Journal of Pediatric Academy

Invited Review

Year: 2024 Volume: 5 Issue: 2
Doi: 10.4274/jpea.2024.309
J Pediatr Acad 2024; 5: 37-43

Integrating Child Life Specialists in Pediatric Oncology and Hematology Care: A Narrative Review

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Article Information

Article Type: Invited Review
Article Group: Pediatric Oncology

Received: 26.04.2024
Accepted: 30.05.2024
Epub: 06.06.2024
Available Online: 01.07.2024

Cite this article as: *Abdelkhalik M, Ibrahim M, Al Maaz F, Boutros E. Integrating Child Life Specialists in Pediatric Oncology and Hematology Care: A Narrative Review. J Pediatr Acad. 2024; 5: 37-43*

Abstract

Many healthcare systems overlook the importance of enrolling a child life specialist (CLS) on board, possibly due to the lack of knowledge and awareness on the impact they might yield. This study highlights the essential contributions of CLS in improving pediatric oncology healthcare experiences. A thorough search of numerous databases was performed to identify English-language publications between 2005 and 2024, using a variety of study methods to establish a diverse evidence base. CLSs offer emotional support, educate patients and their families, implement distraction techniques, and collaborate with healthcare personnel to assist patients throughout their treatment journey. They also aid in providing adequate knowledge to patients and their families regarding medical procedures and treatment outcomes. Hence, CLSs play a vital role to play in the care of pediatric hematology oncology patients. A comprehensive interdisciplinary approach is needed to extend the role of CLS and ensure that every child receives the support and care they deserve.

Keywords: Child life specialist, pediatric oncology, pediatric hematology, pediatric cancer care

Introduction

In the field of pediatric healthcare, where anxiety and uncertainty are common, child life professionals prioritize the emotional well-being of children during these difficult moments. These trained healthcare professionals are specialized in offering emotional, developmental, and psychosocial support for children experiencing illness and advocating for the holistic care of young patients.[1]

The role of child life specialists (CLSs) extends beyond typical healthcare paradigms, embracing a wide range of interventions adapted to each child's individual needs. According to the American Academy of Pediatrics (AAP), CLS can provide expert advice and support in managing a child's pain.[2] Furthermore, CLS reduce the negative effects of treatments by promoting adaptive behavior and resilience. Overall, their role includes providing age-

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appropriate explanations of medical procedures, therapeutic play interventions, active coping strategies, education, play, and expressive activities.[3] By providing all the aforementioned services, CLS has a pivotal role in reducing stress and anxiety for children undergoing painful procedures.[4]

Cancer in children comprises only 2% of all cancer cases, yet it is the second most common cause of death in children older than 1 year after trauma.[5] CLS are vital assets in pediatric oncology, offering crucial assistance to children and families navigating the complex and emotionally difficult treatment journey. Families benefiting from the expertise of certified CLS have reported alleviation of fear, anxiety, and stress, among other positive outcomes. Hence, CLS can aid in reducing the impact of these challenging times on the child and his/her family and improving the overall quality of life.[6]

This study seeks to underscore the invaluable contributions of CLS in enhancing pediatric oncology healthcare experiences. We will shed light on how CLS promotes coping, resilience, and general well-being among pediatric patients and their families by analyzing their contributions in different settings and through different procedures. By highlighting their expertise, interventions, and effects, we aim to stimulate additional study, advocacy, and cooperation to ensure that every child receives the support and care they need during times of sickness or injury.

Methodology

Search Strategy and Inclusion Criteria

This original review was written in April 2024. The authors conducted a search using PubMed, Cinahl, Web of Science, Medline, and Science Direct using the following keywords: "Child Life Specialist", "Pediatric Oncology", and "Hematology".

The following inclusion criteria were used:

1. Articles published in English.

2. Articles published between 2005 and 2024 were deemed to reflect contemporary research and advancements.

3. The study included case-control, cross-sectional, cohort, and review papers to collect a broad variety of information on the subject.

Selection Process

The two authors conducted the literature searches separately, guaranteeing a thorough search of the given databases. Zotero automatically detects and removes duplicate articles. After deleting duplicates, the remaining items were screened on Rayyan. During the screening process, the authors separately assessed the titles and abstracts of these papers, removing any article that did not fulfill the inclusion criteria. The exclusion criteria at this stage included research unrelated to the topic, non-English papers, and those published before 2005.

The following title and abstract screening, the entire text of the submitted articles was examined to determine their suitability for inclusion in the research. The summary and visual depiction of selection process is presented in **Figure 1**.

Data Analysis

Two writers independently extracted data from the included studies. Data extraction included important information such as the function of the CLS, duties, constraints, primary results, and any other information relevant to the review's aims. This technique ensured that the literature was evaluated comprehensively and thoroughly. Following this methodological procedure, we tried to find and select papers that were most relevant to the review's aims, providing a solid framework for our research.

Results and Discussion

Understanding Pediatrics Oncology and Hematology

A child cancer diagnosis is a complex process involving multiple procedures and operations where children often experience anxiety and distress, mostly stemming from the treatment's challenges and not the cancer itself.[7] Patients and their parents often feel the urge to start the treatment as soon as the diagnosis has been confirmed, which negatively impacts their daily routine and causes further distress.[8] Studies have shown that pain and anxiety were reported by 50-60% of children with cancer when receiving various medical operations and nearly 63% developed a fear of healthcare professionals.[5]

In addition to anxiety and fear, pain is among the most prevalent unpleasant feelings experienced by children with cancer. Expressed by crying, twisting, and muscle stiffness,[9] pain is thought to contribute to anxiety and fear experienced by the child. These feelings are heightened during treatment, possibly because of exposure to unfamiliar environments and separation anxiety.[10]

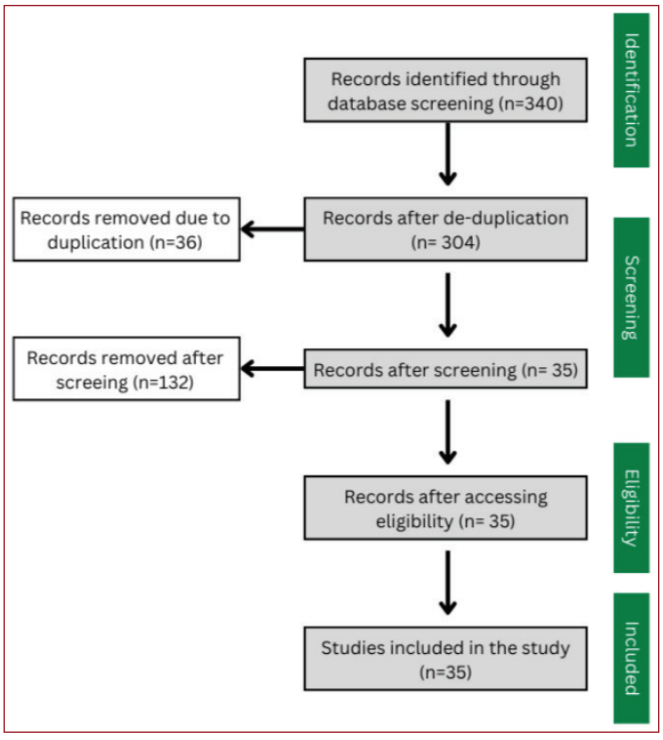

Figure 1. PRISMA flow diagram of literature screening for CLS and pediatric hematology/oncology

CLS: Child life specialist

The prospect of painful treatments, intrusive procedures, and probable side effects looms large, casting a shadow of fear over the treatment journey. Many children are terrified of numerous medical procedures, anxious about the uncertain progression of their disease, and worried that they are different from other children.[11] Surgical procedures can elicit various unfavorable emotions from children, with 50%-65% suffering from perioperative anxiety.[12]

Pediatric hematology and oncology encompass a wide spectrum of illnesses and therapies that require specialized care and attention owing to their complexity and possible influence on a child's well-being. Chemotherapy, radiation therapy, and stem cell transplantation are among the principal therapeutic techniques, each imposing considerable physical and emotional difficulties on pediatric patients. The side effects of these procedures, such as nausea, hair loss, fatigue, and immunosuppression, have a great impact on the child's quality of life and necessitate careful care provided by CLSs.[13-15] Other painful medical procedures that lead to anxiety in children include venipuncture, bone marrow, lumbar punctures, and placement of central venous catheters.[16] In addition, port needle operations are the most disturbing, frightening, and painful aspect of children's chemotherapy treatment.[11] Furthermore, the long-term complications and late effects experienced by childhood cancer survivors, including secondary malignancies, infertility, cardiotoxicity, and neurocognitive deficits, necessitate comprehensive follow-up and survivorship care.[17,18] Considering these complexities, a multidisciplinary approach encompassing the expertise of CLS is important to provide support and optimize outcomes in pediatric hematology and oncology. The main findings of the study are summarized in **Table 1**.

Highlights

- Child life specialists (CLSs) have played a crucial role in the mental and physical aspects of patients' well-being. Unfortunately, many healthcare systems overlook the importance of enrolling a CLS, possibly due to the lack of knowledge and awareness on the impact they might yield.
- The study conducted a thorough systematic search of various databases for English-language articles published between 2005 and 2024 discussing the use of virtual reality in pediatric oncology procedures.
- CLSs offer emotional support, educate patients and their families, implement distraction techniques, and collaborate with healthcare personnel to assist patients throughout their treatment journey. Challenges include insufficient knowledge and awareness of children's needs, lack of recognition of CLS' work, and lack of institutional support.

Role of the CLS

Definition and Historical Background

CLSs emerged in the mid-20th century (1920) as part of pediatric healthcare.[19] In the 1960s, CLS was founded as a medical specialty by Emma's efforts Plank.[20] Emma Plank, a pioneer in the field, emphasized the importance of play therapy and emotional support for hospitalized children. She proposed the idea of playrooms inside hospitals that would allow children to engage in activities.[21] In addition, by 1960, the AAP had published a study and guidelines for the treatment of children in hospitals, advising that all pediatric units include a playroom equipped with suitable items such as games, toys, and books.[3] The Child Life Council, which became known as the Association of Child Life Professionals in 2016, was founded in 1982 to promote child wellbeing while also providing professional support and development opportunities for CLS.[22] The council established criteria for education, training, and certification in the sector, thus promoting its professionalization and growth.[19] Since then, CLS has become a fundamental aspect of pediatric treatment, both inpatient and outpatient, and has achieved favorable results in several settings.[23]

Importance of Psychosocial Support in Pediatric Hematology and Oncology

Hospitalization can be a significant stressor for children, leading to several negative consequences if not managed properly.[24] Indeed, children may retain long-term memories of pain, potentially prolonging the recovery process.[25] Additionally, recurrent hospitalizations may affect cognitive, emotional, and social development.[26] This is where the importance of addressing these challenges reveals itself, as children who received child life services experienced reduced levels of anxiety compared with those who did not.[1] These results have an important impact because lower stress levels are linked to better healing outcomes for children. In addition, CLS has a positive impact on the psychological aspect of anxiolysis and improves the child's experience.[27]

Roles and Responsibilities of CLS

The existing research mainly addresses children's psychological needs in parallel with the role of CLS, focusing on emotional support, proper preparation for medical procedures, play therapy, distraction techniques, education, and advocacy.

Emotional Support for Patients and Families

CLS contributes to the establishment of a safe and supportive environment where children are encouraged to openly express their emotions and receive experience validation when needed. This is done in various ways, including active listening, acknowledgment of the child's emotions, reassurance, and encouragement. This continual emotional validation and support helps to normalize children's emotional responses to illness, hospitalization, and medical procedures.[28]

Child coping, behavioral cooperation, and levels of discomfort were all measured in a study assessing the impact of CLS intervention on the emotional

Table 1.
Showing the main findings of our study

Main findings	Author
50-60% of children diagnosed with cancer experience pain and anxiety when undergoing medical operations.	Miller et al.[5]
Venipuncture, bone marrow, lumbar punctures, and placement of central venous catheters are among the main medical procedures that lead to anxiety in children.	Loeffen et al.[16]
The assistance of child life services reduced the anxiety levels of children, which is linked to better healing outcomes and improvement in experience.	Murag et al.[27]
The reduction of moral distress and burnout among clinical personnel improving their mental health and well-being is also attributable to CLS.	Rosenblatt et al.[28]
A positive correlation between the impact of CLS intervention on the EMS of pediatric patients undergoing polysomnography was described.	Baughn et al.[29]
A significant reduction in healthcare costs is noticed due to a decrease in the need for daily sedation when CLS provides play-based procedural preparation and support for the children.	Grissom et al.[31]
Physical or technology-based distraction tools are important for improving patient satisfaction during cast room procedures.	Burkhart et al.[35]
Child life intervention plays an important role in alleviating the negative symptoms of pain, fatigue, and anxiety in patients with acute leukemia undergoing chemotherapy.	Li et al.[38]
Playing video games daily did not affect the performance of pediatric chemotherapy patients.	Hamari et al.[40]
Almost all physicians in U.S. pediatric urology agreed on the positive impact of CLS on their patients' quality of life.	Mistry et al.[41]

CLS; Child life specialists, EMS; Emotional manifestation score

manifestation score of pediatric patients undergoing polysomnography. Interestingly, a statistically significant positive correlation was observed for those who were offered CLS. Their results also suggest that CLS emotional support not only enhances children's coping mechanisms with medical procedures but also leads to higher satisfaction scores from patients and families.[29]

In parallel to the above, another study compared the experience of children with lacerations in the emergency room with and without CLS and found that CLS engagement was related to decreased emotional distress.[30] In fact, the emotion-focused supportive interventions performed by CLS have been very effective in enhancing resilience, upscaling coping skills, and mitigating traumatic experiences.[28]

Educational Preparation for Medical Procedures and Treatment

CLS plays an important role in introducing patients and their families to upcoming medical procedures using age-appropriate simplified language. They explain the procedure, establish expectations, and support all members using various techniques such as distraction and vocalization. To assist the child in processing the experience, CLS are also in charge of performing post-procedural debriefing.[29] Dolls are useful tools frequently used by CLS as they psychologically prepare their patients, especially pre-operatively.[31]

The role of CLS also extends into the procedure itself, where their presence and interventions reduce the duration of procedures while improving imaging quality in radiology departments.[32]

In addition to the procedure itself, CLS assists families in understanding their child's treatment response and maintaining their caregiving roles. This includes encouraging play sessions, introducing distraction techniques, and training them on emotionally supportive strategies for comforting their children during medical procedures. As for the siblings of young age groups, CLS helped them to comprehend the illness through age-appropriate lectures and repeated visits to the hospital.[33] Specially trained CLSs are also qualified to offer grief support activities for siblings in the setting of catastrophic injury or death or episodes of terrorism.[34]

Play Therapy and Distraction Techniques

Games, being familiar and reassuring to children, have aided in making the healthcare experience more comfortable and less intimidating.[33] Studies on play-based procedural preparation and support intervention provided by a CLS show a significant drop in healthcare costs because it reduces the necessity of daily sedation.[31]

In addition, other interventions, including therapeutic play and distraction techniques, are implemented to reduce fear, anxiety, and pain among pediatric patients and their families. A meta-analysis conducted by Burkhart et al.[35] described physical or technology-based distraction tools as key players in improving patient satisfaction during cast-room procedures. Most of the adopted tools were inexpensive and readily applicable to the clinical setting. Similarly, a cross-sectional study revealed that 45% of parents consider play intervention as one of the key factors in enhancing their experience during hospital stay. Only 5% of the parents had persistent reported stress about the illness after CLS intervention.[31]

Collaborating with Healthcare Teams

CLS cannot yield effective results if operated on its own. They are members of multidisciplinary teams that collaborate with physicians, nurses, social workers, and palliative care centers. CLS not only impacts patients and their families but also has a positive impact on the mental health and well-being of clinical practitioners through their constant support to reduce moral distress and burnout.[28]

Impact and Benefits

Effectiveness of CLS in Pediatric Hematology and Oncology

Here, we may begin by mentioning a case study by Basak et al.[36] that describes the role of CLS in the treatment journey of a 14-year-old boy known to have progressive ependymoma with hydrocephalus and multiple secondary metastases with impending herniation of the brain. The patient was depressed, anxious, and uncooperative with the staff. After several failed attempts by the CLS provider, he noticed that the patient had a special interest in magic. As a result, a medical student, dressed like a magician, helped the patient interact, smile, and relax. The parents and the patient reported feeling more emotionally supported after this initiative.[36] Such a case reveals the importance of adapting one's approach to tailor to the needs and interests of each individual child.

In another retrospective study conducted on sickle cell disease pediatric patients, results showed that a patient's encounter with CLS can enhance health care experience through support and education, especially during the transition process from a pediatric hematology patient to an adult hematology patient.[37]

Similarly, Li et al.[38] assessed the effect of CLS interventions on acute leukemia patients undergoing chemotherapy. Their results show that child life intervention can effectively lessen pain, control anxiety, decrease fatigue, and limit sleep disturbances. Music therapy also appears to help lower anxiety and fear in pediatric oncology patients performing a lumbar puncture.[39]

In contrast, a randomized control trial conducted by Hamari et al.[40] showed no significant difference in terms of physical activity, motor performance, and fatigue in chemotherapy pediatric participants when asked to play video games daily. Although this study does not include CLS, play therapy and distraction techniques do not seem to make a significant difference in the treatment of pediatric oncology patients.

Unfortunately, the current literature lacks sufficient cross-sectional studies on CLS effectiveness specifically targeting the pediatric hematology oncology population.

Patient and Family Perspectives on the Role of CLS

Since CLS is not globally implemented in the healthcare system, examining the knowledge and perspectives of patients and parents on CLS becomes crucial. On the one hand, almost all physicians felt that CLS did benefit their patients' quality of life in a study conducted in the U.S. in pediatric urology.[41] Another study assessing parents' satisfaction and perception of inpatient CLS showed that most parents did not know about CLS before their first admission but were satisfied with the interventions they received on the floor.[42] This shows the need to properly communicate the role of CLS to all parents, possibly during their outpatient visits to their pediatricians, or through informative workshops and training.

Challenges and Future Directions

Challenges Faced by CLSs in Pediatric Hematology and Oncology

Taneja et al.[43] conducted a review of CLSs' experiences in adult oncology settings and highlighted a range of challenges that hinder practitioners from fully implementing their expertise in the children's plan of care. These challenges coexist in adult and pediatric settings and stem from the inherent nature of the work. Insufficient knowledge and awareness of children's needs in such settings and the lack of recognition of CLSs' work often leads to delayed involvement. Furthermore, many of these cases are morally challenging, leading practitioners to struggle to do what they think is best for the child. In addition, the families' wishes to withhold information about the diagnosis from their children add an additional layer of complexity to the responsibilities of CLSs and can potentially lead to resentment and trust issues from the child. Other limitations worthy of consideration include the inconsistency of follow-up frequently encountered (especially post-mortem), minimal involvement of the specialist by the primary care physician, and the overall lack of institutional support.[43]

Opportunities for Further Research and Development in This Area

CLS integration in every pediatric oncology patient's plan of care requires a transformative approach starting at the medical school level. Comprehensive interdisciplinary education programs should underscore the importance of CLS involvement and endorse teamwork, communication, and collaboration skills to meet patients' needs.[44] At the operational level, early involvement of CLSs is vital for establishing trust and rapport with the child and the family.[45] This can be encouraged by an opt-out, rather than opt-in, hospital system. In addition, it is essential that the primary care team educates the patient's family on the holistic nature of child well-being and stresses the family-centered approach for treatment.[46] In this regard, Brosnan et al.[47] also highlighted the importance of implementing sibling assessment and support in the plan of care. An intricate evaluation and quality improvement system that continuously monitors and assesses CLS in oncologic floors and disseminates data should also be established.

Overall, advocacy and awareness campaigns on the unique contributions of CLSs in pediatric oncology care among healthcare professionals and the wider community are essential in promoting policies and supporting CLS integration in the plan of care.

Conclusion

CLS play an important role in pediatric hematology and oncology by providing critical assistance to children and their families as they deal with the emotional challenges of illness. Their expertise in meeting the particular requirements of children with cancer and blood disorders ensures that care goes beyond medical treatment, encouraging resilience and assisting them in overcoming obstacles. As we look ahead, possibilities for research, development, and comprehensive multidisciplinary

education programs hold promise for expanding the role of CLS, especially in the field of pediatric oncology, and ensuring that every child receives the support and care they need.

Acknowledgments

We would like to thank Joseph El Haddad, who contributed to this project by reviewing the manuscript and making the necessary English language edits.

Informed Consent: The consent form was not needed due to the study design.

Author Contributions: Mohamad Abdelkhalik: Concept, Design, Data Collection or Processing, Analysis or Interpretation, Literature Search, Writing.; Maria Ibrahim: Concept, Design, Data Collection or Processing, Analysis or Interpretation, Literature Search, Writing.; Fatima Al Maaz: Literature Search, Writing.; Eliannore Boutros: Writing.

Conflict of Interest: The authors revealed no possible conflicts of interest with regard to the research, authorship, and/or publication of this work.

Financial Disclosure: The authors declared that this study received no financial support.

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