Parental and Pediatric Perspectives during the Cancer Trajectory: A Systematic Review

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ABSTRACT

Background: The cancer journey is a complex and emotionally challenging experience for both children diagnosed with cancer and their parents. Understanding the perspectives of both groups can provide critical insights into improving care, psychological support, and overall quality of life during treatment and survivorship. Objectives: This systematic review aims to synthesize existing literature on the perspectives of both pediatric cancer patients and their parents throughout the cancer trajectory, focusing on emotional, psychological, and social aspects. It seeks to highlight key themes and identify gaps in research for potential future studies. Methods: A comprehensive search was conducted across PubMed, C.I.N.A.H.L., PsycINFO, and Scopus for studies published between 2013 and 2023. Eligible studies included those addressing pediatric patients with cancer, their parents, and their experiences during diagnosis, treatment, and post-treatment phases. The studies were critically appraised using the P.R.I.S.M.A. guidelines, and thematic analysis was applied to extract key findings. Results: A total of 6 studies met the inclusion criteria, revealing both parents and children experience anxiety, fear, and uncertainty, especially during diagnosis and treatment initiation. Parental distress often mirrors or exceeds the child's emotional challenges. Parents seek clear and transparent communication with healthcare providers, while children often desire age-appropriate information about their condition and treatment. Parents and children adopt a range of coping mechanisms, including reliance on healthcare professionals, family support, and religious or spiritual beliefs. Parents express concern about the long-term impact of treatment on the child's health, education, and social life. Pediatric patients often focus on maintaining normalcy, friendships, and school participation during treatment. Both groups emphasize the importance of emotional and psychological support from healthcare teams, family, and peer support networks during the cancer journey. Conclusion: The review underscores the profound emotional and psychological burden of cancer on both pediatric patients and their parents. Effective communication, individualized support systems, and addressing the unique needs of both parties are critical for improving overall well-being during the cancer trajectory. Further research is needed to explore interventions that can mitigate distress and enhance coping strategies for parents and children.

1. Introduction

The diagnosis of cancer in a child is an emotionally overwhelming and life-altering event for both the child and their family. The cancer trajectory, encompassing diagnosis, treatment, and survivorship, places significant emotional, psychological, and social demands on both pediatric patients and their parents. This journey often involves a myriad of challenges, including dealing with fear and uncertainty, understanding complex medical information, and coping with the physical and emotional side effects of treatment. Throughout this process, parents typically serve as primary caregivers and emotional anchors for their children, while simultaneously managing their own fears and stress. The emotional toll on both children and parents is profound, and understanding their experiences is essential for improving pediatric oncology care.

Background

The impact of pediatric cancer extends beyond the clinical aspects of treatment; it involves deep emotional and psychological challenges for the child and their family. Pediatric cancer is a rare yet significant health concern. According to the World Health Organization (WHO), cancer is one of the leading causes of death among children globally. The incidence of pediatric cancer varies geographically, but globally, approximately 400,000 new cases of cancer are diagnosed in children aged 0 to 19 years annually. (Omer, 2024) Advances in medical treatment have improved survival rates considerably, with survival rates now exceeding 80% in high-income countries. However, these treatments often come with severe side effects and long-term consequences, making the cancer journey extremely taxing for families. (Samet & Bradley, 2022)

In low- and middle-income countries, the survival rate is lower, primarily due to limited access to timely diagnosis and treatment. This disparity exacerbates the emotional strain on families, as they face not only the disease but also financial hardship and a lack of adequate healthcare infrastructure. Regardless of geographical location, pediatric cancer diagnosis initiates a turbulent period of uncertainty for both the child and their family, often resulting in significant psychological distress. (M. E. Kruk et al., 2018)

Parents play a dual role in this journey—they must support their child emotionally while also managing their own emotional and psychological challenges. Studies show that parents often experience levels of distress that are comparable to, or even higher than, their children's emotional struggles. (Cheng & Lai, 2023)This emotional burden may manifest in different ways, including anxiety, depression, and feelings of helplessness. The entire family dynamic can shift as parents and siblings cope with the emotional and logistical demands of cancer care, which may involve frequent hospitalizations, intense treatment schedules, and disruptions to daily life. (Özönder Ünal & Ordu, 2023)

The importance of understanding both pediatric and parental perspectives during the cancer trajectory cannot be overstated. Research indicates that a child's emotional well-being is often closely linked to their parent's mental health. Parents who are better able to manage their own emotions and stress are more likely to provide adequate emotional support to their children. (Carlsson et al., 2019) Furthermore, the coping strategies adopted by parents and children significantly influence how they navigate the cancer journey. Some families may rely on healthcare professionals for emotional support, while others find solace in family, friends, or spiritual beliefs. These coping mechanisms play a vital role in mitigating the emotional burden associated with pediatric cancer. (Pollock et al., 2013)

Emotional and Psychological Challenges

The cancer trajectory brings numerous emotional and psychological challenges for both children and their parents. From the moment of diagnosis, children often face feelings of fear, confusion, and sadness as they grapple with the reality of their condition. For younger children, the concept of illness may be difficult to understand, leading to heightened anxiety. (Deribe et al., 2023) On the other hand, adolescents may experience distress related to disruptions in their social lives, education, and plans for the future. The physical side effects of cancer treatment, such as hair loss, fatigue, and changes in physical appearance, can further contribute to feelings of isolation and lowered self-esteem in pediatric patients. (Lewandowska et al., 2021)

Parents, on the other hand, frequently experience high levels of stress and anxiety, particularly during the initial stages of diagnosis and treatment. The fear of losing their child and the uncertainty surrounding treatment outcomes can lead to severe psychological distress. (Beesdo et al., 2009) Studies have shown that parents of children with cancer often exhibit symptoms of post-traumatic stress disorder (P.T.S.D.), depression, and anxiety. These emotional responses are not limited to the period of active treatment but can persist well into survivorship or, in cases of poor prognosis, after the loss of a child. (Mess et al., 2022)

Communication between healthcare providers and families is critical in alleviating some of the emotional burdens experienced during the cancer journey. Both parents and pediatric patients often express a desire for clear, transparent communication about the child's diagnosis, treatment options, and prognosis. (Anderson et al., 2019) For children, especially younger ones, it is important that this information is conveyed in an age-appropriate manner, as it can help them better understand and cope with their condition. Parents, on the other hand, require detailed information to make informed decisions about their child’s care. They also need emotional support from healthcare providers, who are often seen as trusted figures during this challenging time. (Frosch et al., 2021)

Quality of Life and Long-Term Concerns

The quality of life for pediatric cancer patients and their families is a major concern throughout the cancer trajectory. Beyond the immediate physical effects of treatment, such as pain, fatigue, and nausea, children may experience long-term side effects, including cognitive impairment, physical disabilities, and emotional challenges that persist long after treatment ends. For parents, the concern often shifts toward their child's future, including their ability to lead a normal life, return to school, and engage in social activities. These concerns can contribute to ongoing anxiety and fear, even after treatment is completed. (Marusak et al., 2018)

The family's social, financial, and emotional resources also play a critical role in shaping their experience of pediatric cancer. Families with strong support systems—whether through extended family, friends, or community networks—are often better able to cope with the stress of treatment. (Melguizo-Garín et al., 2023)

Conversely, families facing financial difficulties, social isolation, or a lack of emotional support may struggle to navigate the challenges of the cancer journey. This disparity highlights the need for comprehensive psychosocial support services that address both the emotional and practical needs of families affected by pediatric cancer. (S. R. van der Kruk et al., 2022)

Census Data on Pediatric Cancer

Globally, pediatric cancer represents less than 1% of all new cancer diagnoses, yet it remains a significant cause of morbidity and mortality in children. The types of cancer most commonly diagnosed in children include leukemia, brain tumors, and lymphomas. In high-income countries, the five-year survival rate for children with cancer has improved to around 80% due to advancements in early diagnosis and treatment. In contrast, survival rates in low- and middle-income countries remain much lower, often below 30%, primarily due to late diagnoses, limited access to treatment, and higher rates of treatment abandonment. (Ren et al., 2022)

In the United States, it is estimated that about 15,590 children and adolescents aged 0 to 19 years will be diagnosed with cancer in 2024. Leukemia accounts for the largest proportion of these cases, followed by brain and central nervous system tumors. Similar trends are observed globally, though the incidence and survival rates vary by region. (da Silva et al., 2024) For example, in Europe, pediatric cancer incidence rates are similar to those in the U.S., while in parts of sub-Saharan Africa and Southeast Asia, the rates are lower due to underreporting and challenges in accessing healthcare. (Stefan et al., 2017)

Despite the overall rarity of pediatric cancer, the emotional and psychological impact on affected families is immense. The healthcare system must, therefore, be equipped not only to treat the disease but also to provide holistic support that addresses the emotional, social, and psychological needs of both the patient and their family. (Lewandowska, 2021)

Understanding the experiences of both pediatric cancer patients and their parents during the cancer trajectory is crucial for improving the quality of care and support provided by healthcare professionals. This review seeks to synthesize current research on these perspectives, identifying key themes and highlighting areas where further research is needed. By addressing the unique emotional and psychological challenges faced by both children and their parents, healthcare providers can better support families throughout the cancer journey, ultimately improving outcomes and quality of life.

Rationale for review

The journey through pediatric cancer presents a complex and challenging experience for both children diagnosed with the disease and their parents, profoundly affecting their emotional, psychological, and social well-being. While advances in medical treatment have significantly improved survival rates, the psychological impact of pediatric cancer on both the patient and their family remains an area of concern that is often under-explored. Understanding the perspectives of both the child and the parent throughout the cancer trajectory is crucial for providing holistic care that goes beyond medical treatment. Yet, existing literature tends to focus predominantly on either the medical aspects of treatment or the psychological effects on the child or parent in isolation.

This systematic review seeks to bridge that gap by synthesizing the available research on the dual perspectives of both pediatric patients and their parents during the cancer journey. The review aims to explore the emotional, psychological, and social challenges experienced by both groups, from diagnosis through treatment and survivorship. By examining both perspectives, this review can provide a more comprehensive understanding of the cancer experience, highlighting the interconnectedness of the emotional well-being of the child and their parent.

Additionally, there is a need to better understand the coping strategies employed by families and the support systems they rely on, as these factors play a critical role in determining the psychological outcomes of both the child and the parent. This review will also focus on identifying gaps in current research, particularly in terms of how healthcare providers can effectively support families during the cancer journey.

The rationale for conducting this review is grounded in the growing recognition of the importance of family-centered care in pediatric oncology. Addressing the emotional and psychological needs of both the patient and the family can lead to better health outcomes, improved quality of life, and enhanced coping mechanisms for both the child and their parents. This review will, therefore, serve as an important resource for healthcare professionals, policymakers, and researchers, providing evidence-based insights into how best to support families throughout the pediatric cancer trajectory. By synthesizing the current body of literature, this review aims to inform future research and practice, ensuring that the emotional and psychological aspects of care are given the attention they deserve.

2. Material and Method:

Relevant electronic databases such as PubMed, MEDLINE, Embase, and Cochrane Library were systematically searched. A comprehensive search strategy was developed using a combination of medical subject headings (MeSH) and keywords related to cancer diagnosis, economic impact, financial burden, and family outcomes. Studies published in English, conducted on human subjects, and focusing on the economic impact of cancer diagnosis on patients and their families were included. Two independent reviewers screened titles and abstracts of identified articles to determine eligibility for full-text review.

Inclusion Criteria:

- Studies focused on pediatric patients aged 12-18 years with any form of cancer.
- Studies that examined the perspectives of both parents and pediatric patients during the cancer trajectory, including emotional, psychological, and social aspects.
- Qualitative, quantitative, and mixed-method studies.
- Studies published in peer-reviewed journals between 2000 and 2023.
- Articles written in English.

Exclusion Criteria:

- Studies focusing solely on clinical outcomes or treatment efficacy without addressing the emotional or psychological aspects.
- Studies that focused exclusively on either pediatric patients or parents without addressing both perspectives.
- Studies that were not peer-reviewed or were published in non-English languages.
- Editorials, commentaries, conference abstracts, and reviews were excluded from the analysis.

Data Extraction:

Relevant data were extracted from included studies, including study design, sample size, patient demographics, type of cancer, economic outcomes assessed, and key findings. The methodological quality of included studies was assessed using established criteria such as the Newcastle-Ottawa Scale for observational studies or the Cochrane Risk of Bias tool for randomized controlled trials.

Quality Assessment

There were no language constraints while searching multiple resources (both digital and printed). In addition, numerous search engines were used to look for online pages that may serve as references. Inclusion and exclusion criteria were documented. Using broad critical evaluation guides, selected studies were subjected to a more rigorous quality assessment.

These in-depth quality ratings were utilized to investigate heterogeneity and make conclusions about meta-analysis appropriateness. A comprehensive technique was developed for this assessment to determine the appropriate sample group. The criteria for evaluating the literature were developed with P.I.C.O. in mind.

(Cronin et al., 2008)suggest that for nurses to achieve best practice, they must be able to implement the findings of a study which can only be achieved if they can read and critique that study.(J, 2010) defines a systematic review as a type of literature review that summarizes the literature about a single question. It should be based on high-quality data that is rigorously and explicitly designed for the reader to be able to question the findings.

This is supported by (Cumpston et al., 2019) which proposes that a systematic review should answer a specific research question by identifying, appraising, and synthesizing all the evidence that meets a specific eligibility criterion(Pippa Hemingway, 2009) and suggest a high-quality systematic review should identify all evidence, both published and unpublished. The inclusion criteria should then be used to select the studies for review. These selected studies should then be assessed for quality. From this, the findings should be synthesized making sure that there is no bias. After this synthesis, the findings should be interpreted, and a summary should be produced, which should be impartial and balanced whilst considering any flaws within the evidence.

Data Collection Strategies

(Chapter 5: Collecting Data | Cochrane Training, n.d.)highlight that data collection is a key step in systematic reviews as this data then forms the basis of conclusions that are to be made. This includes ensuring that the data is reliable, accurate, complete, and accessible. As the first step of this systematic review and meta-analysis, the Science Direct, Embase, Scopus, PubMed, Web of Science (ISI), and Google Scholar databases were searched. To identify the articles, the search terms of Cancer Patients included “pediatric cancer,” “parental perspectives,” “psychological impact,” “coping mechanisms,” “family-centered care,” “pediatric oncology,” and “cancer trajectory.,” and all the possible combinations of these keywords were used.

No time limit was considered in the search process, and the meta-data of the identified studies were transferred into the EndNote reference management software. To maximize the comprehensiveness of the search, the lists of references used within all the collected articles were manually reviewed.

Keywords used as per MeSH: paediatric cancer, parental perspectives, psychological impact, coping strategies, and emotional support.

Inclusion/exclusion criteria.

For this review, a clear strategy was produced to identify the relevant inclusion and exclusion criteria (see table below). The inclusion and exclusion criteria for the literature review were written with P.I.C.O. in mind. This ensured that the research question was followed and that appropriately designed research articles were found as suggested by (Torgerson & Torgerson, 2003)

As this review focuses on the Parental and Pediatric perspectives during the cancer trajectory were deemed appropriate (Pati & Lorusso, 2017) highlight that the inclusion and exclusion criteria within a literature search is a source of potential bias therefore higher trust and credibility can be gained by the clear documentation of such exclusion and inclusion criteria. Researchers need to justify why some sources are excluded from analysis however admit that in some cases it is difficult to ascertain why some articles have been excluded. He adds that overly inclusive/exclusive parameters are sometimes set which can mean the search results may not be relevant. The inclusion criteria set by PICo. Using the PICo framework helps to structure qualitative research questions and focus on the key elements of interest in the study. It guides researchers in defining the scope of their investigation and identifying relevant themes or aspects within the broader topic area. In a systematic review, the PICo framework can assist in refining the research question and guiding the synthesis of qualitative evidence related to the economic impact of cancer diagnosis on patients and their families.

Population/Problem	Pediatric cancer patients (aged 12-18 years) and their parents
Interest	The experiences, emotional, psychological, and social perspectives of both pediatric patients and their parents throughout the cancer journey.
Context	The cancer trajectory, encompassing diagnosis, treatment, and survivorship, as well as the emotional, psychological, and social challenges faced during these stages.

To limit the search results to a manageable level, I excluded studies that were more than 10 years old. (Lipscomb, n.d.) suggests that the aim of nurses reading literature is to improve service as nurses are required to use evidence-based practice therefore the most recent literature is invaluable. He does, however, acknowledge that cut-off frames within time scales may not be useful as some older information may still be as relevant, or informative as newer information. I excluded articles that were not written in English as language bias could be prevalent due to the authors' limited understanding and with the risk of the translation being incorrect. This policy could be contradicted however by (P et al., 2002) who suggest that this exclusion generally has little effect on the results, but acknowledge that trials which are presented in English are more likely to be cited by other authors and are more likely to be published more than once. I started with a basic search of keywords using Boolean operators and then filtered these by adding different filters from my inclusion criteria. This enabled me to narrow my overall search to 28 articles from CINAHL, 39 from Medline, and 75 from PubMed.

From these 142 articles, I used a PRISMA flow diagram to identify my article selection (See Fig 1). Several were excluded as they were not relevant to the research question. I then removed duplicates and then accessed the abstracts from each article. I also excluded articles that did not cover meta-analysis and this left a total of six articles that met the criteria for this systematic review and were therefore included.

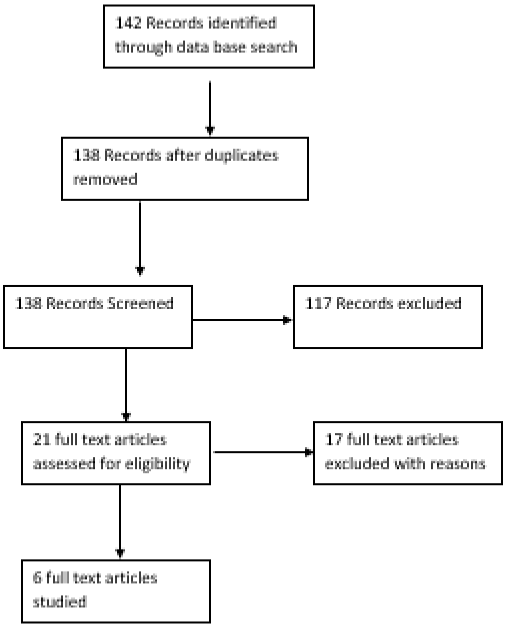

Figure 1. Prisma Flowchart

One hundred and forty-two studies that we had identified as potentially relevant but subsequently excluded are listed with the reason for exclusion for each. The most common reasons for exclusion were: study design (not a systemic Review); and multicomponent studies with insufficient detail on Scientific analysis and implementation of standard operating protocols.

3. Results

The final articles will be critiqued and analyzed. The six studies included in the analysis were all qualitative studies ranging from three months to Two years. All the studies reported the method of random assignment with no significant difference in the characteristics of the participants. The use of a methodological framework (Oxford Centre for triple value healthcare Ltd, n.d.)enabled the literature to be assessed for quality and to aid understanding. The table below is used to display an overview of each article.

Author's/Year	Sample/setting	Methodology and methods	Main findings
(Rosenberg et al., 2013)	32 parents of children with cancer (aged 2-16); Pediatric oncology outpatient clinic, Australia	Mixed-method study; Quantitative distress questionnaires and qualitative interviews; Thematic analysis applied	High parental psychological distress was reported. Coping strategies included religious beliefs and family support. Parental coping directly affected child well-being.
(Barrera et al., 2020)	122 caregivers, 36 patients, 25 siblings; Pediatric cancer centers in Canada	Randomized controlled trial. Families randomly assigned to an intervention group (IG) with psychosocial screening summary given to treating team or control group (CG) with no summary. PAT and QOL assessments at 2-4 weeks post-diagnosis (T1) and 6 months post-diagnosis (T2). Caregivers completed proxy QOL for patients and siblings.	Patient-proxy total QOL improved in the intervention group, but only for high psychosocial risk patients. Caregiver QOL improved over time, as did patient cancer-related QOL regardless of group. This study highlights the benefits of psychosocial screening results, especially for patients at high psychosocial risk, underscoring its clinical value.
(Pierce et al., 2017)	67 parents of pediatric cancer patients (Mage = 9.5 years, SD = 5.5)	Parents completed several psychosocial screening tools, including the Psychosocial Assessment Tool (family risk), Distress Thermometer, PTSD Checklist, and PedsQL 4.0. Parent acceptability questions administered electronically.	The majority (70%-97%) found electronic screening acceptable. Family risk and caregiver distress were significant predictors of poorer HRQL in patients, while age (older) was a significant covariate for total HRQL. Gender, diagnosis, treatment intensity, and time since diagnosis were not significantly correlated with risk or HRQL.
(Nam et al., 2016)	N = 366 pediatric cancer caregivers	The Impact of Event Scale (IES), along with two subscales "intrusion" and "avoidance" measured caregiver cancer-specific distress, with higher scores indicating greater distress. Multivariable linear regression models	Our findings identify socioeconomic and clinical factors that influence psychological distress for caregivers of pediatric oncology patients. These findings underscore the importance of developing and testing interventions aimed at evaluating and

		were used to calculate coefficients (β) and 95 % confidence intervals (95 % CI) of IES by socioeconomic, demographic, and clinical factors.	addressing the psychosocial needs for high-risk caregivers in addition to those of patients.
(Feki et al., 2021)	forty-three parents (34 mothers and 9 fathers) were assessed	This is a descriptive study carried out on parents of children diagnosed with cancer and treated in the department of medical oncology at the Habib Bourguiba Hospital in Tunisia. Over a period of four months, from the beginning of December 2020 until the end of March 2021, forty-three parents (34 mothers and 9 fathers) were assessed, using psychometric scales of anxiety, depression and post-traumatic stress according to respectively to the Hamilton anxiety rating scale (HAM), the Beck Depression Inventory (BDI) and the Impact of Event Scale (IES-R).	The prevalence of anxiety and depressive disorders was high among parents of children diagnosed with cancer and a significant correlation was found between stress and anxiety with the female sex of parents. Our results were similar to several studies although other risk factors for psychological distress in parents of children with cancer were described in the literature.
(Schwartz-Attias et al., 2024)	108 parents of children aged 7–18 diagnosed with cancer	The cross-sectional study included 108 parents of children aged 7–18 diagnosed with cancer at least 6 months prior to the study. The parents completed one questionnaire comprising five instruments: perceived impact of illness, hope, social support, positive and negative affect (the emotional component of well-being) and life satisfaction (the cognitive component of well-being). Descriptive statistics and Pearson correlations were conducted for all study variables. SEM analysis was performed to examine the study's theoretical model.	A parent with social support resources and higher levels of hope experiences higher levels of positive perceptions regarding their child's illness. Higher levels of positive perceptions allow the parent to express more positive than negative emotions, thus maintaining a more optimal level of subjective emotional well-being. The findings offer implications for healthcare teams to enhance sensitivity to parents' needs and to help parents attain more resources, positive perceptions, and well-being.

The first study was conducted by (Rosenberg et al., 2013). The study was conducted to describe the prevalence and factors of psychological distress (PD) among parents of children with advanced cancer. Eighty-six of 104 parents completed the Survey About Caring for Children With Cancer (83% participation); 81 parents had complete Kessler-6 Psychological Distress Scale data. More than 50% of parents reported high PD and 16% met criteria for serious PD (compared with US prevalence of 2%-3%). Parent perceptions of prognosis, goals of therapy, child symptoms/suffering, and financial hardship were associated with PD. In multivariate analyses, average parent Kessler-6 Psychological Distress Scale scores were higher among parents who believed their child was suffering highly and who reported great economic hardship. Conversely, PD was significantly lower among parents whose prognostic understanding was aligned with concrete goals of care.

The second study was conducted by (Barrera et al., 2020). The study was conducted to evaluate whether conducting psychosocial screening using a validated measure (the Psychosocial Assessment Tool, PAT) and providing a summary of PAT results to the patient's treating team improves the quality of life (QOL) in newly diagnosed patients with cancer, their caregivers and siblings, in general, and in relation to the initial family psychosocial risk. In general, patient-proxy total QOL improved in IG compared to CG over time but only for high psychosocial risk patients ($p < .05$). Patient proxy cancer-related QOL improved over time regardless of group allocation; caregiver QOL also improved over time ($ps < .05$).

The third study was conducted by (Pierce et al., 2017). The study was conducted to assess the acceptability of screening for parents and evaluate associations between family risk factors and patient HRQL in the first year post-diagnosis. Patients (Mage = 9.5 SD = 5.5 years) were equally distributed across major pediatric cancer diagnoses. The majority of parents endorsed electronic screening as acceptable (70%–97%). Patient gender, diagnosis, intensity of treatment and time since diagnosis were not significantly correlated with family risk, caregiver distress, traumatic stress, or patient H.R.Q.L. The full regression model predicting total H.R.Q.L. was significant ($R^2 = .42$, $F(4,64) = 10.7$, $p = .000$). Age (older) was a significant covariate, family risk and caregiver distress were significant independent predictors of poorer total H.R.Q.L. The full regression models for physical and psychosocial H.R.Q.L. were significant; age and caregiver distress were independent predictors of physical H.R.Q.L., and age and family risk were independent predictors of psychosocial H.R.Q.L.

The fourth study was conducted by (Nam et al., 2016). The study was conducted to evaluate the association of socioeconomic, demographic, and patient clinical factors on caregivers' self-reported psychological distress associated with having a child with cancer. Average caregiver IES score was 31.2 (standard deviation (SD) = 16.9, range 0-75). Mean intrusion score was 18.1 (SD 9.8, range 0-35) and avoidance score was 12.8 (SD 9.0, range 0-40). Caregivers with household incomes <$40,000 reported higher mean distress scores than those with incomes ranging from $40,000 to $79,999 ($\beta = 4.45$, 95 % CI 0.04-8.87, $p = 0.05$). Infrequently or never attending religious services, younger child age, and a diagnosis of AML were associated with higher intrusion (all $p < 0.05$). Caregivers with a child currently receiving therapy reported higher overall IES ($\beta = 5.9$, 95 % CI 2.15-9.7, $p < 0.01$) and intrusion ($\beta = 4.1$, 95 % CI 1.9-6.3, $p < 0.001$) scores compared to those off therapy ($\beta = 3.13$, 95 % CI 0.93-5.33, $p < 0.01$).

The fifth study was conducted by (Feki et al., 2021). The study was conducted to determine the prevalence and the risk factors of psychological distress among parents of children diagnosed with cancer. Sixteen percent of the parents had scores indicating acute stress and 21% had scores indicating post-traumatic stress. Eighty six percent of the parents had mild to severe depression and 95% had minor to major anxiety. Post-traumatic stress and anxiety are significantly correlated with the female sex of parents. Significant correlations are also found between post-traumatic stress scores and symptoms of depression and anxiety. However, our study did not show a significant correlation between the others factors studied and the parents' psychological distress.

The sixth study was conducted by (Schwartz-Attias et al., 2024). The study was conducted to explore the role of illness impact perceptions in mediating the link between hope, social support and subjective well-being in parents of children with cancer. The current sample included 108 parents of children with cancer recruited from two pediatric hematology-oncology wards in two different hospitals in central Israel. Most participants were mothers (70.4%), and the mean age was 44.46. The main results indicated that hope and social support correlated negatively with perceptions of the illness' impact. Illness impact perceptions mediated the relations between hope, social support and positive emotions, which means that when the parents perceived their child's illness as less impactful on the family, they experienced higher levels of emotional well-being.

4. Discussion

The psychological distress (PD) experienced by parents of pediatric cancer patients is a crucial area of concern, as highlighted by multiple studies. These studies provide insights into the prevalence of PD, its associated factors, and potential interventions to mitigate its negative impact on families. Understanding these findings allows for better support systems and interventions targeting parents throughout their child's cancer journey.

The study by Rosenberg et al. (2013) emphasizes the high prevalence of psychological distress among parents, with over 50% of participants reporting significant distress and 16% meeting criteria for serious PD. This is a stark contrast to the general population in the U.S., where PD prevalence is typically around 2-3%. Factors such as perceptions of prognosis, goals of therapy, and financial hardship were significantly associated with higher PD levels. Parents who believed their child was suffering or faced economic difficulties reported higher PD, while those with a better understanding of prognosis and aligned goals of care experienced less distress. This indicates that targeted interventions focused on improving communication around prognosis and reducing economic stressors could significantly alleviate parental distress.

Barrera et al. (2020) demonstrated the benefits of psychosocial screening using the Psychosocial Assessment Tool (PAT) to improve quality of life (QOL) for high-risk patients and their families. The study found that psychosocial screening had a tangible impact on QOL, particularly for patients with high psychosocial risk. Notably, both patient-proxy QOL and caregiver QOL improved over time, highlighting the value of early psychosocial interventions for families identified as at risk. This underscores the importance of integrating psychosocial assessments into routine pediatric oncology care, particularly for families with higher psychosocial burdens.

Pierce et al. (2017) further explored the role of psychosocial screening, focusing on its acceptability and effectiveness in predicting health-related quality of life (HRQL). The study revealed that electronic psychosocial screening was well-accepted by parents, with 70-97% of parents endorsing its use. Importantly, the study identified family risk and caregiver distress as significant independent predictors of poorer HRQL in pediatric cancer patients. These findings are consistent with previous research, reinforcing the need for early identification of at-risk families to mitigate long-term negative impacts on patient well-being.

Nam et al. (2016) explored the socioeconomic and demographic factors influencing caregiver distress. Caregivers from lower-income households reported higher distress levels, while caregivers with children undergoing active therapy reported higher overall distress and intrusion scores. These findings align with other studies emphasizing the critical role of financial stability and active disease management in caregiver mental health. Financial support programs and better psychosocial care during active treatment phases could be valuable interventions to reduce caregiver distress.

Feki et al. (2021) confirmed that PD is prevalent among parents of children with cancer, with high rates of anxiety and post-traumatic stress. Female parents, in particular, were more prone to psychological distress, which was further associated with symptoms of depression and anxiety. The study's findings highlight the importance of gender-specific interventions and mental health support for mothers, who may be at higher risk for mental health complications during their child's treatment.

Lastly, Schwartz-Attias et al. (2024) introduced the role of hope and social support in mitigating the negative impact of illness perceptions on parental well-being. Their findings suggest that when parents perceive their child's illness as less impactful, they experience higher levels of positive emotions. Hope and social support play a mediating role, reducing the perceived severity of the illness' impact on the family. These findings point to the potential of interventions that foster hope and strengthen social support networks as a means of improving parental emotional well-being during the cancer trajectory.

Overall, these studies underscore the critical need for timely psychosocial interventions aimed at alleviating the psychological burden on parents of pediatric cancer patients. Key strategies include improving prognostic communication, addressing financial hardships, implementing psychosocial screening, and fostering hope and social support. Tailored interventions that consider gender differences and socio-economic status are essential to reduce long-term psychological distress and enhance both parental and patient outcomes. Future research should continue to explore personalized psychosocial support strategies and further evaluate their effectiveness in improving the quality of life for families facing pediatric cancer.

Bias Assessment

A systematic review of published studies is limited by the fact that it excludes unpublished data and this may result in publication bias but till potential publication bias was not assessed using a funnel plot or other corrective analytical methods.

5. Conclusion

The psychological distress experienced by parents of pediatric cancer patients is a significant concern that profoundly impacts their quality of life and emotional well-being. The studies reviewed highlight the high prevalence of distress, anxiety, and post-traumatic stress among parents, with financial hardship, misalignment with prognostic expectations, and child suffering being key contributing factors. The role of psychosocial screening, as demonstrated by Barrera et al. (2020) and Pierce et al. (2017), underscores the importance of early identification of high-risk families and timely interventions to mitigate distress and improve overall quality of life for both patients and caregivers.

Further, the gender-specific differences in distress, noted in Feki et al. (2021) and the critical role of social support and hope, as seen in Schwartz-Attias et al. (2024), highlight the need for tailored, individualized support systems. Interventions that enhance communication about prognosis, reduce economic strain, and foster emotional resilience are crucial in alleviating parental distress throughout the cancer trajectory.

While these findings provide important insights, future research should address current limitations by including larger, more diverse samples, utilizing longitudinal designs to track distress over time, and exploring the unique needs of both mothers and fathers. By improving psychosocial care and support, we can better equip families to manage the emotional challenges of pediatric cancer and improve outcomes for both parents and their children.

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