# THE IMPACT OF CHILDHOOD CANCER BEYOND THE AFFLICTED: A LITERATURE REVIEW

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# Abstract

The sudden diagnosis of childhood cancer can be life-threatening and pose a substantial challenge to families. When a child is diagnosed, the family is expected to take on new responsibilities and learn new skills. The family's functioning may alter for long periods of time, which is not always simple, and for many families, it can result in severe emotional stress that lasts for a very long time. In this literature review, seven articles in the PubMed database met the common themes identified (a) the needs and impacts of the family experiencing childhood cancer, (b) social support and siblings of children with cancer, and (c) parental distress related to the diagnosis of childhood cancer. These themes underline the need to increase awareness of the potential emotional harm that these patients and their families might experience.

Families are often forced to rearrange their current lifestyles by altering routines and family responsibilities. The importance of illness management regimens combined with physical symptoms like pain and exhaustion are likely to interfere with many aspects of everyday life for not only the children but also for their parents and siblings. It is important to properly assess the family involved to provide sufficient care, as they are also affected. Without proper interventions, family members and children can experience a sufficient amount of emotional, psychosocial, and physical distress that can last for many years.

## Acknowledgements

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# Introduction

With advances in treatments and research, the survival rate for childhood cancer has gradually increased over the last few decades. Achieving a 5-year overall survival rate for children with cancer that has increased from 30% in the 1960s to over 80% in recent years is due to a number of factors, including improved treatments, diagnostics, and access to care (World Health Organization, 2022). Understanding the long-term consequences of childhood cancer is important because survival is expected for the majority of children diagnosed with the disease. This increase in survival rates has long-term effects on the lives of children and families. Recurring admissions, invasive procedures for the child, changes in family roles, and prognosis uncertainty can all create stress for the family, which debilitates family functioning. Following the cancer diagnosis, parents are expected to quickly become knowledgeable, develop specific caregiving techniques, and rearrange their family's roles and routines. These changes will cause an array of emotions that can eventually lead to negative psychological effects. As childhood cancer is on the rise, it is important to identify the needs of the family. It is crucial for the interdisciplinary team to support the family just as much as the child.

Despite the fact that a child who is diagnosed with cancer experiences emotional and physical pain, cancer also has an impact on the entire family and causes long-term stress for everyone involved. This creates barriers during the process of treating cancer and is sometimes intolerable for the family. There are many phases' families go through when first adapting to the diagnosis. The parents may experience guilt at first because some common cancer signs and symptoms, such as fatigue and joint pain, are often overlooked. They then meet with unfamiliar medical professionals who are giving them an intense amount of new information about the child's diagnosis, causing the parents to become easily overwhelmed.

Similarly, the siblings are also feeling uncertain due to the diagnosis, as they may feel anxious about the current health of their brother or sister. These siblings also may feel ignored, as all the attention is focused on the sick child. It is crucial to recognize how family functioning, particularly parental adjustment, and distress, might alter throughout treatment to provide appropriate and effective interventions.

## Background

Every year, an estimated 400,000 children and adolescents ages 0–19 are diagnosed with cancer (World Health Organization, 2021). The most common types of cancer in children include leukemia, lymphomas, solid tumors, and brain cancers. In countries with more advanced treatments and funds, the survival rate for cancer is much higher. Unfortunately, these cancers cannot be identified or screened for ahead of time. Early cancer detection increases the likelihood that it will respond to effective therapy, increasing the likelihood of survival, reducing pain, and frequently necessitating less expensive and rigorous treatment. Cancer occurs in people of all ages and can affect different regions of the body. It starts off with a genetic alteration in a single cell and then grows into a mass or tumor. Once this process occurs, it can migrate to other areas of the body, and, if left untreated, it will lead to harm and even death (World Health Organization, 2021).

Since it is impossible to prevent cancer in a child, it is important to reduce the burden of its effects on the family and child. Along with assessing the needs of the sick child, it is important for the healthcare team to identify the needs of the family and not just the patient. There is a need for better education for healthcare professionals that care for pediatric oncology patients and their families. By understanding the emotional impact on these families, it could motivate health care professionals to routinely screen the parents for signs of distress.

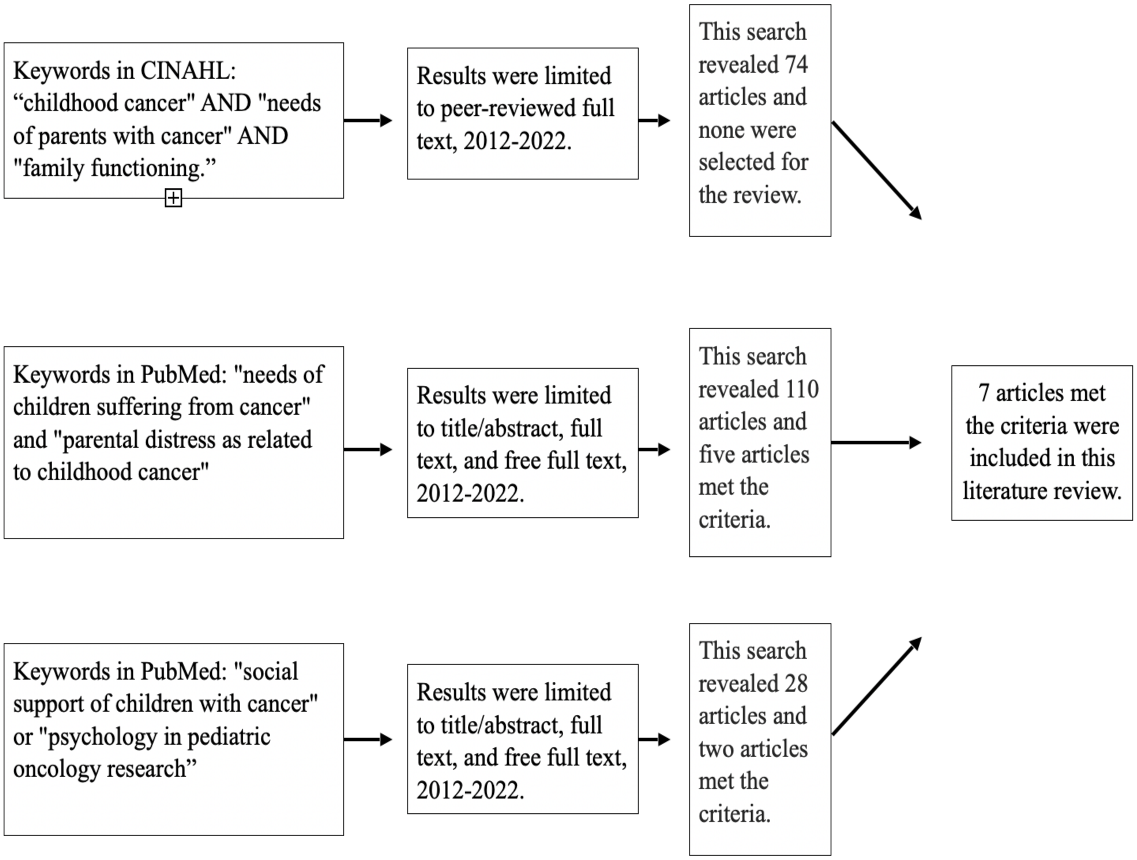
## Methods

A systematic review of the literature was conducted to identify the impact of childhood cancer on families. The literature review searches were conducted using the Cumulative Index of Nursing and Allied Health Literature (CINAHL) Plus with Full Text and the PubMed database. Before the articles were chosen for this review, they were limited and briefly reviewed to address the effects of childhood cancer. The search criteria for both databases needed to meet specific requirements, which are outlined below in Figure 1.

For the CINAHL database, the search included the following key words, which were put into the advanced search engine: "childhood cancer" AND "needs of parents with cancer" AND "family functioning." The criteria also included peer reviews and publications between 2012 and 2022. This search and review revealed 74 articles. After reviewing the articles, none were selected for the final literature review.

For the Pubmed database, one search included "needs of children suffering from cancer" and "parental distress as related to childhood cancer" and was limited to title/abstract, full text, and free full text. This search revealed 110 articles. Of these articles, five met the criteria. The second search included "social support of children with cancer" or "psychology in pediatric oncology research" and was also limited to title/abstract, full text, and free full text. This search revealed 28 articles. Of these articles, two met the criteria.

**Figure 1. Keyword Research Review**



# Results

For this review, seven articles met the criteria for inclusion in this systematic review of the literature, with their full texts readily available through PubMed. In order to access the full text of some of the articles, they were obtained through the Salem State University Library's interlibrary loan system. Three common themes that were identified include (a) the needs and impacts of the family experiencing childhood cancer, (b) social support and siblings of children with cancer, and (c) parental distress related to the diagnosis of childhood cancer.

## The Needs and Impacts of The Family Experiencing Childhood Cancer

Childhood cancer is a life-changing experience for not only the child involved but also the family members. Following the diagnosis, the family is put under pressure to learn and understand the new information they have been given, as well as adapt. This new adjustment is not easy, and many parents may experience significant emotional distress as a result, which will continue to build over time (Sultan, 2015). Families frequently experience shock, pain, and alterations to their family life when informed of a child's cancer diagnosis. Parents become consumed by their child's medical care and immerse themselves in their child's care.These abrupt alterations disturb the everyday functioning of the family (Lewandowska, 2022). The crisis that the diagnosis brings is the main reason for the tension and anxiety that the family faces.

In order to be accessible for the child's frequent hospital trips and stays, the demands of therapy may force the parents to change their occupations. The parents' professional and financial lives are significantly impacted by the child's condition, and as treatment continues, these financial troubles can become more significant, further complicating family dynamics. According to Lewandowski, 96% of parents experienced financial strain connected to care, treatment, and rehabilitation to some degree, and 24% of them were forced to give up their jobs entirely (Lewandowska, 2021). This may lead to an upset in the stability of the family relationship and even result in a divorce.

The family goes through various stages when finding out about the child's cancer diagnosis. The stages and intensity of the diagnosis are determined by the family dynamics and relationships. Each stage results in alterations in family members' behavior and relationships and issues with communication, physical discomfort, and role-swapping. For vulnerable parents, stress may be debilitating, and it may affect how well a child adjusts and copes. It is strongly recommended for parents and caregivers to receive early and continuing assessments of their mental health needs with access to relevant therapies facilitated to optimize parent, child, and family well-being (Kearney, 2016). It is crucial to consider the psychological issues the patient's family is facing and how the patient's siblings are affected by the illness. Families must deal with a variety of difficulties, including side effects of medication, potentially fatal conditions, seeing the deaths of other patients, financial difficulties, unpredictable employment situations, and emotional issues in both themselves and other family members (Lewandowska, 2022).

A cross-sectional study by Lewandowska, was conducted involving 800 family caregivers to assess their needs. The study was carried out between 2015 and 2020. In order to evaluate their needs and challenges, caregivers of children with cancer were invited to participate in the study. Parents were given a questionnaire to fill out that included both open-ended and closed-ended questions in order to obtain epidemiological information. The areas being assessed included psychological, medical, communication, and information needs for everyday life as well as social, spiritual, and financial needs. According to the analysis, 97% of the participants had some need for one or more items, and 73% of the respondents said they had moderate or high needs. In the field of medical information, 70% of respondents had moderate or high needs; 55% of parents reported a moderate or high level of need for help in the psychological or emotional field; and 30% in the financial domain (Lewandowska, 2022). Parents of children who have cancer have several needs, particularly psychological, emotional, and informational demands. These needs have all been associated with family burden and distress and poorer adjustment (Kearney, 2016). If these needs are not met with appropriate interventions, it could deter parents from involving themselves in the child's care and further lead to delays in treatment**.**

## Social Support and Siblings of Children with Cancer

Siblings of these children have understandable and potentially persistent reactions to their siblings' diagnosis and treatment. These siblings experience interruptions to their daily routines, trouble focusing in class, a lower quality of life, struggles with perceived lack of attention and status in the family, extreme negative emotions, and traumatic stress symptoms associated with cancer, as well as concern and worry about the health of their family members (Kazak, 2015). Supportive treatment for siblings is advised as a psychosocial standard of care in pediatric oncology to enhance sibling well-being and is based on prior sibling research (Wawrzynski, 2021). Supportive care can be provided in different ways, but typically contains support groups or services offered by the hospital or community. These programs offer comfort, coping mechanisms, and support, and they improve the quality of life. Social support can act as a distraction from stress and improve coping abilities.

In Wawrzynski’s research, a constant theme that emerged was the need for an improvement in social support for these children. The results indicated that siblings noticed less support and more responsibilities than before the cancer diagnosis. It also revealed a lack of emotional support, resulting in emotional strain related to jealousy, fear, and worry about the sibling diagnosed. These feelings occurred due to the fact that these siblings received little information on the diagnosis and treatment. There is a need for more emotional, social, and informational support throughout the diagnosis. Additionally, the study explored what forms of support are offered to siblings in the healthcare system. It revealed that 71% of parents felt little to no support for their children's siblings, while another it also found that 86% of parents received less psychological and informational help than necessary, making it more difficult to access sibling support or discuss sensitive subjects like the prognosis (Wawrzynski, 2021).

Given the psychological problems that are faced by the patient's family, it is also crucial to take into consideration how the siblings react to the diagnosis. These children can be very sensitive to hidden anxieties and emotions. The constant atmosphere of secrets can have negative effects on the siblings and delay their development (Lewandowska, 2021). Coping with such a drastic change in daily life, as well as their parents' reduced physical and emotional availability, can lead to additional conflicts. In Lewandowska’s research, it showed that the siblings developed tantrums (48%), learning difficulties (21%), and behavioral problems (18%) (Lewandowska, 2021). At the time of diagnosis, the child’s disease inevitably affects all family relationships. If parents are not evaluated for needs and problems, this could further increase the risk for these siblings.

## Parental Distress Related to the Diagnosis of Childhood Cancer

Understanding the long-term lingering effects of childhood cancer is crucial given that most cancer-affected children are expected to survive. Kearney’s research on the mental health of parents of children with cancer have revealed high levels of psychological distress, including post-traumatic stress symptoms, depression, anxiety, sleep problems, somatic complaints, fear of a recurrence, persistent worry, and exhaustion (Kearney, 2016). This distress has been shown to significantly decrease after the diagnosis, though reports show a high level of psychological distress even after the child's treatment is complete. Distress is linked to poor quality of life, functional limitations, difficulties with parenting, and an increased risk of somatic diseases such as coronary heart disease (Ljungman, 2014). Distress is linked to expenses from using medical services, lost productivity, and sick leave.

The high rate of stress observed in Ljungman's study, suggests that a significant proportion of parents continue to experience extreme distress even after their child was diagnosed at least five years ago and/or treatment was completed two years ago (Ljungman, 2014). The study also revealed that parents persistently experience fear about their child's health and well-being, uncertainty about their child's future, and intrusive thoughts about the cancer experience (Ljungman, 2014). In addition to psychiatric symptoms, parents also mentioned feelings of frustration, guilt, self-blame, and fear of recurrence (Sultan, 2015). When parents are trying to provide their child the best care possible, they experience extreme anxiety and burden. In addition to wanting to be heard and respected during the course of treatment and beyond, parents also want to get thorough information from the medical team. Wawryzski's research provides evidence to suggest that caring for a child with cancer causes both hardship and growth in the family. Siblings are understudied in particular and may suffer long-term consequences from having a brother or sister who has cancer (Wawrzynski, 2021).

Ljungman's findings also revealed that childhood cancer survivors are also at risk for psychological effects up to ten years after the diagnosis (Ljungman, 2014). Cancer progresses more quickly in children than it does in adults, and children's bodies can withstand more treatment than adults' bodies. As a result, treatment for pediatric cancer is frequently more rigorous than for adult cancers. Thus, more severe adverse effects of the medication, such as nausea, exhaustion, diarrhea, nausea, and hair loss, may also occur (Marusak, 2018). As these children re-adjust to home and family life and return to school and social situations, the move into survivorship has its own unique set of problems. Children may struggle with persistent attentional and memory issues, hearing loss, and other physical disabilities in addition to being years behind in school. Since the 1980s, researchers have been examining the long-term psychological impact of aggressive cancer therapy on young patients. In general, people with childhood cancer handle the experience psychologically well, but many nevertheless endure anxiety, despair, and even post-traumatic stress. According to Marusak, post-traumatic stress symptoms may impact up to 75% of adolescents receiving treatment for cancer and happen more frequently than the complete range of PTSD symptoms (Marusak, 2018).

## Discussion

In regard to the research reviewed above, there is a greater need to support these family members during these difficult times. Parents are expected to quickly become knowledgeable about cancer, develop specific care techniques, and rearrange their family's roles and routines after receiving the diagnosis. When receiving this news, it can be detrimental to the family and cause an array of emotions that lead to psychological issues. Cancer typically changes the structure of the family's relationship and the relationships between family members.

Healthcare professionals should do more to incorporate the family's emotional distress into the care. Parents should be assessed and referred to appropriate services based on their response to the diagnosis. They should also have follow-ups continuing through treatment and into survivorship. Without proper interventions, this stress could lead to post-traumatic stress, a decline in psychological health, anxiety, and depression. Parental distress can be approached by a variety of measures, including psychological symptom inventories, mixed distress scales, anxiety–depression inventories, mental quality of life subscales, and traumatic stress inventories. These measures allow for evaluation of the severity of symptoms and distress. Once parental distress is appropriately addressed, and proper interventions are put into place, the long-term effects are more positive than those without.

## Limitations

Several important implications have been noted in the research studies. More research on families with a cancer-diagnosed child is urgently needed. If more research is conducted, then healthcare workers can better support these families.

## Conclusion

It is imperative for the healthcare team to incorporate family functioning into the child's realm of care. When the family is active and involved in care, the child has a better chance of understanding the treatment and circumstances. If family functioning is neglected, it may deter parents from involving themselves in the child's care and lead to delays in treatment. Health care professionals frequently incorrectly attribute poor family relationships or parental stress to the cancer, rather than understanding the underlying complexity of these issues. When the family is incorporated into the care, the outcomes are more desirable. Although, the research reviewed in this review suggests that these parents are not adequately supported by current healthcare interventions, there is a high demand for the healthcare system to address these needs. The long-term effects have become more prominent as the childhood cancer survival rate rises. Without adequate support, these families are vulnerable to PTSD, depression, anxiety, and other psychological issues. This distress tends to persist even after the completion of treatment. It is evident from the research reviewed that healthcare workers need to better acknowledge these needs and initiate proper interventions to better support these families. If appropriate interventions are implemented, the staff can better ease the emotional damage that the family experiences.

Siblings are also negatively impacted by the diagnosis of cancer. These siblings face drastic changes in their everyday lives. Despite the limited tools available to measure the social support provided to these siblings, the research reviewed has made it clear that the link between support and coping is strong. Research in the review demonstrated an absence of emotional support, which leads to emotional stress brought on by feelings of jealousy, anxiety, and worry for the diagnosed sibling. However, when appropriate interventions are implemented to support these children, it results in increased confidence, self-reflection, and emotional control. A more in-depth research study needs to be conducted to identify the specific types of social support that make the adjustment easier. In the future, it would be beneficial to identify the most adequate types of support and how they can be implemented into care.

Parents of children with cancer have numerous needs, particularly psychological, emotional, and informational. It is essential to recognize that these children's parents are not provided with sufficient support, which means they will deal with these problems on their own, making them the "hidden patient." If the emotions of these parents are not dealt with, it can lead to long-term strains on the family.

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