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The Forgotten Children

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Abstract

The “forgotten children” of pediatric cancer are the siblings. There is a dearth of literature published on the effects of cancer on the siblings’ psychosocial state. Despite significant improvements made in the survival of pediatric cancer patients, the psychosocial health of the siblings remains the same. The siblings’ need for support and understanding continue to go unnoticed. The aim of this chapter is to shed light on the roles siblings play in the pediatric cancer trajectory, as well as to recognize the emotional and psychological toll they endure through the experience of diagnosis, treatment, survival, and bereavement as the “forgotten children.”

Keywords: forgotten children, siblings of children with cancer, pediatric cancer, psychosocial, siblings cancer trajectory

1. Introduction

“I was the one that had to convince my parents to let Stanley stop all curative treatment. It was traumatic. To feel like you’re giving up, but obligated to do what your dying brother asks, and to realize that his time was up. It wasn’t the palliative service or his primary oncologist’s job to do it. It was my job. I was the only one that could get through to our parents, and ‘til this day I still remember... telling our parents that it’s time to let go.”

The three common themes of siblings of childhood cancer include changing lives, intense feelings, and unmet needs [1]. The sibling bond is one of the most powerful and lengthy connections across a lifetime [2]. It is a source of unconditional love mixed with rivalry. Siblings shape each other’s identity. Thus, understanding how pediatric cancer can affect healthy siblings is fundamental to the patient’s psychosocial care. The siblings of children with cancer are often missed or neglected and known as the “forgotten children” [3–5].

In the late 1980s, the emotional disorders in siblings of children with chronic illnesses were a new focus in the literature [4]. Following these studies were reports focusing specifically on siblings of pediatric cancer patients. Carpenter et al. [6] designed one of the earlier studies to utilize camping programs to address and investigate how siblings of children with cancer were feeling. In 1999, guidelines were established by the International Society of Pediatric Oncology (SIOP) working committee on psychosocial issues in pediatric oncology to provide assistance to siblings of children with cancer [7]. The guidelines addressed different domains of cancer trajectory such as diagnosis, treatment, relapse, and completion of treatment. The authors hoped to involve siblings of children with cancer throughout their siblings' experiences with cancer [7]. However, two decades later, many of these issues they sought to address, such as the feelings of isolation, lack of involvement, and lack of understanding, continue to exist [2].

Pediatric cancer is a disparate illness experience from adult cancer and elicits different approaches in families. The burdens of pediatric cancer include the long-term psychosocial effects, compromised social well-being on the child and the family, chronic medical conditions, and the mental and financial drain upon the families [8]. The initial diagnosis of childhood cancer brings a significant level of distress to the entire family, with the death of a child as the most traumatic experience a family suffers [2].

Caring for a child with cancer is extremely demanding and stressful. Due to the intimate and personal emotional connections of family caregivers, the burdens they face are unequivocally different than those faced by pediatric oncologists or the patient. In addition, family caregivers often unconsciously share the unyielding burden of cancer with the ill child. Throughout treatment, the focus inevitably is on the ill child, leaving the siblings in a vulnerable position [2]. Published literature remains scarce on the psychosocial distress of siblings. These circumstances highlight the need to address pediatric cancer through the siblings' perspective.

2. Body

2.1. Diagnosis

"Seeing him there made me think, 'Why is it him? Why is it not me?' [9]."

From the moment the diagnosis is given, until their death, siblings of children with cancer are unmoored. Cancer affects patients and families both emotionally and physically [10]. From the time of diagnosis to treatment, survivorship, recurrence, and palliation, the incidence of patient's emotional distress ranges from 35% to 45% [11–13]. Psychological distress has become the "sixth vital sign" in cancer care; however, there is little existing research focusing on the "sixth vital sign" of the siblings [10].

Family dynamic is always disrupted when a child is diagnosed with cancer. During diagnosis, families are hurled into chaos and haunted by complex medical language, life-or-death decisions, and emergency admissions of unknown duration [8]. Parents face loss of employment, divorce/separation, relocation of home, and often decide not to have more children [14]. Siblings

become overwhelmed with the lack of support and burden of the unknown. Regardless of age, siblings are often forced to take on roles that exceed their maturity level. They are expected to take on adult responsibilities and decision-making roles, such as caring for the family, becoming financially independent, and making informed medical decisions for the ill sibling [15]. Siblings may also act as the mediator between parents who may disagree about treatment or otherwise face marital difficulties. Ultimately, these myriad roles may lead to intrusive thoughts and conflicting emotions such as anger, jealousy, fear, loneliness, or guilt [16].

“It was exhausting, to say the least, to try to live a normal life. To continue to go to my classes pretending that everything was okay, while deep down inside everything was crumbling apart. Stanley just got diagnosed with cancer. I had to make sure my parents were mentally and emotionally stable. I had to make sure I was there for Stanley, my parents and my younger brother. I was trying my best to hold everything together. Ironically, everything was falling apart, yet no one could tell from the outside.”

2.1.1. Isolation

The “forgotten children” are isolated from support systems both inside and outside the family [3–5]. The siblings may become self-centered, lonely, and envious of diverted parental attention. Their distress stems from the changes in family dynamics and routine; concerns over the cause and outcome of the illness; observing their sibling’s suffering; and feelings of unworthiness, guilt, anger, sadness, and rejection [17–21]. Compared with siblings of children with other chronic illnesses, siblings of children with cancer endure more emotional distress and adaptive difficulties [22].

The difference between patient and caregiver psychological distress varies over time [23]. There is significantly more distress on the caregiver when the patient is receiving treatment initially. However, 1–2 months after initiating treatment, patients report more distress than their caregivers [23]. During their treatment course, siblings experience progressive physical and emotional demands, while the healthcare team tends to the patient. However, as time progresses, the psychological distress between the patient and the siblings becomes the same. SIOP recommends that early intervention with siblings should be implemented to prevent the initial development of psychological distress [7, 23].

“I remember Stanley was brought to the ED once due to shortness of breath. I got a call from my mom yelling that I need to be there immediately. That night felt like an eternity. I thought he was going to die. I didn’t want to let him go, and I wasn’t ready. It happened so quickly. Ever since then, I worry if every day is the last day for him.”

The lack of attention to the siblings is shown in the discrepancy between survivor-parent and sibling-parent reports of health-related quality of life (HRQL) [24]. Survivors reported higher HRQL than parent-proxy reports, whereas siblings reported lower HRQL than parent-proxy reports, suggesting that parents often see their child who survived cancer as doing worse than their child without a history of cancer, although both the survivor and sibling report similar HRQL [24]. This discrepancy between parents’ report and siblings’ own report of their physical, emotion, and social well-being reflects on the inherent parental bias that siblings are always “fine,” thereby requiring less attention than their sick child [24].

Children need to develop competencies across a number of areas as they grow. Yet siblings of children with cancer are often limited to their engagement in daily activities, such as leisure and peer relationships. Infants and toddlers are most at risk for behavioral or emotional problems as they interpret the changes in the family as rejection [25]. Many younger siblings (age, 7–11) have impaired emotional/social and decreased quality of life even 2 years after the cancer diagnosis. Others have reported that adolescent siblings appear to be more at risk for adjustment difficulties [26].

Guggemos et al. [27] compared 14 siblings of children diagnosed with cancer with matched control group of 18 children age 6–12 and discovered that 2 weeks after the cancer diagnosis, siblings of children with cancer displayed more guilt or shame, avoided displaying interpersonal conflicts, showed problems of dysregulation, and had significantly more elements of disruptions, destruction and themes of dissociation. The well siblings have a tendency to manipulate and control the situation and the interviewer by changing the rules of play, which reflects their confusion and fear of losing control over the course of the story [27]. It is suggested that shortly after diagnosis, siblings showed clear reactions of intrapsychic adjustment that may be prognostic for the later development of mental illness [27]. All siblings described a sense of shock, fear, uncertainty, and loneliness following the diagnosis of cancer [9].

“I started drinking and partying but never got in trouble. I would be blackout drunk and driving home... So there, I think, I wanted somebody to ask me, ‘How are you doing?’ but nobody ever did [15].”

2.2. Treatment phase

Through being a sibling-caregiver, siblings have been reported to develop unique ways of being in the world, consisting of three themes revolving around the family: committing to keeping the family together, being present, and enduring sadness [28]. One of the most common experiences that siblings have during treatment is the disintegration of their normal life routine. The continual shift of family’s focus to the child with cancer forces the healthy siblings to experience chaos and disorder in their personal and family life [29].

During the treatment phase, siblings often undergo an emotional roller coaster, experiencing a mixture of positive and negative emotions: the initial feelings of fear and uncertainty continue to linger, their lives revolve around their siblings’ suffering, and family life remains in limbo [9].

“Her [warning sign] is temperatures and infections. We always have a bag packed. We are always prepared to leave [9].”

“I don’t plan anything; I don’t; I haven’t for years. We go from day to day- that’s the only way I can make it work. If I plan for anything further than 2–3 days in advance, it doesn’t work. It never seems to work, and I just don’t bother anymore [30].”

During treatment, siblings often have inadequate information about details of the cancer. The family may withhold information due to concerns of sibling’s young age and their own limited understanding [29]. Younger siblings (6–10 years old) might not comprehend the gravity of the disease until they witness the alopecia, fatigue, weight loss, and other physical changes of their siblings [29]. These siblings can be emotionally trapped, and their peers are too young

or naïve to understand cancer and death. Eventually, the siblings cultivate inexpressible sentiments, and end up internalizing the negative emotions.

A study by Prchal and Landolt [31] showed that at school, siblings are frequently bombarded with questions regarding the ill child's condition and diagnosis from their teachers and classmates. Siblings ultimately preferred to volunteer the information about their ill sibling's condition instead of being forced to report. Many siblings put up a facade of normalcy to avoid discussing their sibling's condition and to avoid pity, which may make them uncomfortable.

"Well, everyone at school came to me and asked how my brother was doing. Even the teachers kept asking. And after a while I thought, why do they always have to come and ask me? [31]"

"Eventually, I started lying to the question 'how many siblings do you have?' just to avoid discussing the fact that my brother has cancer. I hate that question and I hate having to talk about Stanley's cancer. I hate anticipating the sympathetic stares just because Stanley has cancer. Not a lot of people knew Stanley had cancer. I was living a double life."

Older siblings (11–18 years old) may be able to look after their brother or sister with sympathy [29]. However, they may also experience learning difficulties at school and have diminished peer interactions [29]. Siblings may also experience a mix of empathy, worry, anger, jealousy, and a loss of self-esteem [29]. Despite these difficulties, several studies have shown that the "forgotten children" may transcend the chaos [29], reporting strengthened relationships with their ill brother/sister, deep appreciation for time spent together, a desire to do more together whenever possible, and they continue to uphold a positive attitude when assisting with family matters [9, 29]. Siblings become more mature and sensible, independent, and able to help with family routines and household duties [29]. They develop an impeccable sense of resilience, sympathy, and love for others [29]. Many siblings reconstruct their roles as the sick brother's or sister's protector, constantly facing unpleasant situations with an optimistic outlook and making efforts to reconstruct the family order [29]. They learn that "being present" was essential to their peace of mind [28]. They balance solitude and abandonment with a need for belonging and intimacy in the family [29]. Maintaining family cohesiveness becomes the focus during the treatment phase.

2.3. Survivorship

With improved survival, late adverse outcomes of treatment have become more prevalent, posing a new challenge for the family caregivers [32]. As patients gradually transition into survivorship, the roles and demands of caregivers change [33]. The early transition can be uncertain and overwhelm families with a sense of uncertainty about the future [33]. The family may ruminate on the thought of recurrence or a secondary malignancy. Unfortunately, studies on sibling caregivers in these transitional periods have not been done.

During the course of cancer, siblings center activities around their ill sibling. They relinquish valued personal activities, relationships, and opportunities. Once treatment is over, some siblings have an extremely difficult time restoring normalcy. Past relationships may no longer exist; friends, social support, and opportunities may have moved on [33]. Siblings have a strong desire to reintegrate back to a normal life but often end up establishing a new normal instead.

In contrast to the transition period, studies have been done on sibling caregivers after treatment completion. In 2015, Guggemos et al. [27] reported that siblings of children with cancer at the end of treatment continue to display dysregulative behaviors and continue to remain at risk. Several studies have reported that siblings of young cancer survivors have more negative psychological distress (e.g., fear, worry, anger), more posttraumatic stress, and poorer quality of life compared to controls [34, 35]. In contrast, a 1995 study of 60 siblings of cancer survivors measuring psychosocial adjustment found that after treatment, siblings adjusted well with no major differences in psychosocial functioning compared to peers with healthy siblings [4, 36, 37]. They hypothesized that after treatment, siblings are able to distance themselves from the cancer experience, whereas survivors continue to confront the disease [4].

2.3.1. Posttraumatic growth

It has been theorized that after the traumatic experience with cancer, individuals will achieve posttraumatic growth (PTG). PTG is defined as developing resilience from a previous trauma, perceiving benefits from it and developing beyond the original level of psychological functioning [38]. Siblings have been reported to experience less PTG than parents but did experience similar levels of PTG to the survivors [39]. Older siblings were found to utilize more active coping strategies such as actively seeking social support [39]. The longer it had been since the original cancer diagnosis, the less avoidant coping strategies and more positive life satisfaction were present [39]. PTG after cancer experience stimulates the development of five themes, making sense of cancer experience, appreciation of life, greater self-knowledge, positive attitude toward family, and a desire to pay back society [40]. The experience of being a part of their siblings' cancer experience triggers an existential challenge of life, which leads to a search for meaning or purpose to life. Ultimately, siblings may make up their own meaning in order to resolve or make sense of the tragedy [40]. They may live by the *carpe diem* philosophy, living more consciously and able to put things in perspective [40]. Currently, more studies are needed to establish a general consensus on the psychological effects of siblings during the survival stage.

2.4. Bereavement

Although the survival of childhood cancer has approached near 80% due to treatment advances [41], many cancers remain terminal at the time of diagnosis (i.e., intrinsic pontine glioma), or the state of science has stagnated for decades with no increase in survival (i.e., osteosarcoma) [8]. Many of the patients ultimately succumb. The cancer journey initially begins with the hope for cure or remission. Yet the optimism often plateaus as the families eventually realize that the hope may become one for a comfortable ending [8].

2.4.1. Communication

Studies have shown very poor communication with siblings regarding the death of their brother/sister. In the last 24 hours before the loss, 43% of the siblings reported getting no information about the impending death of their siblings from a family member, while 70% were not informed by one of the healthcare professionals [42]. Additionally, it was not until

<24 hours before their brother's/sister's death that the sibling understood their death intellectually (53%) and emotionally (76%) [42]. Eighty-four percent reported that nobody talked to them about what to expect when their brother/sister was dying, and these siblings showed significantly higher levels of anxiety up to 9 years later compared with those who knew what to expect [42]. More than one-fourth did not want to discuss their siblings' death, while one-third wished they had talked more with their families about it [33]. Cancer-bereaved siblings report lower self-esteem, sleep disturbances, and lower levels of maturity 2–9 years after the sibling's loss in comparison with non-bereaved siblings [43]. A nationwide survey in Sweden exploring siblings' experiences of their brother's/sister's cancer death found persistent levels of anxiety 2–9 years later [42].

2.4.2. *Death aftermath*

During the time of death, some siblings described that death came so rapidly that they weren't able to be there [42]. Those that were present at the time of death expressed gratitude and closure, including a sense of relief as death alleviated further suffering [42]. Shortly after death, however, some siblings felt emptiness and guilt that they were the ones still alive [42].

Siblings 12 years bereaved (mean age of 26 years) reported higher illegal drug and alcohol use during the year immediately after their sibling's death than before their sibling's diagnosis but then eventually returned to baseline [44]. Additionally, a similar trajectory was observed with anxiety and depression scores consistent with high distress in those who were unprepared for their sibling's death, unable to say goodbye and had not worked through their grief [44]. Twelve years later, 88% of respondents reported that the loss of sibling continued to affect their daily lives, 12% negatively, 45% positively, and impacted their education and career choices [44]. Although the majority of bereaved siblings have not worked through their grief, most siblings ultimately recover from the cancer experience without residual psychological distress [45].

van der Geest et al. [46] studied parental perceptions of bereaved sibling's well-being. They found that 43% of parents reported that siblings at home experienced a lot of distress in the period immediately before and after the death of the sibling and 46% reported continued negative consequences even after 5 years [46]. This correlates to Rosenberg et al.'s [44] report that during the immediate period surrounding loss, siblings experience severe emotional trauma, but majority ultimately normalize after 12 years.

Time, communication, and consistent support during the bereavement phase may allow siblings to heal. Furthermore, equivalent to PTG in survival stage, positive outcomes upon bereavement were also reported, such as better communication (36%), more maturity (43%), more kindness (45%), and more confidence than peers in their age (17%) [44].

2.5. **Interventions/support**

Since 1999, guidelines have been established to address siblings' needs; however, many of the recommendations relied on the parents, and on supportive services, which typically are not established in the hospital system (psychosocial support programs, sibling support group,

and parent support groups), which make these guidelines unrealistic [7]. Interestingly, majority of the published perspectives on siblings are through pediatric oncology nursing journals, and pediatric oncology nurses often rate the utility of psychosocial screening tools higher than pediatric oncologists and social workers [47]. In 2005, the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom developed guidance for healthcare professions to address siblings of children with cancer [48]. NICE suggested structured psychosocial assessment at significant time points throughout the cancer trajectory such as at diagnosis, treatment, relapse, and bereavement [48]. Although NICE guidelines are helpful, it is unknown if they are being utilized. The NICE guidelines parallel a report from the Institute of Medicine in the United States, which emphasized that the efforts to improve biopsychosocial health of children with cancer should be extended to members of their family [49]. Between 1990 and 2012, various organizations attempted to create standards, guidelines, and consensus reports regarding pediatric psycho-oncology care (**Tables 1–3**). However, rarely do these published reports specifically address siblings as a separate entity from “family” of children with cancer, even though there is an understanding that siblings have a unique cancer experience. Additionally, between 1990 and 2009, publications on the experiences of siblings of children with cancer grew dramatically [34]. Various qualitative and quantitative studies have been published, but little has changed since these reports. Siblings continue to be the “forgotten children” in the family, and their needs remain unmet.

Currently, there is no standardized tool designed for healthcare professionals (HCPs) to screen for psychosocial needs in pediatric cancer [50]. Available comprehensive screening tools are listed in **Table 4**. Psychosocial Care Checklist (PCCL) is a tool developed to address this gap [51]. The results indicated that oncologists and nurses do not seem to have the same awareness of psychosocial problems in the family compared to the social workers [50].

2.5.1. Intervention

One of the earliest interventions developed for siblings of children with cancer was peer support camp [6]. Camp as a therapeutic intervention has been utilized in various chronic diseases such as diabetes, asthma, renal disease, and cancer. However, camps in pediatric oncology have mainly focused on the child with cancer and rarely on the “forgotten children.” Although camps for siblings do exist, the majority of them are for bereaved siblings [52]. Sidhu et al. [2] developed therapeutic peer support camp as an intervention for siblings of 8–13 years of children with cancer on active treatment. Siblings who attended the camp reported lower levels of distress, decreased isolation, decreased anxiety, improved social competence, and greater social acceptance [2]. Through camp, siblings had significant reduction in the fear of cancer, manifested through improved knowledge of cancer and its treatment [2].

2.5.2. What siblings want

Lovgren et al. [53] conducted a nationwide survey of bereaved siblings answering open-ended question about what advice they would give to healthcare professionals (HCPs) working with

pediatric cancer patients and their families. The commonly reported advice was related to the siblings' wish for support regardless of their age [53]. They wanted insight into their own feelings in relation to their family and information about their sibling's disease and care [53]. Siblings also wished for support groups, activities, someone to talk to, and asked HCP to not give up trying to offer help [53]. Surprisingly, the "little things" were just as meaningful, such as when HCPs offered them a game, a sticker, a snack, or a hug [53].

Year published	Standard established by	What did it address?	Did it address specifically to siblings?	Reference
1996	ASPHO Health Care Reform and Public Issues Committee	Rationale and recommendations for a comprehensive pediatric hematology/oncology program to be implemented throughout the disease trajectory with services of psychosocial personnel explicitly described	No	[61]
2002	International Society of Pediatric Oncology (SIOP)	Standards for care of children with cancer that proposed ideal care	No	[62]
2008	US Institute of Medicine	<i>Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs</i>	Minimal recommendations addressed specifically to siblings of children with cancer, e.g., "primary and other HCPs should monitor caregivers, children, and siblings of survivors for signs of psychological distress both during the survivor's treatment and in the post-treatment period. Cancer care providers should inform families of cancer patients about supportive services, including special camps for families and siblings	[63]
2010	Canadian Association of Psychosocial Oncology (CAPO)	"Standards of psychosocial health services for person with cancer and their families." — Developed to assist cancer facilities, administrators, program leaders, and professionals in the delivery of psychosocial health services in Canada by providing a basic framework for these services	No, addressed "family" but never directly addressed siblings	[64]
2013	The European Society of Pediatric Oncology	European Standards of Care for Children with Cancer	No, addressed "family" but never directly addressed siblings	[65]

Table 1. Published standards addressing pediatric cancer population.

Year published	Guidelines established by	What did it address?	Did it address specifically to siblings?	Reference
1999	International Society of Pediatric Oncology (SIOP)	Guidelines for assistance to siblings of children with cancer	Yes	[7]
2000	Researchers at the University of Bonn	Structuring psychosocial care in pediatric oncology – oriented to specific phases of medical treatment of pediatric cancer patients, specifically focusing on the importance of multidisciplinary teams and the role of psychosocial professionals	No, addressed family as a whole and discussed family-oriented care, but never directly addressed siblings	[66]
2005	National Institute for Health and Clinical Excellence (NICE)	Improving outcomes in children and young people with cancer	Yes, addressed siblings but still focused mainly on the family	[48]
2012	National Comprehensive Cancer Network (NCCN)	Guidelines published for the support of adolescents and young adults living with cancer and their families	No, addressed family as a whole and discussed family-oriented care, but never directly addressed siblings	[67]

Table 2. Published guidelines addressing pediatric cancer population.

Information regarding the disease is often intentionally left out to the siblings by parents or HCP. Yet siblings felt that information should be given continuously by the HCPs during treatment, progression, and prognosis [53]. Siblings pointed out that their own needs for information often differed from those of their parents and they had a right to be given information that their parents refused to take in [53]. It was important for HCPs to remain realistic and honest, focus on the bright moments, and promote happiness and hope even during times of suffering [53].

Since 2013, “sibling supporters” have been available to provide support to siblings at six pediatric oncology units in Sweden [54]. They are resource persons whose main task is to see the siblings of those who become sick [54]. They participate in various activities together, listen to their narratives, and are present during the time of illness, survivorship, and bereavement [54]. They facilitated opportunities for similar siblings to meet each other, to discuss things that a sibling was unable to say or understand, and to facilitate conversations with parents and professionals [54]. They were also able to remain positive and create outings for siblings outside the hospital that disassociate them from sickness and death [54].

“In the hospital, there wasn’t really anywhere for siblings to go...I think there needs to be a [designated] place for siblings to go, people for them to talk to [9].”

Siblings are exceptionally vulnerable to Post-Traumatic Stress Disorder (PTSD) during the initial months after diagnosis [44, 46]: in the first 2 months, 23% and 43% of siblings have full and partial DSM-IV PTSD, respectively [16, 44, 46]. With early psychological intervention,

Year published	Consensus statements established by	What did it address?	Did it address specifically to siblings?	Reference
1998	American Federation of Clinical Oncologic Societies	Consensus statement on providing access to quality cancer care—focused on medical treatment and intervention and offered recommendations for support groups, counseling services, and professional psychotherapeutic services	No, focused primarily on the patient	[68]
2004	NCCN	Evidence-based consensus statement regarding the care and support needs of children and young people with leukemia and their families	Yes, a minor chapter on sibling support that consists of one paragraph: "Appropriate support for siblings is crucial. As with parents, this should encompass easily accessible, age appropriate and honest information and opportunities for siblings to discuss their feelings and fears." Additionally, addressed siblings as a separate entity throughout the consensus document	[69]
2010	LIVESTRONG Young Adult Alliance	Recommendations for quality cancer care for adolescents and young adults—identified four critical elements of quality care, access to healthcare professionals, treatment and medical intervention, and psychosocial support	No, focused primarily on the patient and did not address family or siblings	[70]

Table 3. Published consensus addressing pediatric cancer population.

Screening tools	Function	References
Health-related quality of life (HRQL)	Multidimensional construct that encompasses the physical, psychological, and social domains of functioning	[71]
Psychosocial Care Checklist (PCCL)	Instrument developed to assist HCPs to identify psychosocial issues for a child with cancer and his/her family	[50]
Distress thermometer	Assesses general distress using a thermometer-like scale varying from 0 to 10	[72]
Psychosocial assessment tool (PAT) and PAT 2.0	Family-focused instrument designed to be completed by a parent and screens for psychosocial risk factors associated with childhood cancer	[73, 74]

Table 4. Comprehensive screening tools for siblings of children with cancer.

siblings reported better psychosocial well-being, better medical knowledge and better social support, but no statistical correlation with acute anxiety or PTSD [16].

Open age-appropriate communications with siblings regarding the possibility of the ill child dying and giving them a chance to say goodbye can provide comfort and closure. Serious psychological issues are rare with the involvement of palliative care [55]. Siblings need guidance on what to expect [29].

“The moment it came out [diagnosis], I could only think of the fact that my brother could die [31].”

“He was [unreasonably] demanding. Sometimes he wanted sausages with ketchup and all sorts of things at 1 o’clock in the morning, and during a certain phase, he got aggressive very fast [31].”

Bereavement follow-up after the death of a child has been recommended as a standard of care in pediatric oncology [56]. Lichtenthal et al. [56] recommend that a member of the health-care team should contact the family after a child’s death to assess family needs, to identify those at risk for negative psychosocial sequelae, to continue care, and to provide resources for bereavement support. It has been suggested that pediatric palliative care clinicians have an ethical duty of “nonabandonment,” to care for the families of children with life-threatening conditions through their illness and times of bereavement [57]. Perhaps, these recommendations should be adopted for the siblings of children with cancer also.

A standard of care for siblings of children with cancer should also be established [58]. Parents and professionals should be advised about tools and therapies to meet siblings’ unmet needs (Table 4) [58]. These should include psychoeducation, coping and prevention strategies, as well as assessment and treatment of psychopathology spanning diagnosis to bereavement[58].

3. Conclusions

The scope of medical care for pediatric oncology should extend beyond the control of cancer to the psychosocial care of the child and siblings’ family [50]. Standard guidelines, established since the 1990s [7, 48, 49], are rarely implemented as the standard of care. Barriers from implementing them include predisposing factors, enabling factors, and reinforcing factors (Table 5) [59].

Barriers	Examples
Predisposing factors	Lack of knowledge, training, beliefs and attitudes, self efficacy
Enabling factors	Lack of consultation time, assessment skills and systems, skills to intervene, role definition
Reinforcing factors	Lack of feedback, rewards, negative consequences

Table 5. Barriers for pediatric oncologists in implementing psychosocial communication.

In North America’s pediatric cancer centers, early psychosocial screening is neither consistently nor systematically conducted and/or documented [60]. It is imperative that physicians

are aware of the psychosocial issues that exist within the family, as these issues could identify critical factors that may affect the medical treatment and family cohesiveness [50]. PCCL is a promising screening tool that could assist with enhancing HCPs' awareness of the psychosocial issues for the child with cancer and his/her family [50].

Siblings endure various distresses throughout the different stages of cancer trajectory. Although their voices are gradually being heard, the complexity of the roots of their distress requires meticulous attention to dissect and unravel. The goal is to ultimately have a supportive and therapeutic system in place to assist the siblings during their times of distress.

Research on the psychosocial well-being for siblings of children with cancer remains limited. Consistencies with screening and supportive interventions continue to be lacking. A standardized screening tool with early interventional services should be implemented, such as PCCL and sibling supportive camps. Additionally, interdisciplinary awareness of the siblings' psychosocial issues should be increased in order to shed light to their invisibility. The goal is to remember the "forgotten children."

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