experienced throughout the cancer trajectory. Some of the participants even shared that after the cancer experience, they often felt that they had more in common with the adults in their life in comparison to their peers or other children of a similar age.

While the feeling of having to "grow up faster" may have been viewed as a negative experience by participants during cancer treatment, all of the participants acknowledged the increased maturity as a positive outcome of the pediatric cancer experience. A participant shared the following about her increased maturity as a result of pediatric cancer:

> I feel like I'm a lot more mature than a lot of people my age like I'm better friends with the staff at my school than the students. Throughout my life I've always gotten along

> better with adults than kids because I can have conversations about political issues and I like things like that. I'm not saying that relates to cancer but I'm able to have mature conversations and I'm happy about that.

Participants perceived themselves as having more empathy towards others as a result of the pediatric cancer experience. Witnessing their siblings become sick and suffer throughout cancer treatment taught them how to be kind and empathetic and this translated to other aspects of their lives. For example, some of the participants shared that they would often be the individuals that supported their peers in school during difficult times or stood up to bullies. Many of the participants also described that after the completion of their sibling's cancer treatment, they have supported other children with cancer and siblings that have gone through similar experiences as them. Some of them have gotten involved in volunteering with pediatric oncology organizations and camps to support other children with cancer and their siblings. All in all, the enhanced level of maturity and empathy towards others that resulted from the pediatric cancer experience has aided in participants' personal growth and ultimately enabled them to excel in different aspects of their lives such as school, work, volunteering, and extracurricular activities.

Spending Time with Family

Spending time with family was highlighted as a positive experience throughout the pediatric cancer trajectory by all siblings participating in the study. Since the majority of the participants were separated from their ill siblings and parents for significant periods during cancer treatment, they appreciated and valued the time that they got to spend with their family more than ever. Many of the participants explained that before their siblings' cancer diagnoses, they took simple daily routines with their family for granted like having dinner or watching television together. However, going through this life-changing experience completely changed their perspective on the importance of spending time with their families. This new outlook and appreciation for their families have carried on with many of the participants even years after their siblings' cancer treatments.

The participants reflected on the positive experiences they had when spending time with their families during cancer treatment. They described watching movies together, playing games and activities, going to family camps, and even doing nothing at all at home between hospitalizations. One of the participants shared the following reflection on spending time with her sister during cancer treatment:

> I remember there was one night where everything just felt normal. The Leafs game was on and I ordered food with [my sister] and she was so excited to watch even though they lost. We had so much fun. I remember another time when my dad came, and we just had lunch together. It was just one of those good moments because we hadn't had a family dinner or lunch in so long. I love thinking of those memories.

Similarly, another participant shared the following experience of spending time with her mom and sister during cancer treatment:

> One day, we went searching for wigs that she could wear because she was kind of insecure about losing her hair. We ended up finding one and it looked so funny. We all just laughed at it for a while, and I think it was the first time we laughed or were happy since she got diagnosed. It was one of the only times where things felt normal.

Overall, the participants expressed that pediatric cancer caused many abrupt changes in their lives, and therefore spending time with their family as they normally would become very important to them.

Seeing Their Sibling Get Better

All of the participants in the study that had a brother or sister who survived their cancer diagnosis reflected positively on the period when their sibling was nearing the end of his or her treatment. Participants described that at this point they witnessed their sibling begin to feel better and look healthier, spend more time at home than in the hospital, and life started to feel normal again. Ultimately, these positive outcomes made participants feel reassured and certain for the first time that their sibling would survive their life-threatening pediatric cancer diagnosis. Many of the participants shared that the pediatric cancer experience felt like a long marathon for them and their families and described the end of treatment as finally reaching the finish line. One participant shared the following experience with witnessing her sibling finish cancer treatment:

> I just instantly felt better once I knew that he was fine. It was so close to the end of his treatment like he was just getting a few radiation treatments and he had a lot of good days at that point so before he was even finished it already felt like it was over to me. It was like we got past that hard part and it's all up from here. As soon as he was in remission, I stopped feeling anxious and it was all good from there.

Another participant shared her thoughts about her sibling recovering and completing her cancer treatment:

> There were some moments that were really positive during her cancer treatment like when she walked again for the first time. Everyone was very happy about that. Also, at the end of treatment she got to ring a bell which was a nice moment because it meant that she was completely done with cancer.

All in all, the participants described that their stress and anxiety improved significantly towards the end of their sibling's cancer treatment as they were able to witness their brother or sister feel better, spend more time with their family, and life begins to return to normal.

New Experiences and Connecting with Other Families

New experiences and getting the opportunity to connect with other families in similar situations were outlined as positive aspects of the pediatric cancer trajectory by some of the siblings participating in the study. Participants shared that many of the new opportunities that they had and families that they met throughout the cancer experience had a significant and long-lasting impact on them and were only possible because they went through this situation. For example, two of the participants shared that they were actively involved in a non-profit cancer support organization in Oshawa called Hearth Place where they were able to join support groups with other siblings of children with cancer. From this experience, they and their families made life-long relationships, received constant support, and had the opportunity to be involved in several programs, events, and activities. One of the participants shared the following thoughts about her involvement with the cancer support organization, Hearth Place:

> I don’t even know where to start about it. The staff there is so nice. They are honestly like family to us because I’ve grown up with them. I’ve known them all for like eight years and I just couldn’t imagine my life without them. Of course, I would never want my brother to have cancer but they made the experience so much better.

Similarly, two other participants reflected on their experiences with attending summer camps for children with cancer and their families. Through these experiences, their families were able to connect with other families in similar situations and spend time together each summer. Meeting other siblings and families was valuable for participants as they felt that they understood each other and could openly share their experiences and challenges with pediatric cancer. Furthermore, some of the participants described that they had new experiences from various charities and donations such as hockey games and meeting celebrities. One participant shared the following experience:

> When my sister was passing, we got a bunch of phone calls from celebrities like David Tennant and Robin Williams. It was really cool. She got signed autographs of movies from Jim Carrey and the most impressive one is we had an entire Skype call with Anne Hathaway. She asked each one of us individually how we were doing and stuff. She called me funny and that was really cool.

Overall, the new opportunities and relationships that the participants were able to have as a result of the pediatric cancer trajectory were a positive highlight of the experience.

Coping Mechanisms

The siblings participating in the study reflected on the different ways in which they coped with the challenges and difficult emotions that they experienced throughout the pediatric cancer trajectory. While some of the participants shared that they had positive coping mechanisms, many of the participants felt that they did not have the knowledge, skills, or support to deal with the various stressors and challenges that they had throughout their sibling's cancer diagnosis and treatment. Some of the participants explained that not being equipped with appropriate coping strategies has impacted them in many different aspects of their lives and resulted in long-term consequences such as increased stress and anxiety, not openly communicating about their thoughts and feelings, and feeling resentment towards their families.

The participants that felt that they did not have appropriate coping mechanisms shared that they would typically suppress and hide all of their thoughts and emotions from their family and friends throughout the cancer trajectory and beyond. Many of these participants also shared that they would constantly try to distract themselves or pretend that their sibling's cancer diagnosis did not exist so that they could avoid acknowledging and dealing with the difficult emotions that they were experiencing. One participant shared the following experience with trying to isolate herself from her family to cope with her sister's cancer diagnosis and death:

> It's an extremely strange feeling process because I just completely removed myself from the situation entirely and pretended like it didn't exist. That's what I did throughout her treatment and I just continued to do that after she passed. I feel like I was forced to do it at first and then it just became like my coping mechanism. I definitely wasn't dealing with my feelings.

While these participants are now able to reflect and identify that these strategies were not helpful for them to deal with the stressors and challenges that they had throughout the cancer trajectory, they acknowledged that they reacted in this way because they did not have the positive coping mechanisms that they needed at the time.

On the other hand, the participants that felt that they had positive coping mechanisms during the cancer trajectory described using strategies, including: (a) remaining hopeful and positive, (b) expressing their emotions in artistic forms such as journaling and drawing, (c) sharing their feelings and seeking support from close friends and family, and (d) engaging in therapeutic activities. First, some of the participants described the importance of remaining positive and hopeful throughout their brother or sister's cancer treatment. These participants shared that truly believing that their sibling would get better helped them have an optimistic outlook on the experience and relieved some of their fears and worries. One participant described that she would watch videos on YouTube of other children that had completed treatment for pediatric cancer. She explained that these videos would provide her with hope and reassurance that her sister could also be like one of those children.

Furthermore, some of the participants described that they found it helpful to write or draw images in a journal consistently throughout the cancer experience as it provided an outlet for them to express and reflect on their thoughts, feelings, and emotions privately. All of the participants that used this as a coping mechanism shared that they learned this from parents or professionals, and some have continued to use this strategy to help express themselves and manage their stress beyond the pediatric cancer experience. A participant that used journaling as a coping strategy throughout cancer treatment shared the following thoughts:

> I had started a journal at the end of 2012 and I wrote in it all through his treatment and up until now I still have the same journal from like 10 years ago which is crazy. I can look back and remember how I was feeling because I was pretty honest in it. I used to just let all my emotions out in that journal which was really helpful during that time and it still is.

Finding opportunities to express their feelings to and seek support from close friends and family members were additional coping mechanisms adopted by some participants. These participants described that it was important to be open and honest about their emotions. In their experiences, they valued opportunities to "vent" about their emotions and then in response to receive advice from these close friends or family. For these participants, these actions and responses were perceived to help them move forward from this experience. Many of the participants that were in their teenage years during the cancer trajectory found that this was a helpful way to cope with their stress especially because they often had more experience with communicating their thoughts and feelings and had established and trusting relationships with friends or family members. On the other hand, younger participants during their sibling's cancer treatment often did not feel as comfortable or know how to openly share their thoughts and feelings with friends and family. A teenage participant shared the following about discussing her feelings with a trusted family member:

> There is definitely one cousin that I would confide in a lot and we would spend a lot of alone time together like on weekends so I definitely like didn't keep a lot bottled up and I had someone to talk to that I trusted which felt really nice.

In addition, some of the participants reflected on the importance of engaging in therapeutic activities and self-care throughout their sibling's cancer treatment to help cope with their stress. These participants described spending more time doing things that they enjoyed and helped them relax such as participating in extracurricular activities, joining a yoga class, or exploring and going for long walks. Taking the time to focus on themselves and their mental and physical health helped provide a positive escape and distraction from the pediatric cancer experience. In summary, all of the siblings participating in the study highlighted the importance of having positive coping mechanisms to manage the stressors associated with pediatric cancer and wished that there was additional education and support to equip them with these strategies.

Types of Psychosocial Support

In addition to understanding the participants' emotions, experiences, and coping mechanisms, the main focus of the interviews was to explore the different ways in which their psychosocial needs were addressed throughout the pediatric cancer trajectory. Psychosocial support has been broadly defined as "the provision of assistance, comfort, or resources to individuals to help them cope with stressors" (Wawrzynski et al., 2021). As previously identified in the literature review, there are two overarching categories of psychosocial support that include support from formal and informal sources. Formal support consists of programs, services, or resources that are provided by professional sources such as hospital systems or community organizations. On the other hand, informal support is provided by social sources such as family, friends, peers, teachers, and others (Wawrzynski et al., 2021).

In the interviews, all of the participants identified that they primarily received psychosocial support from informal sources. Only a small number of participants received formal or professional support throughout the pediatric cancer trajectory. While there were several similarities among participants' emotions and experiences, it was evident that the psychosocial support that they received was often variable from person to person and dependent on various factors such as age, family dynamics, cultural beliefs, and location of residence. The following sections will provide an in-depth description of the participants' experiences with receiving psychosocial support from several formal and informal sources, including: (a) family, (b) peers (c) community members and organizations, (d) schools, and (e) hospital systems.

Family Support

The family was identified as the main source of psychosocial support throughout the pediatric cancer trajectory from all the siblings participating in the study. In particular, participants perceived their parents as being the primary providers of support for them and shared that they offered their support in many different ways. First, participants described that their parents supported them by offering reassurance and validation about their sibling's cancer diagnosis and treatment. Participants outlined that their parents would frequently reassure them that everything was going to be okay and put focus on highlighting positive aspects of their brother or sister's cancer diagnosis and treatment. Since parents were viewed by participants as trusted sources for information, this reassurance and validation provided them with a more optimistic outlook on the experience and helped address some of their fears and uncertainties. One participant shared the following experience with receiving this type of support from her mother after being told about her sister's cancer diagnosis:

> [My mom] was trying to reassure us that it's all going to be okay. She told us that we caught it early, she's going to do chemo, and she's going to be okay. She made sure we knew that we were going to be okay as a family and we were going to go through this together and be okay. That obviously made me feel a lot better about it.

Furthermore, many of the participants shared that their parents supported them by providing information and updates about their sibling's cancer diagnosis and treatment. This was commonly reported among participants that were in their teenage years throughout the illness trajectory. On the other hand, some of the younger siblings during this experience described that their parents did not provide them with adequate information about their sibling's illness. These participants felt that their parents would intentionally withhold this information in hopes of protecting them from additional emotional distress; however, the lack of information only intensified their fears and worries.

While parents provided varying amounts of information, all participants noted that their parents were their main sources of medical information due to their physical distance from the hospital and limited interactions with their sibling's healthcare team. A participant shared: "I got all of my information from my parents about [my brother's] treatment and hospital things in general since they always knew what was going on." All of the participants in the study described that receiving information about their sibling's diagnosis and treatment from their parents helped them understand what was going on and make sense of the situation which alleviated some of their uncertainties, anxieties, and fears. It also made them feel more involved in the experience and allowed them to then explain confidently what was happening to other important people in their lives such as friends and teachers.

Moreover, parents were identified as an important form of support as they shared similar emotions and thoughts and had a good understanding of what the participants were feeling since they were going through this unique experience as a family. Participants described that it was difficult to receive psychosocial support from individuals outside of their families because they could not completely understand their thoughts, emotions, and experiences. Finally, participants reported that their parents supported them by encouraging them to get involved and partake in activities and hobbies that they were interested in throughout the cancer trajectory. Many participants described that engaging in new activities helped them cope with the stressors related to pediatric cancer by providing them with a distraction, maintaining normalcy in their lives, and allowing them to focus on a role outside of the family. For example, one of the participants shared that her mom would plan a new activity for them to do together in Toronto each week. This provided an opportunity for them to spend time together and gave the participant something to constantly look forward to. Similarly, another participant shared: “[my parents] paid for things that I really enjoyed like hot yoga and dance classes so it could be a way for me to relax and have fun during such a stressful time.”

Although parents were identified as a primary form of support, participants outlined that there were several barriers for them to provide this support throughout the pediatric cancer trajectory. The reported barriers included: (a) physical separation and lack of time spent with parents, (b) parents’ limited understanding of their emotions and psychosocial needs, (c) lack of emotional availability from parents, and (d) parents not being informed on how to provide appropriate psychosocial support. First, parents were often physically separated from the participants for extended periods and spent limited time with them due to the significant demands of pediatric cancer treatment. As a result, participants felt that this made it difficult for their parents to have the time and opportunities to give them attention and provide emotional support. In addition to this, participants felt that the physical distance and lack of time spent with parents during cancer treatment made it difficult for their parents to fully understand their emotions and challenges, as well as their needs for psychosocial support. Many of the participants highlighted that this often led to their parents downplaying their difficult emotions and assuming that they did not need additional psychosocial support from formal and informal sources. Participants also noted that when their parents were at home they tried to focus on remaining optimistic, spending time together, and ultimately avoiding having cancer-related discussions. While this time spent together was important, it left participants feeling that their emotions were not addressed and a lack of psychosocial support.

Furthermore, participants identified that they constantly witnessed that their parents were visibly overwhelmed with stress, anxiety, and exhaustion throughout the pediatric cancer trajectory. This hindered them from openly sharing their thoughts and feelings or seeking psychosocial support from their parents because they wanted to avoid being a burden and causing additional stress. In addition, many participants felt that their parents may have been upset and disappointed if they were aware of some of the thoughts and feelings that they experienced such as jealousy or loss of attention. They thought that their parents would not understand their difficult emotions because they were viewed as healthy children who were not diagnosed and being treated for pediatric cancer and therefore did not have a valid reason to be feeling the way that they did. One participant shared the following regarding her parents' limited understanding of her emotions and need for psychosocial support:

> It kind of felt like [my parents] didn’t understand how I was feeling which may or may not be true but that’s how it felt. It didn’t really help for me to talk to my parents about how I was feeling because I didn’t feel like they really understood my perspective. I think I still had a positive relationship with them throughout his treatment but it was just a little tense because everyone was on edge and kind of stressed depending on what happened or they’re tired because they had been in Toronto for several days and not at home.

Finally, many of the participants described that their parents did not know how to appropriately support them particularly because the diagnosis and treatment of pediatric cancer was a first-time experience for both the participants and their parents. One participant shared: “My parents had no idea how to support me and my siblings. They could barely cope with it themselves and there’s no handbook for them on how to navigate it.” This statement highlights that participants understood why their parents may not have always provided them with adequate emotional support throughout this experience. Many of the participants outlined that it would have been beneficial if their parents were given anticipatory guidance from healthcare professionals on how to appropriately support siblings; however, all participants noted that this direction and support was not provided to parents from the healthcare team. In summary, all participants reflected on their parents being the primary providers of support throughout the cancer trajectory. While their parents were not always able to provide them with the psychosocial support that they needed, participants acknowledged that their parents did the best that they could to support them through this difficult experience.

In addition to parents, many participants reflected on the support that they received from extended family members including grandparents, aunts, uncles, and cousins. This form of support was variable among participants as some did not have many extended family members. For most of the participants, the support that was provided by extended family members was focused on helping them continue with their daily lives and routines as normal as possible. For example, many participants described that they lived with extended family members while their ill siblings and parents were at the hospital so they could continue with school and stay close to home. They also shared that extended family members would often cook meals for them and support them with transportation to school and extracurricular activities. One participant shared the following experience with receiving support from extended family members.

> I got a lot of support from my aunt and uncle who picked me up from school every day, as well as my cousins. I spent so much time with them. I felt like I got a lot more attention from them and we kind of built a new relationship. We were already pretty close before but we got so much closer after going through that together.

Moreover, three of the participants described having close personal relationships with extended family members. These participants shared that these family members supported them by creating a safe space for them to openly discuss their thoughts and feelings, offering advice and reassurance to help manage their stress, and spending quality time with them. A participant shared the following experience with receiving this support from her family:

> I am so close to my aunt and cousins who live next door and they always told me that they were there for me if I needed someone to talk to even through they didn’t fully understand what I was going through. They were always there for me and I would always go to them to talk about my feelings if I was really overwhelmed and scared which was a really big support for me.

Having these relationships provided an outlet for some of the participants to express their feelings and their family members were viewed as positive and trusted resources that ultimately helped them cope with the stressors that they experienced during the pediatric cancer trajectory.

In contrast, many of the participants acknowledged that it was difficult for them to openly share and discuss their thoughts, feelings, and experiences with extended family members for several reasons. One of the main reasons for this was that extended family members were not directly involved in the cancer experience and therefore participants felt that they could not completely understand their thoughts and emotions. Some of the other reasons included that participants feared that extended family members may inform their parents of their thoughts and feelings and they did not want to cause additional stress for family members who were also feeling upset and experiencing challenges related to their sibling’s pediatric cancer diagnosis. One of the participants in the study had a unique experience with her extended family members as they did not provide any support and completely distanced themselves from her and her family as soon as her sibling was diagnosed with pediatric cancer due to cultural beliefs. This participant described that the ‘evil eye’ is a common belief in her culture and as a result, her extended family believed that her family was envious of them due to her sister’s diagnosis of cancer and would ultimately inflict harm or misfortune and cause bad luck in their lives. This participant shared the following experience with the lack of support she received from her extended family members due to their cultural beliefs:

> To be honest I feel like they didn’t want to be associated with us because in our culture they thought we would have brought like evil eye to them which is like they thought maybe we would have been jealous of them because their kids were healthy and they were living a good life or something like that. They thought maybe we would have been so jealous of them that we would have made something bad happen to them. Our cousins, aunts, and uncles avoided us and that made me so angry. I didn’t understand how they could think like that like my sister gets cancer and the first thing they were worried about was themselves.

It is evident that the distanced relationships and lack of support from extended family significantly impacted and caused additional stress for this participant and her family throughout the cancer trajectory. In summary, the siblings participating in the study highlighted the importance of support from family throughout the cancer trajectory. Extended family members often stepped in to provide support to help them maintain a sense of normalcy in their lives while their siblings and parents were in the hospital. Ultimately, the support from extended family members was valuable but variable among the participants in the study.

Peer Support

Peer support was identified as an important source of psychosocial support throughout the pediatric cancer trajectory for many of the siblings participating in the study. The amount and type of support that the participants received from their peers and friends were often dependent on their age during the time of their sibling's pediatric cancer diagnosis and treatment. In particular, younger participants during this experience typically described that they received support from their peers by spending more time with them. This included going to their houses to play or for dinner after school and getting dropped off at school and extracurricular activities by their parents. These participants shared that they rarely discussed their sibling's cancer diagnosis or treatment, and they did not feel comfortable sharing their thoughts and feelings with peers. This was often related to the participants not knowing how to discuss these topics with their friends at such a young age.

In comparison, participants that were in their teenage years during their sibling's cancer treatment reported having more mature and developed relationships with their friends. These participants shared that they could openly discuss their thoughts and feelings, and in turn receive emotional support from their friends in a safe and non-judgmental environment. Many participants that were in their teenage years found that it was helpful to share their difficult emotions with their friends because they were not directly involved and could hear about the cancer experience directly from their perspective. It was also reassuring for participants that their friends provided them with attention and support and their conversations were private so they could be certain that their parents would not become aware of what they discussed.

While the type of support that participants received from their peers varied significantly by age and personal factors, all participants highlighted that their peer relationships served as a positive distraction from the cancer experience and provided a sense of normalcy during a difficult period in their lives. They also valued spending additional time with their friends as they often felt isolated, lonely, and distanced from their families. A teenage participant described the following about the support she received from her friends during her sister's cancer treatment:

> They were very supportive. They didn't treat me any differently. If anything, they would reach out to me more just to make sure I was doing okay. They checked up on me a lot and we spent a lot of time together so I really had a good group of friends in high school and I'm still friends with them till this day which is nice.

Although the participants shared that the support that they received from peers was valuable, they also outlined that there were several barriers to seeking and receiving this form of support during the pediatric cancer trajectory. First, many of the participants experienced challenges with determining how to appropriately articulate and share their emotions with peers, and if they did, they did not know exactly how their friends would respond. Since cancer tends to be a taboo topic, both the participants and their peers often did not know how to initiate these discussions and ultimately would avoid talking about it because it felt uncomfortable. One participant shared: "there was like this sadness and awkwardness where [my friends] knew I was going through something really hard but they also had no idea what to say to me because we were all just kids." Similarly, another participant shared the following thoughts regarding the challenges that she experienced in openly discussing pediatric cancer with her friends:

> I didn't really talk about my brother's cancer often with friends because people don't really know how to talk about it like there's nothing they can say to make it better. I feel like I'm actually babysitting them in that conversation and saying like 'oh no it's okay' and I just end up acting like I'm okay for their sake. It wasn't very helpful.

In addition, participants shared that they did not seek out support from their friends and peers because they did not want their sibling's cancer diagnosis to become their identity. Since pediatric cancer is uncommon, they were often the only people at their school or in their community that had a sibling with cancer. Many of the participants described that they wanted to avoid being known as the “sibling of a child with cancer” and as a result, they would often completely avoid talking about cancer with their peers. Finally, two teenage participants shared that they completely distanced themselves from their friends due to the significant stress that they experienced during their siblings’ cancer treatments. These participants shared that they isolated themselves and stopped talking to most of their friends during their sibling’s cancer treatment. One of the participants shared the following experience with this:

> After my brother got diagnosed, I was very quiet and anxious a lot of the time. I kind of distanced myself from a lot of my friends so I didn’t really talk to many people like I just kind of stepped back. I wasn’t very social in high school during this time.

Although both participants noted that having peer relationships would have been helpful throughout the cancer experience, they felt that the significant stressors that they had hindered their ability to navigate their friendships and appropriately seek the support that they needed from their peers.

Moreover, another form of peer support that some participants received was from other siblings of children with cancer. Typically, participants met other siblings during their time spent at the hospital or through pediatric oncology camps and community support organizations. This type of peer support was particularly impactful for participants because they were able to understand and identify with each other on another level since they shared many similar thoughts, feelings, and experiences as siblings of children with pediatric cancer. Participants described that they could openly discuss their thoughts and feelings in a safe, comforting, and non-judgmental environment, as well as receive valuable guidance and advice on how to navigate their situation and cope with stressors related to pediatric cancer. They reflected on times when they did not even necessarily talk about cancer, but they still felt support simply from their presence and having an ongoing shared understanding of each other and what they were experiencing. This support ultimately provided them with a sense of belonging, recognition, and acceptance during a difficult period in their lives. One participant shared the following about her relationship with another sibling of a child diagnosed with cancer:

> We didn’t talk about cancer much but there was like a mutual understanding between us. We knew why we became friends and we knew what each of us was going through. It’s like we didn’t have to talk about it because we just knew. It was great to have a friend that just understands you. I guess it felt like strength in numbers.

Although the participants that received this form of peer support highlighted the positive impact it had on their experience, only three of the participants were able to connect and develop relationships with other siblings of children with cancer. This was primarily related to the lack of opportunity to meet other siblings including the participants' limited presence in healthcare settings, as well as variability in availability and their involvement with pediatric oncology support camps and organizations in the community.

In summary, the siblings participating in the study outlined that peer support can be provided in many different ways from spending time together to having relationships that allowed them to talk about their situation. This form of support can be provided by friends at school or even other siblings of children with cancer. While peers were a valuable source of psychosocial support for participants, it is important to highlight that there are limitations to the amount of support that peers can provide due to several factors including age, maturity, communication, and willingness to share.

Community Support

Community support was identified as a common source of support among the siblings participating in the study. Approximately half of the participants stated that they received some form of support from their community, including: (a) religious or cultural organizations, (b) neighbours, and (c) community-based pediatric support organizations. First, three of the participants shared that their families received a significant amount of support from religious and cultural groups that they are a part of. One participant became emotional as she reflected on the immense ongoing support that her family received from members of her church throughout her brother's cancer treatment. Some of the main ways that members of religious and cultural groups provided support included prayers, cooking meals, visiting the hospital, and collecting monetary donations to alleviate some of the financial challenges associated with pediatric cancer treatment. A participant also shared that she was connected with a mentor from her church who supported her by allowing her to share her thoughts and feelings and offering advice and guidance. She shared the following experience with this form of support:

> I used to have a youth group worker at my church and that's who I would always go to if I didn't want to talk to my parents about things. She wasn't involved in the hospital and cancer-related things so I could go and talk to her about how I was feeling and she would give me really good advice.

Furthermore, a few of the participants described the support that they received from neighbours and other members of their communities. This support was especially prevalent among participants that lived in smaller or tight-knit communities compared to those that lived in larger cities. Similar to the support from religious and cultural groups, neighbours would often provide support by cooking meals, watching over their homes, and donating money. Two of the participants shared that members of their community would host events such as car washes or bake sales to help raise money and donations for their families. This type of support was important for participants as it signified that several people truly cared for their families and wanted to help them as much as possible.

Moreover, pediatric oncology support organizations were identified as a major form of support; however, these resources are limited and only two of the participants received this type of support. Typically, these organizations are non-profit, and may only be available in certain areas, and families often have to seek out these organizations themselves or be told about them by other families or healthcare professionals. The participants that were involved in these cancer support organizations reflected positively on their experiences and how they helped them cope with the stressors associated with pediatric cancer. The main components of these organizations included: (a) meeting other siblings and families impacted by pediatric cancer and (b) programs and events that supported their psychosocial needs and challenges.

Both participants that were involved in these organizations described that they were a part of children and family programs that allowed them to connect with other siblings and families to learn about pediatric cancer, share their thoughts and feelings, gain new coping skills, and receive acknowledgement and validation. For example, one participant shared that a group of siblings of children with cancer would meet every month for an activity night that was focused on creating a safe environment to share their feelings and provide them with acknowledgement and coping strategies. One activity that she described was creating buttons that outlined each of the additional responsibilities that they took on during their sibling's cancer treatment and putting those buttons on a lanyard that they could wear. The intent of this physical item was to serve as a reminder to them of the many important contributions they made to their family during this experience. In addition, a participant shared that she received one-time support from a community organization called 'SuperSibs' where she received a certificate and gift bag that congratulated her on being an amazing sibling through such a difficult experience. While she only received this support once, she identified that the acknowledgement meant a lot to her and was one of the only times she received validation and recognition during her sister's cancer treatment.

Three of the participants in the study also discussed attending camps for children with cancer and their families. Two of the participants attended camp with their entire family, whereas one of the participants attended camp for families and siblings only. This form of support was offered during and after their brother or sister's cancer treatment was completed. The main focus of these camps was reconnecting with each other and engaging in fun activities such as canoeing, swimming, archery, and crafts. These camps provided participants with a great opportunity to enjoy themselves, spend time with their families, and meet other families going through similar situations in a safe and comforting environment. While all of the participants that attended these camps found it a positive experience, they noted that they tried to avoid talking about cancer as much as possible so that they could enjoy themselves because these camps were only offered a few times per year.

In summary, community support was important for many of the participants and their families throughout the pediatric cancer trajectory. This support was often provided by religious and cultural groups, neighbours, and pediatric cancer support organizations. However, based on the participants' experiences, it is evident that the support that they received within the community was variable and dependent on several factors such as the location of residence and availability of resources. This highlights the need for additional funding and support from cancer support organizations in the community.

School Support

The siblings participating in the study were at various levels of education during the pediatric cancer trajectory. Four of the participants were in elementary school, four were in high school, and two were completing post-secondary education. Despite the participants' ages or levels of education, all of them reported that they were expected to continue with school as normally as possible throughout this experience. Some of the participants felt that it was helpful for them to continue with school without any disruptions as it provided a positive distraction from their brother or sister's cancer treatment. These participants identified that school provided a sense of normalcy and was a source of stability in their lives during a period when they were experiencing several changes. They also shared that the pediatric cancer experience did not impact their ability to excel in school and complete their required work. One participant shared the following about her positive experience with school during her sister's cancer treatment:

> I think school has always been such a place of refuge and stability like I always tried really hard in school. It was where I definitely got the most validation in my life was from teachers and so I think I was able to just continue with what I was really comfortable with and confident with and like even though I would be worried about [my sister] I don't think it like impacted my performance at all or distracted me or anything.

In contrast, some of the participants in the study experienced challenges in school during their sibling's cancer treatment. These participants described feeling that it was "unfair" that they had to continue with school as normal during such a difficult time in their lives. They described that it was hard for them to focus and pay attention in school and ultimately their grades and ability to learn suffered throughout this experience. One teenage participant shared the following perspective on her challenges in school during her sister's cancer treatment:

> When [my sister's] whole cancer treatment was going on my marks were kind of dropping. I just couldn't focus on school anymore because there were more important things going on. I wasn't doing well and then that continued on into the next year.

Furthermore, the participants reflected on the psychosocial support that they received at school during their sibling's cancer treatment. From the interviews, it was evident that the support that participants received from teachers, guidance counsellors, and other school staff was variable from person to person. Half of the participants (n=5) reported that they received no support from school staff. These participants described that they felt like their sibling's pediatric cancer “did not exist” when they were at school. They also shared that the staff at their school did not ask about their sibling’s cancer diagnosis or treatment and did not provide any leniency with schoolwork despite being aware of the situation. This was most commonly reported among participants that were in high school or completing post-secondary education during their sibling’s cancer treatment.

Two participants shared extremely difficult experiences in which they were bullied in elementary school in relation to their sibling’s cancer. One participant described that other children made fun of her brother with cancer when he returned to school due to the significant changes in his appearance such as his hair loss and weight gain. The other participant reflected on the bullying that she experienced from other children at school who intentionally distanced themselves from her because they feared that her sister’s cancer was contagious and that she would give it to them. This participant shared the following experience with bullying during her sister’s cancer treatment:

> People used to not talk to me because they thought I was going to give them cancer because my sister had it. People would be like ‘don’t go near her because she’s going to give you cancer.’ They were kids so they didn’t understand that it’s not contagious like a cold but it really hurt my feelings at the time.

These participants experienced several challenges at school because they felt misunderstood and embarrassed. The lack of support ultimately resulted in them feeling withdrawn from school.

Moreover, the other half of the participants described that they received some type of support from school staff, which was primarily provided by teachers and guidance counsellors. These participants received two main forms of support at school that included: (a) sharing their thoughts, feelings, and experiences and (b) flexibility and leniency with schoolwork. Many of these participants shared that they were able to openly express their thoughts, feelings, and experiences with their teachers and guidance counsellors who created a safe and comforting environment. They shared that it was particularly helpful to be able to share their feelings with an adult that was not directly involved in the experience because they could share their perspectives and receive practical advice and guidance. One participant described that "it was nice to know that I could rely on my teachers and talk to them when I needed to." Similarly, another participant shared the following experience with receiving support from her teacher:

> I felt most comfortable talking to my teacher and I'd stay after class a lot and explain what was going on and what home life was like. She provided me with a comfortable enough space where I felt like I could talk to her about how I was feeling. I could tell my teachers cared about me which made me feel more comfortable talking to them.

Another participant described that she received a significant amount of support from her guidance counsellor who was previously diagnosed with cancer. She outlined that they would meet once each week and her guidance counsellor was able to provide her with knowledge about cancer, a safe environment to discuss her feelings, and reassurance and validation. This participant shared the following regarding her experience with receiving support from her guidance counsellor:

> My guidance counsellor actually had lymphoma as well so she would meet with me weekly. She would talk to me about it and she also explained it to me which was really helpful because she had gone through it. It kind of reassured me that he was going to be okay because she was living proof that you can survive cancer. That really helped calm my anxiety and fear.

In addition, participants shared that their teachers would support them by allowing them to have extra time with homework and tests and being understanding if they were having a difficult day or feeling distracted at school. The participants found that this type of support was particularly helpful as it helped alleviate some of the stress associated with school and allowed them to focus on their sibling's cancer treatment when needed. While many of these participants felt that they were able to manage their responsibilities at school, it was reassuring for them to know that their teachers understood and acknowledged the other stressors that were impacting them and their families.

Another form of psychosocial support that was described by two participants, was a nurse that visited their school to discuss their sibling's cancer diagnosis with their teachers and classmates. These discussions were focused on explaining pediatric cancer and how it would impact the ill child and their sibling in an age-appropriate manner. For one of the participants, this was arranged through a cancer support organization in the community and for the other participant it was arranged by the hospital. The participants found this form of support helpful as they felt less pressure to share this information with their classmates and teachers and it dispelled some of the myths and misconceptions that their peers may have had. These participants also felt that people were more understanding, and open to talking, and would check in with them more often after the visit from the nurse. One of the participants shared the following perspective on the school visit from a nurse:

> She told my entire class what was going on with my sister being diagnosed with cancer. They wanted to make sure that everyone was informed and if I needed support from my classmates, they wanted to make sure I got that. It was helpful to have her explain it because I had no idea how to explain it and people were just more understanding after.

In summary, school was an important aspect of all of the participants' lives throughout the pediatric cancer trajectory. However, their experiences with receiving support were variable. Based on their experiences, there was no consistent or standardized form of support at school and the amount of support that they received was often dependent on their teachers or guidance counsellors. Ultimately, participants that received more support from staff and classmates had more positive experiences with school, while those that received no support had additional challenges.

Hospital Support

A lack of psychosocial support from healthcare professionals and hospital systems were identified as a significant gap during the pediatric cancer trajectory by all siblings participating in the study. The participants described that they often felt non-existent and ignored in healthcare settings, as the majority of the attention was focused on their ill siblings and parents. They reported limited personal interactions with their sibling's healthcare team and minimal formal support offered to them during cancer diagnosis and treatment. One participant emotionally stated: "no one talked to me. No one checked in with me. There was no support at all." Similarly, another participant shared the following perspective on the lack of acknowledgment and support she received in the hospital during her brother's cancer treatment:

> For all intents and purposes, I never existed in the hospital. It was just [my brother] and my parents. They didn't provide me with any support or even share any resources that I could potentially seek out myself. I just felt like they ignored me.

Many of the participants shared that the limited interactions that they had with the healthcare team were primarily centered on their ill sibling and parents. For example, when nurses were completing assessments or administering medications to their sibling, they would occasionally greet them or informally ask how they were doing. One participant shared the following experience related to this:

> My interactions with [the nurses] were definitely facilitated through my sister. They would like say hi to me and then ask my sister about how excited she was that I was there and what we were going to do together. It felt like my presence was something that they and my sister could like share and bond over. They were kind but I definitely didn't have relationships with any of them and I don't think they really noticed that I was there.

Another example of the participants' lack of involvement in the hospital was when the healthcare team would provide their family with medical information or updates about their sibling's cancer diagnosis or treatment. In these situations, the healthcare team would focus on providing the information and answering questions from their ill sibling and parents while they felt completely ignored and left out of the discussion.

While the majority of the participants felt that there were significant gaps in the healthcare system in terms of providing them with psychosocial support, all of the participants described that the hospital was a comforting and safe environment for their siblings. The participants explained that they felt reassured that there were trusted healthcare professionals present to help their sibling get better, especially at times when their brother or sister was feeling unwell. Participants also felt more optimistic and less anxious when they were able to spend time and be present with their sibling in the hospital. One participant stated: “I definitely felt less stressed when I was in the hospital because I could see what was happening to her like when she was getting treatment.” Participants also shared that although they may not have received any formal psychosocial support or resources from a healthcare perspective, they appreciated that the staff in the hospital were always kind, positive, and friendly. A participant shared the following perspective on the nurses in the hospital during her sister’s cancer treatment:

> [The nurses] do a really good job at keeping the environment very positive. You would expect the hospital to be a sad place because there’s a bunch of cancer patients but it really is such a positive place and that always made me feel better.

Furthermore, some of the participants recalled instances where informal support was provided to them in the hospital, specifically by nurses. A participant shared that one of the nurses caring for her sibling always explained what she was doing in an age-appropriate way and tried to involve her whenever possible. For example, while this nurse was completing her brother’s vital signs, she would allow her to listen to his heartbeat with her stethoscope and assist with her assessments. Another participant discussed feeling involved in her brother’s care when the nurses would explain what medications and treatments they were administering. This involvement helped participants feel that they understood what was happening to their siblings and made them feel less isolated and distanced from the experience.

Moreover, only two participants reported receiving some form of formal support at the hospital. One participant shared that she was involved in a sibling support group at the hospital where they would meet biweekly to learn more about pediatric cancer and had the opportunity to openly discuss their thoughts, feelings, and experiences. This participant shared that she did not find this support group helpful because it took place in the hospital which made it difficult for her to attend consistently as her home was over an hour away from the hospital. In addition, she expressed that it was difficult to openly discuss her thoughts and feelings with a group of siblings and healthcare professionals that she did not know or feel comfortable with. The other participant that received formal support in the hospital described meeting with a child life specialist when her brother was initially diagnosed. During this meeting, the child life specialist explained pediatric cancer and how it would impact her and her family through play. This participant shared the following experience with receiving support from a child life specialist:

> She had kind of explained everything to me and said ‘you’re going to be spending a lot more time in the hospital, you might not be able to concentrate in school’ and things like that which was obviously true. I guess she kind of helped me prepare for what was about to happen which was helpful.

This participant also described being a part of hospital-wide “sibling days” where they would play games and activities with other siblings throughout the hospital; however, these events took place infrequently. Many of the participants shared that there were several volunteers throughout the hospital as well but they were typically focused on supporting the patients instead of siblings.

Overall, all of the participants expressed that they felt disappointed by the lack of psychosocial support and resources available to them from a healthcare and hospital system perspective. Many of them believe that healthcare professionals would be the most well-positioned and equipped to provide psychosocial support for siblings of children with cancer because they have extensive knowledge and experience with pediatric cancer and understand how it would impact families and their lives. In addition to wishing that they received direct support and resources from the healthcare team, participants shared that it would have been helpful if their parents were provided with education and guidance on how pediatric cancer impacts their other children and how to best support them throughout the experience.

In terms of the type of support that would have been helpful from a hospital perspective, participants wanted healthcare professionals to provide them with information about their sibling's cancer diagnosis and treatment in an age-appropriate manner. Participants also wished that someone from the hospital to check in with them so that they could openly express their thoughts and feelings and receive reassurance and guidance to help them navigate and cope with the stressors associated with pediatric cancer. Finally, another way the participants expected to receive support from the hospital was to be more open and flexible with visitor policies for siblings. The participants wanted to spend more time with their ill sibling and parents in the hospital and be present for their treatments however, the strict visitor restrictions in the hospital made it difficult for them to do so. For example, two of the participants shared that they were not able to visit at all during their sibling's cancer diagnosis and treatment due to strict visitor restrictions during the COVID-19 pandemic. All in all, the participants highlighted the current gaps in the provision of psychosocial support from healthcare professionals and hospital systems, and the importance of this type of support for siblings throughout the pediatric cancer trajectory.

Needs for Psychosocial Support

The siblings participating in the study reflected on their needs for psychosocial support during the pediatric cancer trajectory and shared their perspectives on how support for siblings of children with cancer could be improved in the future. Since the interviews with participants occurred within a range of one to ten years since the sibling's cancer treatment, participants were able to thoughtfully reflect on and identify several resources and strategies that would have helped them cope with the stressors associated with pediatric cancer. This included: (a) knowledge and information about pediatric cancer, (b) involvement in the cancer experience, (c) professional support and resources, (d) peer support and mentorship, and (e) long-term support beyond the completion of treatment. The following sections will provide an in-depth description of the participants' reported needs for psychosocial support.

Knowledge and Information about Pediatric Cancer

All of the siblings participating in the study described a need for more information and updates about their brother or sister's cancer diagnosis, treatment, and prognosis. They explained the importance of understanding what was happening to their brother or sister, and how not having this information caused them additional emotional distress and uncertainty. Due to their limited involvement in the hospital and lack of interactions with the healthcare team, the participants primarily relied on their parents for medical information about their sibling. Parents were not always able to provide adequate information in as they were also feeling stressed and overwhelmed, were not always present in the home, and may not have known how to share this information with their children in an age-appropriate way. All of these factors combined resulted in participants feeling like they were not informed and did not understand what was happening to their sibling.

The participants shared several potential interventions and methods that could have been used to provide them with information about pediatric cancer. This could include scheduled meetings with the healthcare team where they provide information about their sibling's pediatric cancer diagnosis and treatment in an age-appropriate manner and allow time to answer any questions that they may have. Another intervention that all of the participants thought would be useful is physical resource packages such as child-friendly and creative books and videos that explained pediatric cancer, treatments, and procedures. Finally, participants felt that it would have been helpful for their parents to receive education and information on how to appropriately share medical information and the importance of having open and honest communication about cancer with their other children.

Involvement in Cancer Experience

The siblings participating in the study expressed a need to be more involved in the cancer experience. This included being present with their ill sibling and parents in the hospital and having more knowledge about their sibling's cancer diagnosis and treatment. The participants felt that being more involved in the experience would help alleviate many of the difficult emotions and stressors that they had such as fear, loss of control, and uncertainty. They proposed potential interventions that could promote their involvement in the hospital which could include reducing visitor restrictions, encouraging their presence, and offering additional sibling-focused activities. In addition, parents could promote their involvement by having more cancer-related discussions and finding time to bring their other children to the hospital.

Professional Support and Resources

All of the siblings highlighted that they received minimal formal support from professional sources. Several trained professionals within the hospital have extensive experience with pediatric cancer and would be qualified to provide psychosocial support to siblings in many different ways. For example, they would be well-equipped to assess their psychosocial needs, offer one-on-one support, and connect them with appropriate resources in the community. The participants expressed a need for having a safe space to express their thoughts and emotions and learn new coping strategies to manage their stress related to pediatric cancer. This support can be provided by various healthcare professionals including nurses, physicians, child life specialists, social workers, and child psychologists.

Peer Support and Mentorship

Mentorship and support from peers that have gone through similar experiences were identified as potential support that would have been helpful for many of the participants. They highlighted that this form of support would have allowed them to speak with someone that understands them and could provide them with guidance and advice based on their previous experiences. It would also allow them to openly share their thoughts and feelings with someone who is not directly involved and would not inform their parents of what they had discussed. One participant shared the following perspective on having this need for support during her brother's cancer treatment:

> I think it would have been so nice to have someone to talk to that has gone through a similar experience kind of like an older mentor. I could have asked them questions and they would just understand me on a different level. They would also be able to validate that how I was feeling was normal like jealousy for example. I definitely needed that.

Long-term Needs for Support

All of the participants reported that there was limited formal support offered to them during their sibling's cancer treatment however, they also identified that they received even less support after their treatment was completed. The participants outlined that the impact of pediatric cancer is long-lasting and many of them continued to experience ongoing stress and anxiety once their brother or sister's cancer treatment finished. This was particularly relevant for the bereaved sister participating in the study who shared that she received no formal support after her sister's death. She shared the following experience with the lack of long-term psychosocial support after her sister's death:

> The first time I spoke to a therapist was nine years after my sister's death and I had to seek out that support myself. I completely avoided thinking or speaking about her death and my family never talks about it either. It has been extremely helpful to figure out how I was feeling because I had just buried it for the longest time.

This highlights the need for long-term psychosocial support for siblings of children with cancer to help them express and cope with the ongoing stressors associated with pediatric cancer even beyond the illness trajectory.

Summary of Findings

Overall, the siblings participating in the study provided in-depth insight into both their difficult and positive experiences throughout the pediatric cancer trajectory. They highlighted that their sibling's cancer diagnosis and treatment was a life-changing experience that presented several challenges and stressors in all aspects of their lives. They reflected on the sadness and worry they had when they witnessed their brother or sister become unwell and experience significant physical changes from their cancer symptoms and aggressive treatments. They also described feeling isolated, neglected, and lonely because they were often physically distanced from their ill sibling and parents for extended periods while they were in the hospital. In addition, many participants identified that they had limited knowledge and understanding of their brother or sister's cancer diagnosis and treatment due to the lack of age-appropriate explanations and resources provided by their parents and the healthcare team.

Another negative aspect of the pediatric cancer trajectory was the sudden and unexpected changes in participants' relationships with their ill siblings and parents. They specifically described their sibling no longer having the energy to play and interact with them and losing the attention of their parents as they focused on cancer treatment. Participants also outlined that they felt a loss of control as they realized that there was nothing they could do to make their sibling get better. Furthermore, they reflected on feeling jealous of their siblings due to the constant attention and gifts they received from family, friends, and healthcare professionals while also feeling significant guilt for having these feelings as their siblings were ill and needed this support. Finally, the participants described the challenges that they experienced with hiding their thoughts and feelings during cancer treatment because they sensed that they were not as important as the other issues that their family was experiencing.

On the other hand, the participants reflected on the positive aspects of the pediatric cancer trajectory. This included gaining independence and taking on new responsibilities to support their families in a way that they never needed to before. They also reported increased maturity and empathy for others as they understood complex concepts and feelings at a young age such as illness, death, and grief. Furthermore, participants reflected positively on spending time with their family and witnessing their sibling finally get better and look healthier towards the end of treatment. Finally, participants enjoyed gaining new experiences and connecting with other families in similar situations because they were able to create life-long friends and memories. In summary, the participants in the study highlighted the unique challenges, stressors, and needs that siblings of children with cancer experienced throughout the illness trajectory. Their experiences emphasize the importance of them receiving comprehensive psychosocial support to help them cope appropriately with these stressors and mitigate the potential for long-term consequences.

The interviews with the siblings participating in the study also explored the different ways in which they received psychosocial support from formal and informal sources including family, peers, community, school, and hospital systems. Although many of the participants shared similar emotions and experiences, the amount and types of psychosocial support that they received were variable from person-to-person and dependent on several different factors. Some of the factors that impacted the psychosocial support that was provided to them included their age, family dynamics, location of residence, and cultural beliefs. All participants described that the primary forms of support that they received throughout the pediatric cancer trajectory were provided through informal sources including their family, friends, and community. At the same time, only a few of the participants received psychosocial support from formal or professional sources.

Participants identified that their families were the main providers of psychosocial support. In particular, their parents offered support in several different ways which included providing information about their sibling's cancer diagnosis and treatment, maintaining an optimistic outlook by giving ongoing reassurance and validation, and encouraging them to continue with their daily routines and partake in activities that they enjoyed. While parents were viewed as their primary providers of support, participants identified that they were limited in the support that they could offer due to their lack of available time and physical separation, as well as their limited understanding of their other children's psychosocial needs and how to appropriately support them. Many of the participants were also reluctant to seek support from their parents because they did not want to burden them or cause additional stress. Extended family members were also identified as a major form of support including grandparents, uncles, aunts, and cousins. They provided support by helping them continue with their daily routines as normally as possible such as living with them, cooking meals, and transportation to school. Some participants also relied on extended family members for emotional support throughout the pediatric cancer trajectory.

Furthermore, the participants described that their friends and peers were valuable sources of psychosocial support. This was commonly reported among participants that were in their teenage years during their sibling’s cancer treatment. Eight participants outlined that friends were a positive distraction from the cancer experience and allowed them to openly share their thoughts, feelings, and experiences. In addition, the participants also discussed receiving support from their community including neighbours, individuals from religious and cultural groups, and cancer support organizations in the community. Cancer support organizations were identified as a major form of support however, these resources are limited and only two of the participants received this type of support. These organizations provided participants with the opportunity to meet other families going through similar experiences and offered programs that supported them throughout the cancer trajectory.

Moreover, the participants' experiences and perspectives on school and academics during cancer treatment were variable. Some participants felt that it was helpful for them to continue with school as normal because it provided a sense of stability. However, others felt that they were distracted at school and their academic performance declined. In terms of support, there were varying levels of support provided at school and the amount and type of support that they received was different from person to person. Based on the interviews, participants that were in their teenage years typically reported receiving less support from school than those that were younger. The participants that received support noted that it was most often provided by teachers and guidance counsellors who allowed them to share their thoughts and feelings, provided them with guidance, and offered flexibility and leniency with school work. Two participants described extremely challenging experiences at school with bullying related to their sibling’s cancer.

From a hospital perspective, all of the participants noted that there were significant gaps in the provision of psychosocial support from healthcare professionals and within the hospital. The participants identified that there was limited support provided in the hospital and those that did receive some form of support shared that was often informal or not helpful. All participants felt disappointed with the lack of support from healthcare professionals and hospital systems as they felt that they would be most well-positioned due to their extensive experience and knowledge about pediatric cancer and how it impacts families.

Overall, the majority of the participants expressed that they did not receive enough formal support throughout the pediatric cancer trajectory. While the informal support from family, friends and community members was valuable, they all felt that they needed more psychosocial support from formal sources. In particular, the participants highlighted that their support needs included increased knowledge and information about their sibling’s cancer, involvement in the cancer experience, mentorship, professional resources, and long-term support beyond the cancer trajectory. In summary, the participants’ experiences highlight that they had unmet psychosocial needs and gaps in the formal support provided to them.

CHAPTER 5: DISCUSSION

In this qualitative study, participants described their previous experiences and perceptions in receiving psychosocial support from formal and informal sources when a sibling was undergoing treatment for cancer. Study findings detail their perceived needs for psychosocial support throughout their sibling's pediatric cancer trajectory, as well as their recommendations for how this type of support can be enhanced. Four key issues grounded in this analysis of siblings' experiences were identified. These include: (1) siblings experienced isolation from the pediatric cancer experience, (2) there is limited parental awareness of siblings' psychosocial needs for support, (3) siblings identify a critical need for consistent academic and school support, and (4) needs for standardized psychosocial support from hospital systems are recommended. While the issues identified in the current study generally concur with existing literature that have explored siblings' emotions and experiences during the illness trajectory, new insights and considerations have emerged. In this chapter, each of the key issues will be further examined and discussed in context with findings from previous studies in this field.

Siblings' Isolation from the Pediatric Cancer Experience

It is significant to note that all participants expressed feeling isolated and distanced from their families throughout their sibings pediatric cancer experience. Many of the participants described that they felt overlooked, left out and forgotten as their family members focused their attention on the ill sibling and prioritized meeting their emergent health, medical and social needs. It became evident that the participants' lack of involvement and isolation resulted in several negative emotions including fear, uncertainty, loneliness, anger, jealousy, and sadness. There were multiple factors reported that contributed to the participants' feelings of isolation. These were: (a) changes in family dynamics and loss of parental attention, (b) strict visitor restrictions and physical distance from the hospital, (c) limited medical information and updates about their sibling's diagnosis and treatment, and (d) expectations to continue with their daily lives and routines. Siblings' feelings of isolation during the pediatric cancer experience, as well as the associated long-term emotional, behavioural, and psychosocial consequences have also been documented extensively in previous literature (Alderfer et al., 2010; Gerhardt et al., 2015; Weiner & Woodley, 2018; Woodgate, 2006; Wawryznski et al., 2021; Zegaczewski et al., 2016).

Changes in Family Dynamics and Loss of Parental Attention

The changes in family dynamics and loss of parental attention were described in detail by all of the siblings participating in the study and significantly contributed to their feelings of isolation throughout the pediatric cancer trajectory. The participants reflected on how their relationships within their family changed completely during this experience, particularly with their ill siblings and parents. Before their sibling's cancer diagnosis, the majority of participants were used to living at home with their families, being present in each other's lives, and spending a lot of quality time with one another. After the cancer diagnosis, their relationships with their ill sibling changed as they became unwell from their cancer symptoms and aggressive treatments and had to spend a significant amount of time in the hospital and away from home. Similarly, their parents were visibly stressed and had to focus most of their attention on their ill child and cancer treatment. Ultimately, these changes in their family relationships and the loss of attention from their parents made the participants feel distanced, lonely and isolated from their family during the pediatric cancer experience. These feelings occurred even within the context of the participants being cared for by friends and family, which was an arrangement made by parents to ensure that their other children's needs were attended to.

The existing literature that explores the experiences of siblings of children with cancer aligns with these study findings. A systematic review by Alderfer et al. (2010) examined 65 studies and evaluated the psychosocial impact of pediatric cancer on siblings. The most common themes across studies were a disrupted sense of normalcy and loss of attention. Siblings reported spending less time with their parents and feeling neglected, ignored, isolated, uncared for, and lonely within their families (Alderfer et al., 2010). Similarly, a longitudinal mixed methods study by Woodgate (2006) explored 30 siblings' experiences during the childhood cancer trajectory through observations and interviews. The findings outline that changes in family functioning cause significant distress for siblings and the cancer experience is often viewed as a "different way of being in the family" (Woodgate, 2006). In particular, siblings reported experiencing disruptions in how they and their family members related to each other and functioned together, as well as a loss of their sense of self within the family unit (Woodgate, 2006). Siblings desired to maintain a sense of presence within their family and feel like they were a part of the cancer experience; however, they often felt alone and abandoned throughout the illness trajectory due to the changes in family dynamics and loss of attention (Weiner & Woodley 2018).

Strict Visitor Restrictions and Physical Distance from Hospital

The participants in the study described that they were not physically present with their family for the majority of their siblings' treatments which created a sense of isolation from the cancer experience. This was primarily related to strict visitor restrictions and their distance from the hospital. In most situations, the participants and their families lived in suburban areas with distances ranging from one to three hours away from their sibling's treatment hospital, typically located in a large urban centre. As a result, their ill siblings and parents spent a significant amount of time away from home as they were in the hospital for treatments, symptom management, and follow-up. At the same time, all of the participants reported that they continued to live at home or with extended family members throughout cancer treatment so they could continue with school and their daily activities and routines.

In addition to this, the participants shared that there were strict visitor restrictions in the hospital that limited their ability to be involved and spend time with their ill siblings and parents throughout cancer treatment. For example, all siblings shared that they were not allowed to stay at the hospital overnight and some events reported that they were not able to visit their sibling in the hospital throughout the COVID-19 pandemic. Ultimately, the participants' physical distance and separation from the hospital resulted in them spending minimal time with their ill siblings and parents and significantly contributed to their feelings of isolation throughout the cancer experience.

The current literature emphasizes the importance of siblings being present and involved in the hospital. A qualitative study by Prchal and Landolt (2012) described the experiences of seven siblings in the first 6 months after cancer diagnosis through semi-structured interviews. The findings highlight that siblings reflected positively on being present in the hospital and involved in the care of their ill brother or sister (Prchal & Landolt, 2012). The literature also outlines that siblings may not be able to visit the hospital regularly due to physical distance and competing priorities such as school and extracurricular activities (Gerhardt et al., 2015). However, the literature does not describe the challenges that siblings may experience with visitation policies in the hospital which were identified by many of the participants in the study.

Limited Information about their Sibling's Diagnosis and Treatment

The study participants described feeling isolated from the pediatric cancer experience because they were given minimal information and updates about their sibling's cancer diagnosis, treatment, and prognosis from their parents and the healthcare team. All participants expressed a need for more knowledge and understanding of their sibling's cancer such as the type of cancer they had, treatments they were receiving, their chances of survival, and the side effects that they would experience. It is important to note that the average age of participants at the time of their sibling's cancer diagnosis was 12.6 years with a range of 2 to 17 years. Thus, for some participants it may not have been appropriate or realistic for them to receive and understand this information. This highlights the need for informational support for siblings to be developmentally and age-appropriate. The participants reported several factors that resulted in them receiving minimal information, including: (a) the complexity of pediatric cancer, (b) lack of openness and communication from parents, (c) limited interactions with their sibling's healthcare team, and (d) limited time spent in the hospital.

First, pediatric cancer can be difficult and complex for children to understand as it involves several complicated procedures and treatments, and many aspects of the illness trajectory can be unpredictable. Due to the complex and unpredictable nature of pediatric cancer, parents and healthcare professionals may be reluctant or not know how to share cancer-related information in an age-appropriate manner. In addition, parents often did not openly communicate with their other children and withheld medical information to protect them and avoiding causing additional emotional distress. Participants also felt that their parents may not have known how to share cancer-related information with them. Finally, participants had limited interactions with the healthcare team and spent minimal time in the hospital which resulted in them receiving minimal information about their sibling's cancer diagnosis and treatment. Consequently, the lack of involvement and information provided by the participants' parents and the healthcare team was a major contributing factor to their feelings of isolation throughout the cancer trajectory.

The existing literature outlines the need for siblings of children with cancer to receive information about the illness and treatment, as well as opportunities to talk about the impact of the illness on their lives and adjustment (Gerhardt et al., 2015). A systematic review by Gerhardt et al. (2015) included 125 studies and examined current psychosocial standards of care for siblings of children with cancer. The results of the review highlight that siblings are not provided with adequate information about pediatric cancer by their parents and healthcare professionals in a developmentally appropriate manner (Gerhardt et al., 2015). Similarly, a scoping review by Wawrynzski et al. (2021) examined social support for siblings of children with cancer. The study findings outline that siblings share feelings of worry and isolation when they did not understand what was happening with their brother or sister and need more informational support through open and honest communication with their parents and healthcare professionals about cancer and involvement in treatment. The literature also emphasizes that an increase in knowledge about cancer including its causes and treatments can decrease anxiety and promote positive coping mechanisms among siblings (Long et al., 2018).

Expectations to Continue with Daily Lives and Routines

The siblings participating in the study described that they felt distanced and left out from the cancer experience because they were expected to continue with their daily lives including school, part-time jobs, extracurricular activities, and household chores. The majority of the participants wished that they could have focused more on being present and supporting their siblings and parents during this difficult experience. They also expressed that the pressures of continuing with their normal lives caused additional stress and anxiety for them because they were less focused and engaged in school, lacked interest in extracurricular activities, and had fewer opportunities for social activities. Siblings of children with cancer often feel that they are expected to continue with their daily lives as normally as possible, but find this task difficult due to competing priorities, increased stress, and distractions related to cancer treatment (Long et al., 2018; Prchal & Landolt, 2012). All in all, it is evident that the expectations and pressures for siblings to continue with their daily lives and routines can contribute to their feelings of isolation and lack of involvement throughout the pediatric cancer trajectory.

Limited Parental Awareness of Siblings' Psychosocial Needs

A key finding of this study was that parents had a limited understanding of the participants' psychosocial needs throughout the pediatric cancer trajectory. In the study, parents were identified as the primary providers of support for all participants during the cancer experience and beyond. However, the majority of the participants felt that their parents had limited awareness and understanding of their thoughts, feelings, and experiences, as well as their needs for psychosocial support. This lack of awareness impacted the amount and types of support that participants received and ultimately was identified as a significant contributing factor to many of the participants feeling that they did not receive enough psychosocial support throughout the pediatric cancer experience.

The findings of the current study are consistent with previous research that highlights limited parental awareness of their healthy child(ren)'s psychosocial needs. While this study obtained the perspectives of siblings of children with cancer, it is important to note that majority of the previous literature has primarily captured the perspectives of parents concerning their awareness of their other child(ren)'s psychosocial needs. A systematic review of 65 studies by Alderfer et al. (2010) examined the psychosocial impact of pediatric cancer on siblings. The study findings outline that parents experience challenges attending to the needs of both their sick and healthy children throughout the pediatric cancer trajectory. At the same time, a common theme in the literature is that parents frequently expressed feeling guilty for not being physically and emotionally present for their other child(ren) and worried about the potential long-term consequences it would have on them (Alderfer et al., 2010).

Furthermore, siblings and parents often have differing perspectives on siblings' psychosocial functioning and needs, which may reflect parental unawareness of siblings' adjustment to cancer and increase the risk for negative sibling outcomes (Pariseau et al., 2020). A qualitative study by Pariseau et al. (2020) recruited 13 families to examine parental awareness of sibling adjustment and the needs for psychosocial support. In the study, siblings and parents reported that parents were often unaware of the presence, severity, or content of siblings' cancer-related feelings. Similarly, a scoping review by Wawrynzski et al. (2020) examined social support for siblings of children with cancer. The study findings highlight that a lack of awareness from parents regarding siblings' needs may lead to parents interpreting that siblings do not require psychosocial support from a formal or informal perspective which ultimately may result in them receiving a lack of support throughout the cancer trajectory (Warynzski et al., 2020).

In the current study, participants reported several factors that contributed to their parents' limited awareness of their psychosocial needs, including: (a) physical distance and lack of time spent with parents, (b) minimal communication of cancer-related emotions to parents, (c) parents were emotionally unavailable and focused on cancer treatment, and (d) parents were not equipped to appropriately identify and address their psychosocial needs. Many of these factors were also highlighted in the existing literature and will be further explored in the following sections.

Physical Separation and Lack of Time Spent with Parents

First, the siblings participating in the study described that the physical separation and lack of time spent with their parents contributed to the limited awareness and understanding of their psychosocial needs. Parents were often physically separated from the participants for extended periods due to the significant demands of pediatric cancer treatment. As a result, participants felt that this made it difficult for their parents to have the time and opportunities to provide them with attention and offer emotional support. In addition to this, participants felt that the physical distance and lack of time spent with parents during cancer treatment made it difficult for their parents to completely understand their thoughts, feelings and challenges, as well as their needs for psychosocial support. Many of the participants highlighted that this often led to their parents downplaying their difficult emotions and assuming that they did not need additional psychosocial support from formal and informal sources. Participants also noted that when their parents were at home they tried to focus on remaining optimistic, spending quality time together, and ultimately avoiding having cancer-related discussions. While this time spent together was important, it left participants feeling that their emotions were not addressed and they received inadequate psychosocial support.

The existing literature validates that limited parental awareness of their healthy child(ren)’s psychosocial needs is related to the physical distance and lack of time spent together during the pediatric cancer trajectory. In the qualitative study by Pariseau et al. (2020), parents reported that they spent less time with their other child(ren) during the cancer experience which resulted in fewer opportunities to observe their behaviour and affect, identify challenges in their psychosocial functioning, and provide or seek out appropriate support for them.

Minimal Communication of Cancer-Related Emotions to Parents

Another factor that contributed to parents' limited awareness of the participants' psychosocial needs was the lack of communication about cancer-related emotions to their parents. The participants identified that they constantly witnessed that their parents were visibly overwhelmed with stress, anxiety, and exhaustion throughout the pediatric cancer trajectory. This hindered them from openly sharing their negative emotions and experiences or seeking psychosocial support from their parents because they wanted to avoid being a burden and causing additional stress. In addition, many participants expressed that their parents may have been upset and disappointed if they were aware of some of the thoughts and feelings that they experienced such as jealousy or loss of attention. They thought that their parents would not understand their difficult emotions because they were seen as healthy children who were not diagnosed and being treated for pediatric cancer and therefore did not have a valid reason to be feeling the way that they did. For these reasons, participants described that they often suppressed their emotions throughout the pediatric cancer trajectory and tried to remain positive and be helpful in the presence of their parents.

Both siblings and parents report that it is often challenging for siblings to clearly and directly communicate their cancer-related emotions and concerns with their parents (Pariseau et al., 2020). Many parents focus on remaining positive and limiting their expression of negative emotions when they are around their children which may hinder siblings' emotional expression (Pariseau et al., 2020). Parents also indicate that conversations about siblings' emotions often require parental initiation because siblings rarely seek out these discussions and appeared resistant to sharing their cancer-related emotions with them (Pariseau et al., 2020). Overall, these findings emphasize the importance of parents consistently initiating conversations about cancer and encouraging open and honest communication from the time of diagnosis onward (Pariseau et al., 2020).

Parents are Emotionally Unavailable and Focused on Cancer Treatment

Furthermore, many of the participants perceived that their parents had limited awareness and understanding of their psychosocial needs because they were emotionally unavailable and were completely focused on their child with cancer. As previously described, participants witnessed their parents constantly overwhelmed and exhausted from the stressors related to pediatric cancer. In addition to spending significant amounts of time in the hospital with their ill child, parents also had to manage several other competing priorities and responsibilities including their careers, finances, and caring for their other children. As a result, parents were often distracted, did not notice or acknowledge the participants' psychosocial needs, and had the minimal emotional capacity to address their needs. The participants highlighted that the emotional unavailability and lack of attention from their parents were particularly prevalent at the time of and shortly after their sibling's cancer diagnosis. This was challenging for participants because this was the period where they felt that they needed the most attention and psychosocial support from their parents.

The existing literature supports the findings from the current study that parents have limited awareness of their other child(ren)'s psychosocial needs due to the significant emotional demands of pediatric cancer. The findings of a systematic review by Alderfer et al. (2010) outline that parents expressed that they must prioritize their child's cancer treatment which often makes them physically and emotionally unavailable for their other child(ren). In addition, the findings of the qualitative study by Pariseau et al. (2020) highlight that many parents report that with the emotional and practical demands associated with cancer, they felt unable to handle any additional stressors which result in higher expectations for their other children, less tolerance of their negative emotions, and difficulty recognizing their cancer-related adjustment issues (Pariseau et al., 2020).

Parents Unequipped to Identify and Address Psychosocial Needs

Another factor that contributed to the limited parental awareness of participants' psychosocial needs is the lack of information and knowledge provided to them by the healthcare team. All of the participants described that their sibling's pediatric cancer diagnosis was shocking and unexpected for their family. For the majority of the participants and their parents, this was their first encounter with pediatric cancer and they did not know what to expect throughout this experience. As a result, the participants felt that their parents were not aware of their other child(ren)'s thoughts, feelings, and experiences during the pediatric cancer trajectory. The siblings participating in the study noted that the interprofessional healthcare team would be well-positioned to provide parents with information and guidance on their other child(ren)'s psychosocial needs and how to appropriately support them. However, the participants described that the healthcare team did not have these discussions with their parents which ultimately left parents in a situation where they were unprepared to identify and address their other child(ren)'s psychosocial needs appropriately.

The existing literature also highlights that parents' lack of awareness of their other child(ren)'s psychosocial needs is associated with the limited information and guidance they receive throughout the pediatric cancer trajectory. Kenny et al. (2021) conducted surveys with 550 families of children with cancer to explore parents' experiences with communicating about illness their ill child and other children. Parents described that they were often unaware of their healthy child(ren)'s emotions and psychosocial needs. Parents desired additional information about their psychosocial needs and requested sibling-specific interventions from healthcare professionals, including: (a) the creation of resources for siblings, (b) coaching for parent-sibling conversations, and (c) standardized family meetings with the multidisciplinary team that includes siblings. Parents valued when the healthcare team shared age-appropriate vocabulary and coached them in having cancer-related conversations with their children (Kenny et al., 2021). In addition, a scoping review of 57 studies by Warynzski et al. (2021) outlines that majority of parents reported little to no formalized support for siblings throughout cancer diagnosis and treatment. Parents also reported receiving less informational and psychological support than they needed which ultimately made it difficult for them to access support for siblings or even address difficult subjects with siblings such as prognosis (Wawryznski et al., 2021).

In summary, parents are often the primary providers of psychosocial support for their children throughout the pediatric cancer trajectory. Thus, parents need to have a comprehensive understanding of their child(ren)'s thoughts, feelings, and experiences. Ultimately, limited parental awareness of their child(ren)'s psychosocial needs can lead to them not providing or seeking appropriate support. As outlined in this study, this can result in siblings of children with cancer having unmet psychosocial needs and receiving inadequate support.

Need for Consistent Academic and School Support

School was an important aspect of all of the participants' lives as this was where they spent the majority of their time throughout the pediatric cancer trajectory. However, it was evident that the participants' experiences with receiving support at school were variable from person to person. The siblings participating in the study highlighted that there were no consistent or standardized forms of support provided to them and the amount of support that they received was often dependent on the school staff such as teachers and guidance counsellors.

In the study, only half of the participants reported that they received some form of psychosocial support at school; whereas, the other half of the participants shared that they did not receive any cancer-specific support. It was noted that the participants that received support at school were primarily in elementary school while those that did not receive any support were either in high school or completing post-secondary education at the time of the pediatric cancer diagnosis. This may indicate that siblings of children with cancer that are younger receive more support at school in comparison to teenagers.

The participants that received support at school described that it was most commonly provided informally by school staff including teachers and guidance counsellors. Some of the common forms of support offered by school staff included providing opportunities to openly discuss their emotions and experiences, as well as allowing them to have extra time and flexibility with school work. Two of the participants described receiving a formal type of support in which a nurse visited their school to educate their peers and teachers about pediatric cancer. All in all, it was evident that the participants that received support had a more positive outlook on school throughout the pediatric cancer trajectory. On the other hand, the participants that did not receive any support described having negative experiences at school and felt that their academic performance and relationships with their peers suffered. A few of these participants also reported that they experienced cancer-related bullying from peers at school which was commonly associated with a lack of understanding and misconceptions about cancer.

The existing literature highlights the challenges that siblings of children with cancer experience in school, especially within the first 6 months after diagnosis (Alderfer et al., 2015). The primary themes documented within this body of literature were disruptions in school performance, behaviour changes, as well as a perceived need to be more responsible for independently completing their school work (Alderfer et al., 2010). Siblings of children with cancer often report feeling that they are expected to continue with their daily lives as normally as possible, but find this task difficult due to competing priorities, increased stress, and distractions related to cancer treatment (Long et al., 2018). While siblings' difficulties with academics throughout the pediatric cancer trajectory have been identified, there is limited information regarding the support that they receive at school including their experiences, support needs, and the types of resources and supports available.

Overall, the findings of this study suggest that the support that the participants received at school was inconsistent and often inadequate to address their academic and psychosocial needs. Therefore, consistent and standardized forms of support must be implemented at school for siblings of children with cancer. The siblings participating in the study outlined various forms of psychosocial support that would have been helpful from a school perspective, including: (a) information and resources about pediatric cancer for peers and school staff, (b) ongoing psychosocial support from school staff, and (c) flexibility and support with school work.

Information About Pediatric for Peers and School Staff

The siblings participating in the study outlined that there was a need for their peers and the staff at their school to have more knowledge and information about pediatric cancer including general information and how it may impact them. Many of the participants described feeling that their peers and the staff at their school did not fully understand them, their situation, and the challenges that they had related to their sibling's pediatric cancer diagnosis. At the same time, it was difficult and uncomfortable for the participants to explain this information themselves and answer questions that were frequently asked at school. This often resulted in the participants acting like their sibling’s illness did not exist and completely avoiding any cancer-related discussions at school.

The two participants that had a nurse visit their school to discuss their sibling’s cancer diagnosis with their peers and teachers shared that this form of support made them feel less pressure to share information themselves and it dispelled some of the misconceptions that their peers may have had about pediatric cancer. These participants also felt that their peers and teachers were more understanding, open to talking, and would check in with them more often after the visit from the nurse. These participants’ experiences highlight the need for appropriate cancer-related information and resources to be shared with peers and staff at school.

The existing literature outlines that support from peers and teachers is valuable for siblings of children with cancer; however, to provide the support they require knowledge and education about pediatric cancer (Prchal & Landolt, 2012). Several studies emphasize the positive impact of educational school visits from a nurse, particularly for children with cancer. At this time, there is limited literature on the value of this intervention for siblings.

In a recent study by Sjoberg et al. (2018), the impact of the Ontario Oncology Nurse School Visitation Program on the well-being and school adjustment of siblings was examined. The intervention was delivered by a Registered Nurse, who provides a 20 to 60-minute age-appropriate presentation for the sibling’s class followed by a period where students are allowed to ask questions and have a discussion about pediatric cancer (Sjoberg et al., 2018). Siblings described that the nurse visit helped their peers better understand the complex situation that they were experiencing and avoided them having to answer uncomfortable questions about cancer. Ultimately, this increase in knowledge and awareness resulted in siblings feeling that there was more acceptance, kindness, and support from their peers at school (Sjoberg et al., 2018).

Ongoing Psychosocial Support from School Staff

The participants expressed a need for ongoing psychosocial support from the staff at their schools including teachers and guidance counsellors. Since the participants spent a significant amount of time at school during the pediatric cancer trajectory, they identified that the staff at their schools would be well-positioned to check in on how they are doing regularly, provide them with opportunities to share their emotions and experiences, and advocate for them or connect them with appropriate support resources if needed. The participants that received this type of ongoing support from staff at their school shared that this was valuable as they felt comfortable with their teachers and were able to receive helpful advice and guidance, especially during a time when they were experiencing physical distance and a loss of attention from their parents. While this form of support was important, many participants noted that it was often provided informally and inconsistently such as after school.

Ultimately, all of the participants highlighted that ongoing support from school staff creates a more positive experience with the school throughout the pediatric cancer trajectory. The existing literature clearly describes the challenges that siblings of children with cancer experience at school. However, there is no available literature that outlines their experiences with receiving support or how they could be supported appropriately at school by staff such as teachers and guidance counsellors. All in all, the study findings emphasize the need for ongoing psychosocial support at school and further research is required to explore the types of support and resources that can be offered to siblings of children with cancer.

Flexibility and Support with School Work

The participants in the study described that the significant stressors associated with their sibling's pediatric cancer diagnosis and treatment made it difficult for them to focus on school.

In addition to this, the participants reported receiving less support with school work from their parents which made them feel increased pressure to complete their schoolwork independently. As a result, some of the participants expressed challenges with completing their school work and felt that their grades suffered. They described a need for additional support with academics and flexibility with completing school work throughout the pediatric cancer trajectory. Some examples of this form of support may include one-on-one tutoring and extra time to complete assignments or tests.

The participants in this study that received additional academic support and flexibility with school work found it helpful as it allowed them to focus on spending time and being present with their ill sibling and parents. This form of support also confirmed that their teachers understood and acknowledged the challenges that they were experiencing during this time. The existing literature highlights that siblings of children with cancer often have challenges with their academic performance during the pediatric cancer trajectory (Prchal & Landolt, 2012). These difficulties are often associated with the changes in routine and stressors related to pediatric cancer, as well as the limited parental support and the need to be more independent with schoolwork (Alderfer et al., 2010). Although the literature outlines the disruptions in school performance for siblings of children with cancer, there is limited evidence on how they can be appropriately supported academically. In summary, the findings from this study emphasize the importance of providing siblings with additional support and flexibility with academics throughout the pediatric cancer trajectory.

Need for Standardized Psychosocial Support from Hospital Systems

A key finding that emerged from the current study is the lack of psychosocial support provided to the participants by healthcare professionals and hospital systems throughout the pediatric cancer trajectory and beyond. This highlights the need for standardized and evidence-based psychosocial care to be provided to siblings of children with cancer from a healthcare perspective. This includes the implementation of ongoing psychosocial screening and assessments, as well as appropriate supportive services to address their psychosocial healthcare needs. All of the siblings participating in the study reported that they received either no or minimal support from healthcare professionals. They described that they often felt ‘non-existent’ and ‘forgotten’ in healthcare settings, as the majority of the attention from healthcare providers was focused on their ill sibling and parents. The participants also outlined that they had limited personal interactions with their sibling’s healthcare team and there were minimal formal sources of psychosocial support available to them during cancer diagnosis and treatment. In addition to this, there were strict visitor restrictions in the hospital that limited their ability to visit and spend time with their ill sibling and parents throughout cancer treatment. As a result, all of the participants strongly felt that there were significant gaps in the psychosocial support provided to them from a healthcare perspective and this is a major area for improvement in the future.

While the participants had unmet needs and psychosocial support was limited from healthcare professionals, they described that the hospital was a comforting and safe environment for their ill sibling. The participants explained that they felt reassured that there were trusted healthcare professionals present to help their sibling get better. Many of the participants described that the most support that they received in the hospital was provided informally by nurses such as asking them how they were doing and involving them in the medical assessments or interventions that they performed. Only two participants received formal support in the hospital which included a biweekly sibling support group and one meeting with a child life specialist after her sibling’s diagnosis.

The findings from this study align with existing literature that emphasizes the critical importance of establishing evidence-based standards of psychosocial care for siblings of children with cancer in efforts to encourage the provision of more consistent and comprehensive services for this population (Gerhardt et al., 2015). Psychosocial support for siblings can have a major impact on their adjustment to the cancer diagnosis and can mitigate potential negative emotional and behavioural consequences (Zegaczewski et al., 2016). This support allows siblings to express their thoughts and feelings, promotes positive coping mechanisms, and facilitates open communication (Zegaczewski et al., 2016). Healthcare providers are well-positioned to provide psychosocial support for siblings of children with cancer by assessing their psychosocial needs, implementing supportive interventions, assisting with family communication, and advocating for additional resources (Gerhardt et al., 2015).

Siblings need access to timely screening and supportive care; however, these services are often limited throughout the pediatric cancer trajectory (Mooney-Doyle et al., 2021). Currently, there are no evidence-based standards for the initiation, or delivery of providing supportive services and psychosocial care for siblings within the healthcare system (Barrera et al., 2020; Gerhardt et al., 2015). A major barrier to evidence-based psychosocial care is the lack of research and resources focused on sibling-specific assessment tools and interventions (Barrera et al., 2020; Gerhardt et al., 2015). Therefore, the provision of psychosocial support for siblings is often not implemented from a healthcare perspective and siblings report having unmet needs related to social and emotional support, cancer-related information, and involvement in cancer treatment (Long et al., 2018; Gerhardt et al., 2015).

In addition, the majority of pediatric oncology centres and children’s hospitals within Canada provide guidelines and policies to promote the delivery of family-centred care within their organizations. However, the findings of this study reflect that siblings may not be appropriately engaged in this model of care. This emphasizes the importance of evaluating the current provision of family-centered care and establishing guidelines to ensure that siblings are considered and included. Existing literature also highlights the importance of providing family-centred care in healthcare settings. A qualitative study by MacKay and Gregory (2011) examined the experiences of pediatric oncology nurses in providing family-centred care. The findings demonstrate that pediatric oncology nurses often face challenges and barriers when attempting to provide family-centred care including a lack of time, education, and resources. It also outlines the need to establish clear guidelines or policies regarding family-centred care to ensure that it is provided consistently and comprehensively by healthcare professionals to all members of the family (MacKay & Gregory, 2011).

The participants in the study reflected on their needs for psychosocial support during the pediatric cancer trajectory and shared their perspectives on how support for siblings of children with cancer could be improved in the future. They highlighted several forms of psychosocial support that should be consistently offered from a healthcare perspective, including: (a) providing information about their sibling’s diagnosis and treatment, (b) offering opportunities to discuss their emotions and experiences, (c) providing guidance and navigation to supportive resources, and (d) flexibility in visitor policies for siblings. The following sections outline the participants’ perspectives on hospital support that should be offered to siblings of children with cancer, as well as the existing literature in this area.

Information about Sibling’s Diagnosis and Treatment

All of the siblings participating in the study described the need for receiving information and updates about their brother or sister’s cancer diagnosis, treatment, and prognosis from the healthcare team. They explained the importance of understanding what was happening to their brother or sister, and how not having this information caused them additional emotional distress and uncertainty. Due to their limited involvement in the hospital and lack of interactions with the healthcare team, the participants primarily relied on their parents for medical information about their sibling. Parents were not always able to provide adequate information as they were also feeling stressed and overwhelmed, were not always present in the home, and may not have known how to share this information with their children in an age-appropriate way. All of these factors combined resulted in participants feeling like they were not informed and did not understand what was happening to their sibling.

Many participants shared that the healthcare team treating their sibling provided in-depth explanations and frequent updates about the cancer diagnosis and treatment to their brother or sister and parents; however, the participants were rarely involved in these conversations and felt ignored by the healthcare team. When the participants were present for these discussions, they often felt overwhelmed and confused with the medical jargon that was used by the healthcare team and was not allowed to ask questions or receive more age-appropriate explanations.

The participants shared several potential interventions and methods that could have been used by healthcare professionals to provide them with information about pediatric cancer. This could include scheduled meetings with the healthcare team where they provide information about their sibling's pediatric cancer diagnosis and treatment in an age-appropriate manner and answer any questions that they may have. Another intervention that the majority of participants thought would be useful are educational resources such as child-friendly and creative books and videos that explained pediatric cancer, treatments, and procedures. Finally, participants expressed that it would have been helpful for their parents to receive education and information on how to appropriately share medical information and the importance of having open and honest communication about cancer with their other children.

The existing literature also outlines the importance of healthcare professionals providing information about pediatric cancer to siblings of children with cancer. A systematic review of 125 studies by Gerhardt et al. (2015) examined psychosocial standards of care for siblings. The study findings highlight the importance of communication with siblings throughout the illness trajectory. Siblings need information about the illness and treatment, as well as the impact of the illness on their lives and adjustment (Gerhardt et al., 2015). It also indicates that siblings should be updated by healthcare professionals regularly and provided information about the disease and treatment in a developmentally and age-appropriate manner (Gerhardt et al., 2015). At this time, the literature does not outline any interventions or resources that can support healthcare professionals with the provision of this information for siblings.

Opportunities to Discuss Emotions and Experiences

All of the participants reported that they received minimal formal support from professional sources. There are several trained professionals within the hospital systems that have extensive experience with pediatric cancer and would be qualified to provide psychosocial support to siblings in many different ways. For example, they would be well-equipped to assess their psychosocial needs, offer one-on-one support, and connect them with appropriate resources in the community. The participants expressed a need for having a safe space to express their thoughts and emotions and learn new coping strategies to manage their stress related to pediatric cancer. This support can be provided by various healthcare professionals including nurses, physicians, child life specialists, social workers, and child psychologists.

Much of the published literature describes that sibling support groups and camps are the primary formal resources offered to siblings of children with cancer for psychosocial support throughout the illness trajectory (Gerhardt et al., 2015; Sidhu et al., 2006). The existing research highlights the benefits of these interventions as they focus on focus on facilitating discussions with peers and healthcare professionals, addressing emotional concerns, providing reassurance and validation, bolstering self-esteem, and improving knowledge about cancer and treatment. While sibling support groups and camps are positive forms of psychosocial support for siblings, these resources are limited, not offered consistently, and difficult for them to access as they are often based in the hospital.

Guidance and Navigation to Supportive Resources

The participants outlined the importance of guidance and navigation to supportive resources from healthcare professionals. Many of the participants shared that they were not aware of any available resources that could provide them with psychosocial support throughout the cancer trajectory such as child psychologists and pediatric support organizations in the community. They also highlighted that their parents were not informed of these resources and consequently could not access them for their child(ren). While the availability of supportive resources is limited, healthcare professionals would be well-informed to make referrals, educate parents, and navigate them to supportive resources that could support siblings throughout the pediatric cancer trajectory. The existing literature highlights the barriers to providing psychosocial support to siblings including limitations in the availability of trained psychosocial staff and community resources (Gerhardt et al., 2015; van Warmerdam et al., 2020). However, it also outlines the importance of sharing information about supportive resources available for siblings (Gerhardt et al., 2015).

Flexibility in Visitor Policies

The siblings participating in the study consistently expressed a need to be more involved in the pediatric cancer experience. A major aspect of this is being present and spending time with their ill sibling and parents in the hospital. Many of the participants described that they were not able to spend a lot of time in the hospital due to strict visitor restrictions. This was especially common among the participants whose siblings were diagnosed with cancer during the COVID-19 pandemic. The participants felt that being more present in the hospital would help alleviate many of the difficult emotions and stressors that they had such as fear, loss of control, and uncertainty. They proposed potential interventions that could promote their involvement in the hospital which could include reducing visitor restrictions and encouraging their presence in healthcare settings.

The existing literature highlights that siblings desire to be present in the hospital and actively involved in care (Prchal & Landolt, 2012). At this time, the literature does not address how strict visitor policies that may impact siblings’ ability to be present in healthcare settings. It is important to note that this may be an area of importance, especially with the COVID-19 pandemic which has created stricter visitor restrictions and further limited siblings’ opportunities to be present in the hospital.

Summary of Discussion

In summary, the current study provides insight into the significant stressors and challenges that siblings of children with cancer experience throughout the illness trajectory, as well as the importance of providing them with comprehensive and consistent psychosocial support. In the study, it was evident that the support that participants received from formal and informal sources was variable and the majority of the participants felt that they had unmet needs and did not receive enough psychosocial support throughout this experience.

Previous literature has outlined that siblings experience unique challenges that put them at risk for acute and long-term psychosocial consequences (Alderfer et al., 2010; Gerhardt et al., 2015; Prchal & Landolt, 2012). The existing literature also outlines that there are no current evidence-based standards for the supportive care of siblings of children with cancer and psychosocial support is often limited (Gerhardt et al., 2015). This emphasizes the critical importance of establishing evidence-based standards of care for siblings of children with cancer to ensure consistent and comprehensive services for this population (Gerhardt et al., 2015). This study provides new insights into siblings' experiences with receiving support from both informal and formal sources, and how support can potentially be improved in the future. Specifically, the findings outline the importance of ensuring that siblings' are involved in the cancer experience and increasing parental awareness of siblings' psychosocial needs as they are often the primary providers of support. Finally, it highlights the gaps and needs for additional support at school and from hospital systems such as increased knowledge and information about their sibling's cancer, opportunities to have open communication about their emotions and experiences, and long-term support beyond the cancer trajectory.

CHAPTER 6: CONCLUSION

The study provided insights into the experiences and perceptions of siblings of children with cancer concerning the different ways in which they received psychosocial support from formal and informal sources. The study also detailed siblings' perceived needs for psychosocial support throughout the pediatric cancer trajectory, as well as how this support can potentially be improved in the future. In this chapter, the strengths and limitations of the current study will be discussed. Following that, key implications for nursing practice, policy, education, and research will be highlighted. The chapter concludes with a summary of recommendations and strategies for knowledge translation and exchange.

Study Strengths and Limitations

The current study has several methodological strengths; however, some limitations were noted. A major strength of the study is it provided an in-depth exploration of the experiences and perceptions of siblings of children with cancer with receiving psychosocial support through individual interviews and questionnaires. In addition, there was variation in the participants' demographic characteristics and their sibling's cancer characteristics including the ages of the participants and their siblings, locations of residence, levels of education, types of cancer diagnosis, and lengths of cancer treatment. This variation allowed for the representation of multiple different perspectives and experiences from the participants. Furthermore, for siblings to be eligible for the study, their brother or sister's diagnosis of pediatric cancer must have occurred within the past ten years. This allowed participants to reflect and provide insight into their experiences, whereas the majority of the existing research that has been conducted with siblings takes place during the pediatric cancer trajectory.

A notable limitation of the study is it only captured the experiences of female siblings of children with cancer and did not include any male siblings due to challenges with recruitment. Challenges with recruiting male participants is not unique to this study as this limitation has been outlined in existing literature, particularly research focused on exploring experiences with health and illness. An example of challenges with recruitment of male participants was demonstrated in a study by Smith et al. (2018) that examined the psychological and social impacts of cancer and health-related quality of life among adolescents and young adults. Furthermore, Gattuso et al. (2006) examined rates of refusal for participtation in pediatric oncology research studies and highlighted that eligible male participants had consistently higher rates of refusal in comparison to females. Consequently, it is important to consider that research related to health and illness experiences are biased towards females, and the experiences of males are underrepresented. In the future, further research should focus on exploring male siblings' experiences and perceived needs for psychosocial support throughout the pediatric cancer trajectory. Ultimately, this will help identify commonalities and differences in male siblings' experiences, as well as their unique needs for psychosocial support.

Another limitation of the study is that the majority of the participants' siblings were treated for pediatric cancer at the same hospital in Toronto, Ontario (n=9). While this hospital is the largest pediatric oncology centre in Canada, there may be differences in the experiences and provision of psychosocial support for siblings at different pediatric oncology centres outside of Ontario. Finally, a limitation of the study is that most of the participants identified their ethnicity as white (n=7) and some ethnicities were not represented in this study. Therefore, it was difficult to completely explore how potential ethnic and cultural influences impact siblings' experiences and needs for psychosocial support, which would be important to examine further in the future.

Implications on Practice, Policy, Education and Research

Implications on Practice

The study findings raise critical implications for clinical practice for nurses and other healthcare professionals that work in pediatric oncology healthcare settings. The participants in the study highlighted the significant gaps in the provision of psychosocial support from healthcare professionals. They also emphasized the need for increased psychosocial support from healthcare professionals and provided several potential forms of support that can be provided. Therefore, nurses and other healthcare professionals need to increase their knowledge, skills and comfort with providing psychosocial support to siblings, integrate this into their daily clinical practice, and advocate for standardized and evidence-based support for siblings.

Previous literature highlights that pediatric oncology nurses experience challenges with providing siblings with psychosocial support due to a lack of understanding of their needs and limited access to standardized psychosocial screening tools and interventions (Gerhardt et al., 2015; MacKay & Gregory, 2011). This study provides nurses and other healthcare professionals with insights into siblings' current experiences with support in healthcare settings, as well as their perceived needs for ongoing support. This new knowledge and understanding can be used to inform and implement appropriate psychosocial screening tools and interventions. These findings can also provide the opportunity to clarify the role of various interprofessional healthcare providers in the psychosocial care of siblings. Ultimately, this may reduce emotional distress and promote adjustment for siblings throughout the pediatric cancer trajectory.

Implications on Policy

The study findings provide important implications for policy focused on psychosocial support for siblings of children with cancer. Evidence-based standards and guidelines for psychosocial screening and provision of support for siblings of children with cancer need to be established and outlined. This will help to ensure that psychosocial care for siblings is provided in a timely, consistent, and comprehensive manner. To support the development and implementation of these policies, institutions should have adequate psychosocial staff and engagement should be encouraged from various members of the interprofessional healthcare team including nurses, physicians, social workers, and child life specialists. The psychosocial care that is provided to siblings should be documented to promote collaboration, as well as ongoing assessment and follow-up.

The majority of pediatric oncology centres and children's hospitals within Canada provide guidelines and policies to promote the delivery of family-centred care within their organizations. However, the findings of this study reflect that all family members may not be appropriately engaged in this model of care particularly siblings. Ultimately, this highlights the need to evaluate the current provision of family-centred care within healthcare settings and develop policies and guidelines to ensure that siblings are considered and included in this model.

In addition, the participants highlighted strict visitor policies within healthcare settings that limited their ability to be involved and spend time with their families in the hospital and ultimately contributed to their feelings of isolation throughout the pediatric cancer trajectory. These hospital policies have become more strict and inflexible due to the COVID-19 pandemic which has further limited siblings' ability to visit the hospital. The hospital policies that limit siblings' presence in healthcare settings should be considered and evaluated to assess the impact that it has on them and their ability to receive adequate psychosocial support. In summary, various hospital policies can be assessed and implemented to support the provision of psychosocial support and the involvement of siblings in healthcare settings.

Implications for Education

The current study provides several recommendations for education for nurses and other healthcare professionals that work in pediatric oncology healthcare settings. The study findings highlight the unique stressors and challenges that siblings of children with cancer experience and the significant gaps in the psychosocial support provided to them from a healthcare perspective. Previous literature also outlines that limitations in knowledge and skills related to siblings' psychosocial needs is a barrier for pediatric oncology nurses in providing appropriate support. Therefore, siblings' psychosocial healthcare needs and guidelines for providing support must become a vital concept that is integrated into education and training for pediatric oncology nurses. This education should be mandatory for new and experienced nurses, as well as all other members of the interprofessional healthcare team.

Furthermore, continuing educational opportunities should be available for nurses and other healthcare professionals that are focused on the provision of family-centred care with a specific emphasis on siblings. Many of the current existing educational opportunities related to family-centred care are concentrated on the care of the patient and parents, with less of a focus on siblings. As a result, current family-centred care training programs can be modified to include the psychosocial needs of siblings, as well as the different ways in which they can be supported. Finally, on an individual level, nurses and other healthcare professionals need to recognize the gaps in their knowledge and skills in providing psychosocial care to siblings of children with cancer. In addition, they should seek self-directed learning and educational opportunities to address these gaps in their clinical practice. Pediatric oncology centres should promote continual and self-directed learning of their staff to promote the provision of family-centred care.

Implications for Research

Various implications and recommendations for future research arose from the current study. First, this study explored the experiences and perspectives of female siblings of children with cancer related to receiving psychosocial support. However, further research is needed to explore the perceptions and needs of male siblings of children with cancer. Furthermore, there is a significant need for additional research on the effectiveness of supportive services for siblings of children with cancer including psychosocial screening tools and interventions. The participants highlighted several potential interventions and methods of support that may have been helpful for them throughout the pediatric cancer trajectory. These insights can be used to inform the development of assessments and interventions. This research will help establish evidence-based standards of care for siblings which will encourage the provision of more consistent and comprehensive services for this population.

Moreover, the majority of existing studies that explore the experiences of siblings of children with cancer have applied qualitative methodology. While this provides in-depth and insightful information, future research should focus on applying more quantitative and mixed methods designs. Finally, future research should further explore siblings’ unique experiences and psychosocial healthcare needs based on sociodemographic factors such as ethnicity and socioeconomic status. This would help inform potential psychosocial risk factors for siblings, as well as screening tools and interventions.

Conclusion

This qualitative study explored the different ways in which siblings of children with cancer perceive their psychosocial needs were addressed throughout the illness trajectory. The findings highlight that siblings have unmet psychosocial needs and limited support is provided to them from a healthcare perspective. Thus, it is important to establish evidence-based and standardized psychosocial care for siblings of children with cancer to provide comprehensive family-centred care. In summary, the findings from this study can address the current gaps in the provision of psychosocial support through clinical practice, policy, education, and research.

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Appendix A

Search Strategy for Literature Review

Key Search Terms
“sibling*” AND “pediatric cancer*” OR “childhood cancer*” AND “psychosocial” OR “support*” AND “experience*” OR “impact*”

Inclusion Criteria
• Published in English
• Published from 2000 to 2021
• Focused on siblings’ experiences with receiving psychosocial support
• Includes participants that are between the ages of 0 to 18 years

Database	Search Results
CINAHL	1 result
PubMed	67 results
Embase	35 results
Medline	10 results
Google Scholar	1200 results

A total of 174 articles were initially screened. Duplicate and irrelevant articles were excluded. From this search, 27 citations were selected for the literature review.

Appendix B

Characteristics of the Included Studies in the Literature Review

Authors/Year	Study Design	Ages of Participants	Objective	Findings	Implications/Limitations
Quantitative Reviews					
Alderfer et al. (2003)	78 siblings - Cross-sectional study	10 – 20 years old Mean age = 14.2 years	• To investigate whether adolescent siblings of childhood cancer survivors experience posttraumatic stress (PTS). • The study was conducted 1 to 10 years after cancer treatment.	• Nearly half (49%) of the sample reported mild PTS and 32% reported moderate to severe PTS • Siblings reported more PTS symptoms than a reference group of nonaffected teens	• Levels of PTS are elevated for siblings of pediatric cancer survivors • It is important to develop interventions to ameliorate or prevent PTS symptoms • Limitations include that the study used self-reported questionnaires rather than structured clinical interviews (gold standard for assessing PTS)
Alderfer et al. (2014)	87 siblings and 256 demographically matched peers - Case-control study design	8 – 16 years old	• To examine social functioning among siblings of children with cancer.	• No differences between siblings and comparisons for social reputation, number of friendships, reciprocated friendships or peer acceptance • Mothers reported less involvement in activities and poorer school performance for siblings than comparisons	• Peer relationships of siblings of children with cancer are similar to their classmates • Siblings experience small decrements in activity participation and school performance • Limitations include that findings may not be generalizable because the

					sample did not include in variations in demographic characteristics (e.g. ethnicity, socioeconomic status)
Barrera et al. (2020)	122 caregivers, 36 patients, 25 siblings - Randomized controlled trial	Mean age of siblings = 10.74 years old	• To evaluate if an intervention (providing psychosocial risk information to the patient’s treatment team) would result in decreased depression and anxiety in caregivers, patients and siblings	• No significant difference in caregiver depression and anxiety symptoms between intervention and control group • Inconclusive results for patients and siblings	• One of the first randomized controlled trials to examine the impact of a psychosocial screening intervention • Limitations include that there was a small sample size
Erker et al. (2018)	105 siblings and 160 patients - Cross-sectional study design	8 – 17 years old	• To assess and compare children’s experiences of family relationships in patients receiving active therapy, those who have completed therapy and siblings • Siblings of patients that were on-therapy and off-therapy included	• Siblings of patients on-therapy had worse family relationships than patients on-therapy • Family relationships of patients off-therapy did not differ from their siblings or patients on-therapy • Siblings family relationships were impaired when their own depression increased	• Family relationships change during cancer therapy for siblings of children with cancer • Increased psychosocial resources for patients and siblings of children with cancer is warranted • Limitations include that the study did not measure family relationships over time (prospective/longitudinal studies needed)

Kaplan et al. (2013)	125 siblings - Cross-sectional study design	8 – 17 years old	• To explore cancer-related posttraumatic stress reactions in siblings of children with cancer • Study completed 4 to 38 months after cancer diagnosis	• More than half of the sample (60%) scored in the moderate to severe range for PT and 22% fulfilled full criteria for PTSD • Approximately 75% reported "feeling upset when you think about or hear about the cancer" and "trying not to think about, talk about, or have feelings about the cancer"	• Siblings of children with cancer experience cancer-related PTS reactions and greater attention should be paid to ameliorating their cancer-related distress with evidence-based interventions • Limitations include that all of the measures used were questionnaires whereas the gold standard for assessing PTSD is a structured clinical interview
Prchal et al. (2012)	30 siblings - Randomized controlled trial	6 – 17 years old	• To evaluate the effectiveness of a two-session psychological intervention for siblings of newly diagnosed pediatric cancer patients • The intervention provided to siblings in the first 2 months after diagnosis included medical information, promotion of coping skills and psychoeducational booklet for parents	• At follow-up, siblings in the intervention group showed better psychological well-being, had better medical knowledge, and reported receiving social support from more people • The intervention had no effects on PTS symptoms and anxiety	• A two-session sibling intervention can improve siblings' adjustment, particularly psychological well-being, in the early stage after a cancer diagnosis • Limitations include that recruitment was challenging as the intervention was for the early time period after diagnosis and a subgroup analyses was not conducted

van Warmerdam et al. (2020)	7897 siblings and 4773 mothers - Matched cohort study	N/A	• To examine the long-term mental health of mothers and siblings of children with cancer • The study included mothers and siblings of children diagnosed between 1998 and 2014	• Mothers and siblings experience elevated rates of mental health-related outpatient visits • The risk of severe psychiatric events was not increased in either cohort • Mother and sibling demographic factors associated with increased risk of adverse mental health included younger maternal age, low socioeconomic status, rural residence	• Both mothers and siblings experience elevated and prolonged need for mental-health related health care as compared with the general population • Increase psychosocial support for family members during and after cancer therapy is warranted
Qualitative Reviews					
Brosnan et al. (2021)	27 psychosocial care providers - Descriptive study	N/A	• To examine barriers to supporting siblings at the health care system, oncology center and family levels from the perspective of psychosocial care providers	• There are barriers to providing psychosocial care to siblings at multiple levels (health care system, oncology center, family) • Siblings are underprioritized and there is limited utilization of existing services which results in a lack of support	• Addressing healthcare system and oncology center barriers to implementing sibling assessment and support may important potential targets for interventions to help ensure siblings receive needed psychosocial assessment and support • A limitation is that participants' disciplines and training may have influenced both their perceptions of barriers

D’Urso et al. (2017)	6 siblings - Descriptive study (phenomenology)	12 – 18 years old	• To explore the experiences of siblings of children with cancer using semi-structured interviews • The study was conducted at least 6 months and no more than 5 years post diagnosis	• Siblings experience a range of difficult emotions throughout the cancer trajectory including both positive and negative • Negative emotions include shock, fear, uncertainty, guilt, anger, helplessness, jealousy, sadness • Positive changes include increased empathy and resilience, improved family relationships, disrupted routine, increased responsibility and perceived changes in the ill child	• Siblings experience significant changes in their lives when a child is diagnosed with and treated for cancer • Additional support is required to facilitate positive psychosocial adjustment
Gregory et al. (2022)	10 siblings (6 non-bereaved, 4 bereaved) - Descriptive study	8 – 16 years old	• To examine the perceptions and experiences of siblings of children with cancer who attended a peer support camp	• Four themes emerged: social connection (feeling of belonging, mentorship and expressing feelings), personal growth, identity and freedom to have fun and relax	• This study provides new insights into siblings’ experiences and outcomes associated with participation in a peer support camp • Findings can be used to inform future interventions • Limitations include the small sample size which may not be representative of all siblings and it did not address race, ethnicity, or socioeconomic status

Long et al. (2018)	29 parents	18 years or younger	• To assess a sibling-specific screening instrument that assesses siblings' psychosocial risk at diagnosis and several months thereafter	• Parents recommended changes to improve the screening format, developmental sensitivity, and content	• Psychosocial screening for siblings is important but infrequently implemented • Validated, sibling-specific screeners will facilitate identification of siblings with elevated psychosocial risk
Pariseau et al. (2020)	13 parents and 17 siblings - Descriptive study	8 – 17 years old	• Characterizes siblings' and parents' perceptions of parents' awareness of siblings' psychosocial functioning and describes how family functioning influences parental awareness	• Parental awareness was hindered by siblings' reluctance to communicate their feelings to parents, siblings' hesitancy to rely on parents for emotional support and parents not consistently asking about siblings' emotions • High parental awareness was facilitated by close relationships pre-diagnosis, consistent communication and affective problem-solving	• Findings provide a comprehensive understanding of the family processes underlying parental awareness and inform best practices for sibling assessment and support • Study sample lacks diversity in terms of race and geographic location
Prchal & Landolt (2012)	7 siblings - Descriptive study (phenomenology)	11 – 18 years old	• To describe the experiences of siblings of pediatric cancer patients in different areas of life in the first half-year after cancer diagnosis • The study was conducted between 6	• In all areas of life, siblings reported difficulties such as absence of parents, dealing with the ill child's suffering or impaired school achievement • Siblings described important resources such as peer relationship, helpful coping	• The cancer experience impacts siblings in all areas of their lives • These findings can be used to improve sibling support and develop standardized sibling interventions • The study allowed siblings to report their experiences

			months to 2 years after diagnosis	strategies and increased family cohesion	rather than parents/healthcare professionals • Limitations include that the sample size is small so findings may not be generalizable
Sidhu et al. (2005)	31 families (14 siblings) - Descriptive study	4 – 16 years old	• To examine parent perceptions of the needs of siblings of children with cancer using focus groups	• Parents reported a loss of maintaining a sense of control, loss of security, loss of childhood for siblings • Parents noted the following behavioural challenges including anxiety, attention seeking, academic issues, and somatic complaints	• Parents provide key insights on the impact of cancer on siblings • Limitations include that researchers were unable to generalize findings from the study
Toft et al. (2019)	7 siblings - Descriptive study (phenomenology)	15 – 25 years old	• To explore experiences related to interpersonal relationships following a cancer diagnosis in a sibling • The study was conducted 5 to 18 years after cancer diagnosis	• Two categories portrayed the experiences related to interpersonal relationships following a cancer diagnosis including: *feeling excluded while wanting to maintain a relationship with their ill sibling* and *feeling stigmatized and exposed in social contexts while needing an allowing space to talk about their experiences*	• Siblings of children with cancer experience emotional difficulties and are at risk of experiencing psychosocial distress

Woodgate (2006)	30 siblings - Longitudinal study (interpretive interactionism)	6 – 21 years old	• To understand how childhood cancer is experienced by siblings using open-ended individual interviews • The study was conducted during cancer treatment	• Cancer is experiences as a different way of being within their family and involved siblings undergoing a family way of life and a loss of self within the family	• Siblings experience significant changes in family functioning when a child is diagnosed with cancer • These changes can result in psychosocial distress and further support is required
Mixed Method Reviews					
Sjoberg et al. (2018)	14 siblings - semi-structued interview and questionnaire	5 – 13 years old	• To examine the impact of the Ontario Oncology Nurse School Visitation Program on the well-being and school adjustment of siblings of pediatric cancer patients	• School attendance showed a reduction of days missed • No significant impact on quality of life • Positive feedback from siblings on increased awareness and support from peers	• Siblings and their peers benefit from understanding more about cancer • A class visit is one intervention that has a positive impact on siblings • There are other social groups of peers that may benefit from this such as hockey and soccer teams or a group of close friends
Systematic and Integrative Reviews					
Alderfer et al. (2010)	65 studies	Preschool – adult	• To promote a broader understanding of the psychosocial impact of pediatric cancer on siblings	• Siblings of children with cancer do not experience elevated mean rates of psychiatric disorders but a significant subset experiences post-traumatic stress symptoms, negative emotional reactions, and	• Methodological limitations among research regarding siblings of children with cancer • Conclusions of quantitative and qualitative studies differ

				poor quality of life in emotional, family and social domains - School difficulties evident within 2 years of diagnosis - Qualitative studies reveal family-level themes such as loss of attention and status as well as positive outcomes including increased sibling maturity and empathy	- Siblings of children with cancer are a psychosocially at-risk group and should be provided with appropriate supportive services
Gerhardt et al. (2015)	125 studies	4 – 26 years old	- To provide evidence for supporting siblings as a standard of care in pediatric oncology	- Descriptive studies indicate family disruption and added stressors in the home increase risk for sibling difficulties - Descriptive studies and guidelines for care suggest communication and involvement are important for siblings - Controlled longitudinal research suggests risk for psychopathology is highest early in treatment and in the first 2 years after a child's death - Qualitative and quantitative studies demonstrate sibling resilience - Small number of intervention studies provide preliminary	- Siblings of children with cancer are a psychosocially at-risk group and should be provided with appropriate supportive services - Parents and healthcare professionals should be advised about ways to anticipate and meet siblings' needs

				support for evidence-based practice	
Hancock (2011)			• To review literature on camps as an intervention to facilitate coping in siblings of children with cancer	• The literature has demonstrated that camps have a positive impact and offer siblings a supportive peer environment • Camp provides a supportive peer environment to encourage discussion between and participation in activities that improve knowledge, social confidence, and self-esteem	• All siblings of children with cancer are at risk for difficulty with coping and adapting to this change in the family's life • Summer or weekend camps can be a therapeutic intervention for both patients and siblings to facilitate camping • Nurses can support sibling camps by recommending them to families
Kazak et al. (2015)	149 studies	6-19 years old	• To provide evidence for psychosocial assessment as a standard of care in pediatric oncology for patients and families	• The evidence for psychosocial distress among patients and families is strong and consistent across multiple areas related to family functioning during cancer treatment • Several assessment tools recommended for use including the psychosocial assessment tool (PAT) or distress thermometer tool (DT)	• Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial healthcare needs
Kelada et al. (2020)	19 studies	19 years or younger	• To understand the evidence-based benefits of camps for children with cancer and their families	• Camps for children and families provide the opportunity to reconnect, social support and fun/respite	• Literature is limited by small sample sizes and lack of longitudinal and controlled designs

					• There is a positive short-term impact of camps but future research should assess the long-term impact of camps
Long et al. (2018)	102 studies	25 years or younger	• To examine psychosocial functioning and risk factors among siblings of children with cancer	• Mean levels of anxiety, depression and general adjustment are similar across siblings and comparisons but symptoms of cancer-related posttraumatic stress are prevalent • School-aged siblings display poorer academic functioning and more absenteeism but similar peer relationships when compared to peers • Adult siblings engage in higher levels of risky health behaviours and poorer health outcomes than comparisons • Risk factors for poor sibling adjustment include lower social support, poorer family functioning, lower income, non-white race, and shorter time since diagnosis (inconsistent findings) • Qualitative themes include siblings' maturity, compassion and autonomy but also strong negative emotions including	• Methodological limitations among the studies • The literature indicates a strong need for sibling support • Clinical recommendations include identifying at-risk siblings and developing interventions to facilitate family communication and increase siblings' social support, cancer-related knowledge and treatment involvement

				uncertainty, family disruptions, limited parental support, school problems, altered friendships and unmet needs	
Mooney-Doyle et al. (2021)	20 studies	6 – 18 years old	• To describe outcomes and general characteristics o effective interventions intended to support sibling well-being and psychosocial health in pediatric oncology	• Most interventions were theory-based using a group format with multiple sessions • The most frequently assessed outcomes were depression, anxiety, posttraumatic stress symptoms and health-related quality of life	• Understanding outcomes and characteristics of effective interventions is important to translate sibling support interventions into standard practice • It is important to target high-risk siblings, partner with community resources and incorporate family into sibling support
Prchal & Landolt (2009)	14 studies	6 – 20 years old	• To review existing reports of evaluated psychological interventions with siblings of pediatric cancer patients	• 11 different sibling interventions were reviewed including one individual intervention, three camps, and seven groups • Objectives of interventions concentrated on enhancing siblings' coping and improving their medical knowledge • Findings showed significant improvements in siblings' depression symptomatology, medical knowledge and health-related quality of life	• There is tentative evidence that psychological interventions with siblings of childhood cancer patients can effectively reduce psychological maladjustment and improve medical knowledge about cancer • However, the number of studies is small and the studies have several methodological limitations

				- Findings inconsistent regarding anxiety, behavioural problems, social adjustment, self-esteem and posttraumatic stress symptoms	
Wawrzynksi et al. (2021)	43 studies	27 years or younger	- To examine how social support has been conceptualized, operationalized and studied among siblings of children with cancer	- There are several types of support that are needed by siblings - Greater levels of social support have been linked to better adaptation among siblings	- Future research is warranted to identify most beneficial types of support for siblings based on their age, developmental stage and the cancer trajectory
Zegaczewski et al. (2016)	12 studies	1 – 19 years old	- To identify factors related to the psychosocial adjustment of healthy siblings of children with cancer	- Siblings' characteristics (e.g. age and gender), perceived social support from family and summer camps, and perceived contextual factors (e.g. role overload, family adaptability) were significant factors that correlated with siblings' psychosocial adjustment	- When caring for a child with cancer, nurses must include siblings in the assessment of a family unit's adaptation to cancer distress and provide appropriate interventions to promote sibling psychosocial well-being

Appendix C

Recruitment Poster

Research Study Participants Needed

Are you a sibling of a child that was diagnosed with cancer in the past 1   years?

Would you like to share your experiences with receiving psychosocial support?

We want to hear from you!

What is psychosocial support?
Psychosocial support refers to actions and resources that address one's psychological and social needs. This can be provided by friends, family, peers, teachers, healthcare professionals and community members.

Why are we doing this study?
We are looking to understand siblings' experiences with receiving psychosocial support. This will help us improve support for siblings of children with cancer in the future.

What does this study involve?
- Complete a short demographic questionnaire
- Participate in a 6   minute interview over the phone or Zoom

If interested, please contact:
Reenu Chhokar RN, BScN
MSc Student
chhokar@mcmaster.ca

School of Nursing | McMaster University

This study has been reviewed by the Hamilton Integrated Research Ethics Board under Project # 14122 (Version 1: November 2, 2 21)

Appendix D

Recruitment Scripting

Hello, my name is Reenu Chhokar and I am a graduate student in the Master of Science in Nursing program at McMaster University. I am calling because you expressed initial interested in participating in my research study regarding your experiences as a sibling of a child with cancer.

Are you interested in hearing more about the study?

I am interested in exploring siblings' experiences with receiving psychosocial support from social and professional sources throughout pediatric cancer diagnosis, treatment and beyond. I want to better understand siblings' experiences to increase awareness about siblings' psychosocial needs and improve support for siblings in the future.

Participation is voluntary and you would be required to completed a brief questionnaire and an interview over the phone or Zoom with myself, the student researcher, for approximately one hour. I will schedule the interview for a time that is convenient for your schedule. If you are interested, a summary of the findings may be e-mailed to you ate the end of the study.

Would you be interested in participating in this study?

If yes, what dates and times would be best for you to have the interview? I am happy to provide any additional information about the study and answer any questions that you may have. If you need more time to think about your participant then you can contact me at a later time by either email or telephone.

If no, thank you so much for your time.

Appendix E

Socio-demographic Questionnaire

Participant name: ____________________

Date of interview: _____________________

1. Age: ______ years old
2. Sex: ☐ Male ☐ Female
3. What city do you currently live in? _____________________
4. What is your ethnic background?
   - ☐ Black
   - ☐ East Asian
   - ☐ Latino
   - ☐ Middle Eastern
   - ☐ South Asian
   - ☐ Southeast Asian
   - ☐ White
   - ☐ Other (please specify)
5. What is the highest level of education you have completed?
   - ☐ Elementary school
   - ☐ High school diploma
   - ☐ College degree
   - ☐ University degree
   - ☐ Graduate degree

6. What type of pediatric cancer was your sibling diagnosed with?

   ☐ Leukemia/lymphoma

   ☐ Solid tumour

   ☐ Neuro-oncology

7. How old was your sibling when he or she was diagnosed with pediatric cancer?

8. How old were you when your sibling was diagnosed with pediatric cancer?

9. What was the approximate length of your sibling’s cancer treatment?

10. When did your sibling’s cancer treatment finish? (in years)

Appendix F

Participant Interview Guide

Study Background Information

This study will be looking at your experiences with receiving support during your sibling's cancer treatment. I am interested in understanding your experiences during treatment so that nurses, doctors, and other hospital staff can have a better understanding of siblings' needs while children are getting treatment for cancer and we can find new ways to help support siblings. I appreciate you taking the time to speak with me today.

Initial Grand Tour Question

1. Can you tell me what it was like for you to have a sibling go through cancer treatment**?**

Emotional Impact

1. Can you tell me about your thoughts and feelings during your sibling's cancer treatment?
2. Can you tell me about the hard/difficult parts of your sibling's cancer treatment?
3. Can you tell me about the good/positive parts of your sibling's cancer treatment?
4. How did you handle your stress during your sibling's cancer treatment?

Family Functioning

1. Can you tell me about your relationship with your sibling during his/her cancer treatment?
2. Can you tell me about your relationships with your parents during your sibling's cancer treatment?
3. In what ways did your family provide you with support during your sibling's cancer treatment?

School Performance

1. Can you tell me about how your sibling's cancer treatment affected your life at school?

2. How did your teachers support you at school during your sibling’s cancer treatment?
3. Was there any additional support provided to you at school?

Social Relationships

1. Can you tell me about your relationships with your friends during your sibling’s cancer treatment?
2. How did you feel when your friends ask about your sibling’s cancer treatment?
3. How did your friends provide you with support during your sibling’s cancer treatment?

Hospital Experience

1. How did you feel when you were at the hospital during your sibling’s cancer treatment?
2. How did the nurses, doctors, and other staff in the hospital interact with you during your sibling’s cancer treatment?
3. Did you receive any support from staff at the hospital during your sibling’s cancer treatment? If so, who provided support and what type of support was provided?
4. What could have improved your experience in the hospital during your sibling’s cancer treatment?

Psychosocial Support

1. Do you feel that you received enough support during and after your sibling’s cancer treatment?
2. What type of support do you think would be helpful in the future for siblings during cancer treatment?
3. What type of support do you think would be helpful in the future for siblings after cancer treatment?

Conclusion

Thank you for taking the time to be part of this interview. Is there anything else you would like to talk about before the interview ends? I am going to summarize what we talked about during this interview. Please let me know if you have any feedback on this summary and feel free to clarify or expand on anything if needed.

Appendix G

Ethics Approval Letter

HiREB
Hamilton Integrated Research Ethics Board

Nov-09-2021

Project Number: 14122

Project Title: Siblings' Experiences with Psychosocial Support Throughout the Pediatric Cancer Trajectory: An Interpretive Description Research Proposal

Student Principal Investigator:

Local Principal Investigator: Dr. Diana Sherifali

We have completed our review of your study and are please to issue our final approval. You may now begin your study.

The following documents have been approved on both ethical and scientific grounds:

Document Name	Document Date	Document Version
Recruitment Scripting	Sep-26-2021	1
Research Study recruitment- RC	Nov-02-2021	1
Consent Form RC	Nov-02-2021	1
Study Key	Nov-02-2021	1
Participant Interview Guide	Nov-02-2021	1
Questionnaire	Nov-02-2021	1
Thesis Proposal - Reenu Chhokar, Nov 2021	Nov-02-2021	2

The following documents have been acknowledged:

Document Name	Document Date	Document Version
Summary of Changes	Nov-02-2021	1
tcps2_core_certificate (5)	Nov-04-2021	1

In light of the current COVID-19 pandemic, while HiREB has reviewed and approved this application, the research must be conducted in accordance with institutional and/or public health requirements.

Any changes to this study must be submitted with an Amendment Request Form before they can be implemented.

This approval is effective for 12 months from the date of this letter. Upon completion of your study please submit a **Study Completion Form**.

If you require more time to complete your study, you must request an extension in writing before this approval expires. Please submit an **Annual Review Form** with your request.

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

Good luck with your research,

Kristina Trim, PhD, RSW
Chair, HiREB Student Research Committee
McMaster University

Appendix H

Research Study Information and Consent Form

LETTER OF INFORMATION / CONSENT

Experiences with Psychosocial Support for Siblings of Children with Cancer

Investigators:

Local Principal Investigator:	**Student Investigator:**
Dr. Diana Sherifali	Reenu Chhokar, RN
School of Nursing	School of Nursing
McMaster University	McMaster University
Hamilton, ON, Canada	Hamilton, ON, Canada
(905) 525 - 9140 ext. 21435	(647) 983 - 7336
E-mail: dsherif@mcmaster.ca	E-mail: chhokar@mcmaster.ca

What am I trying to discover?

As a part of my Master of Science in Nursing degree, I am conducting a research study on the experiences of siblings of children with cancer. I am interested in exploring siblings' experiences with receiving psychosocial support from social and professional sources throughout pediatric cancer diagnosis, treatment and beyond. I would like to interview siblings of individuals that were diagnosed and treated for pediatric cancer within the past 10 years.

If you are interested, you are invited to take part in this research study that will explore siblings' experiences with receiving psychosocial support. I am trying to learn about the experiences you had as a sibling to increase awareness and improve support for siblings in the future.

What will happen during the study?

If you are interested, with your permission, I will first collect background information about you and details about your sibling's cancer diagnosis and treatment. Next, you will take part in an interview that will be approximately 1 hour in length over the phone or Zoom with myself, the researcher. The interview will consist of various questions regarding your experiences during your sibling's cancer diagnosis and treatment. Some of the questions will include:

1. *Can you tell me about the challenging or difficult aspects of your sibling’s cancer treatment?*
2. *Can you tell me about the good or positive aspects of your sibling’s cancer treatment?*
3. *Did you receive any support from staff at the hospital during your sibling’s cancer treatment? If so, who provided support and what type of support was provided?*
4. *In what ways did your family provide you with support during your sibling’s cancer treatment?*
5. *What type of support do you think would be helpful in the future for siblings during and after cancer treatment?*

We can arrange for the phone or Zoom interview based on a date and time that works best for your schedule. The interview will be audio recorded so that the responses you provide can be further analyzed. The audio recordings will be safely protected with secure passwords on a laptop that only the researcher has access to. These recordings will be transcribed word-for-word and the transcripts will be analyzed by the researcher and three other faculty members on the research team.

You have the right and are free to stop the interview at any given point and withdraw from the study if you choose to at a later time. You are not obligated to share any information you feel is too personal or that you do not feel comfortable sharing. For the purposes of ensuring the proper monitoring of the study, a member of the Hamilton Integrated Research Ethics Board may access your research data. By participating in this study, you authorize such access.

Are there any risks to doing this study?

There are minimal risks involved in participating in the study. The topic of the interview pertains to your experiences with receiving psychosocial support throughout your sibling’s cancer treatment. Some of the discussions will include challenges that you may have experienced throughout the cancer trajectory. As a result, you may recall difficult emotional events or experiences, which you may decide to share at your own discretion. If you identify a need for any additional support, I will seek to provide resources and refer you where appropriate. By participating in this study, you do not give up any rights which you may have under the law.

Are there any benefits to doing this study?

I hope that this study will help us understand more about siblings’ experiences throughout the pediatric cancer trajectory. I hope this study provides awareness about siblings’ psychosocial needs so that additional resources and interventions can be developed to support siblings throughout pediatric cancer diagnosis, treatment and beyond.

Who will know what I said or did in the study?

All audio recordings, transcripts and notes will be kept safe and secure to protect your privacy and confidentiality. Participants should not make a recording of the interviews. They will be saved only on the researcher's password protected laptop within an encrypted folder and original recordings will be deleted. All printed documents including signed consents will be stored in a locked cabinet in the supervisor's office in HSC 3N28F at McMaster University. All efforts will be made to protect both your privacy and confidentiality. Any personal contact and identifying information that you provide will be destroyed immediately after completion of the study. You will be assigned a participant identification code, which will be used in replacement of your name. In addition, any personal identifying information will not be included in transcripts or final write-ups of the findings. Transcripts and data without any identifying information may be kept for up to 5 years after the end of the study. The final write-up of findings will be published and presented as part of the researcher's thesis work and will be accessible to the public. Your participation in the study will remain anonymous to everyone aside from members of the research team including myself.

This study will use the Zoom platform to collect data, which is an externally hosted cloud-based service. A link to their privacy policy is available here https://explore.zoom.us/en/privacy/. While the Hamilton Integrated Research Ethics Board has approved using the platform to collect data for this study, there is a small risk of a privacy breach for data collected on external servers.

What if I change my mind about being in the study?

Your participation in this research study is voluntary. If you decide to be part of the study, you can withdraw for any reason and at any given time, even after signing the consent form. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data provided up until that point will be destroyed if you should request to have it removed. You can choose to not answer any questions in the survey or interview based on your comfort and preference. If you choose to withdraw from the study after the interview has been completed, you may request to have any data you provided removed from the study until approximately June 2022.

How do I find out what was learned in the study?

I expect to have the study completed by approximately August 2022. If you would like a brief summary of the results, please feel free to contact the research team and this can be provided via e-mail.

Who do I contact if I have questions about the study?

If you have any questions or need more information about the research study, please contact me by phone or e-mail:

Telephone: (647) 983 - 7336
E-mail: chhokar@mcmaster.ca

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013

CONSENT

I have read the information presentation in the letter about a study being conducted by Reenu Chhokar of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a signed copy of this form. I agree to participate in the study.

Consent form explained over telephone by:

Name and Role (Printed)	Signature	Date

Verbal consent obtained from:

Name of Participant (Printed)	Date

The following to be completed over e-mail with electronic signature and returned to chhokar@mcmaster.ca for paper documentation.

Name of Participant (Printed)	Signature	Date

If you are not able to sign the consent form electronically, a mailing address is required below so that a printed copy of the consent along with a pre-stamped envelope can be mailed to you. You are required to review and sign the consent form, and mail it back at your earliest convenience.

Mailing address: ______________________________
____

Appendix I

Characteristics of Participant and Sibling

Participant Characteristics							Sibling’s Cancer Characteristics		
Participant	Current Age (in years)	Age at Sibling’s Diagnosis (in years)	Time Since Completion of Sibling’s Treatment (in years)	Location of Residence	Ethnicity	Highest Level of Education	Sibling’s Type of Cancer	Age of Sibling at Diagnosis (in years)	Length of Treatment
1 (CS)	16	4	9	Oshawa	White	Elementary	Leukemia	2	3.5 years
2 (AT)	21	11	9	Waterloo	White	College	Brain Tumour	12	2 years
3 (EB)	18	16	1	Kitchener	White	High School	Lymphoma	14	4 months
4 (AR)	21	15	6	Brampton	South Asian	High School	Solid Tumour	13	4 months
5 (EP)	23	15	9	Orangeville	White	College	Solid Tumour	12	7 months
6 (SC)	23	18	4	Toronto	White	Graduate	Leukemia	16	2.5 years

7 (BS)	20	18	1.5	Woodbridge	White	High School	Lymphoma	15	6 months
8 (JL)	20	11	8	Brampton	South Asian	Elementary	Lymphoma	16	7 months
9 (LI)	16	14	1	Mississauga	Middle Eastern	Elementary	Solid Tumour	17	1 year
10 (OF)	16	4	10	Whitby	White	Elementary	Leukemia	2	2.5 years