International Journal for Multidisciplinary Research (IJFMR)
E-ISSN: 2582-2160 ● Website: www.ijfmr.com ● Email: editor@ijfmr.com

Child Life Services in India: A Pilot Study

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Abstract

Paediatric patients face various emotional, physical, psychological and psychosocial problems when they are admitted to hospitals. The most common symptoms among these children are anxiety and fear, which can manifest as psychosomatic symptoms. These can cause an imbalance in the regulation of our body, leading to decreased chances of proper recovery. Child Life Services (CLS) within healthcare organisations aim to reduce this fear and other side effects and promote the well-being of the patients and their families. It is grounded in basic principles of psychology, childcare and health. This article highlights the origin of CLS and the problems that occur during the hospitalisation of paediatric patients. This helps establish the need for CLS in collectivistic countries like India. While hardly a few hospitals in India have these services, the implementation of these services nationwide has been discussed. The article focuses on the nature of these services in Aster Hospital, based in Bengaluru, Karnataka, where this support system was initiated as a Pilot project and is now running as an important part of Paediatrics. The tools, techniques, and systems of these services in the hospital have been described from the lens of a Child Life Intern undergoing training. The descriptives of the paediatric patients admitted from October to December and the type of interaction facilitated by the intern have been elaborately discussed. The article concludes with the need for research opportunities to help bridge the gap between the knowledge and implementation of CLS in India.

Keywords: Child Life Services, Paediatric, Psychological Support, India

Introduction

The Past And The Present Of Child Life Services

In the early 1920s of the medical world, infant mortality was correlated with a lack of family support, sensory stimulation, and human contact. "Play ladies" were employed in the field to mitigate these issues in response to this research and to provide games and activities. In 1922, Mott Children's Hospital established the first play program for paediatric patients and in 1955, Emma Plank developed the first Child Life Program, encompassing hospitalised children's developmental, educational, and psychosocial needs. From the 1960s to the early 1980s, the field of child life experienced exponential growth. Play ladies were called child life specialists, who worked relentlessly to educate others about the psychosocial needs of children in hospitals. As a result, the Association for the Care of Children's Health, a multidisciplinary organisation, was established to make changes in health care that would reflect the needs of families and create a more child-friendly environment. A professional organisation, the Child Life Council, was established, along with skilled resources and official documents to outline the many facets

of the child life profession and standards of clinical practice. The certification for Child Life Specialists was established in 1986 [1, 2].

The Association of Child Life Professionals (ACLP) is responsible for establishing and maintaining professional standards, enhancing members' professional growth and development, and advancing the credibility of the child life profession. This non-profit organisation promotes the practice of Child Life Services (CLS) internationally. Apart from the USA, countries such as Canada, Japan, Kuwait, the United Kingdom, South Africa, New Zealand, and Switzerland are countries where Child Life Specialists actively work [3].

Child life specialists are presently defined as professional workers who focus on the development and well-being of infants, children, adolescents, and young adults by minimising the adverse effects of hospitalisation and other potentially stressful situations in a hospital. Child Life Specialists lead Child Life Programs to address the psychosocial concerns arising during hospitalisation or various health care experiences, including inpatient paediatric health care, outpatient paediatric health care, emergency departments, rehabilitation settings, ambulatory clinics, radiology and pre-surgery departments [4]. Child Life specialists must often develop specific skills to cater to the needs of their working population, like developing an understanding of the family of the children hospitalised and recognising developmental issues related to illness. They use assessments to determine children's comprehension levels and plan better therapeutic interventions [5]. Therapeutic interventions administered are developmentally appropriate play, psychological preparation, coping and distraction strategies, and psychoeducation of the family members to involve them in patient care. The goals of these interventions are to (a) promote near-optimal development, (b) present and communicate information, (c) plan and rehearse helpful coping strategies for medical procedures, (d) work through feelings about past or impending disturbing experiences, and (e) establish therapeutic relationships with children and parents to support family involvement in each child's care [6]. Achieving these goals decreases anxiety and increases cooperation during the procedures [7], reports less fear during the procedure [8], requires minimum sedation [9] and has a shorter recovery time [10]. The frequency and intensity of interventions provided by CLS lead to lowered anxiety and lowered distress [11]. Reduction of stress and the presence of a Child Life specialist have also been reported to provide overall satisfaction to the family [12].

While hospitalising a child in India, common symptoms observed are pain, bleeding, restricted movement of limbs, loss of consciousness, seizures, swelling of the injured site and excessive crying [13]. Children, when admitted to the hospital, are reported to be fearful of invasive procedures [14]. The anxiety level of parents and their respective socioeconomic status can significantly influence the anxiety of the children before inducing anaesthesia [15]. Arising from the need to cure the illness, pain management is usually neglected in children, leading to emotional and psychological scars, heightening anxiety and fear in children [16]. Needle pricks, intravenous catheter phlebitis, tubes, and procedures such as lumbar puncture have fear-inducing properties and can cause pain [17]. The unfamiliar imaging environment, such as an MRI, and the presence of healthcare professionals who are unknown to the child can create agitation and anxiety in young children [18].

To mitigate the problems faced by the children, Child Life Specialists can help discuss family-based strategies and interventions for their children's speedy recovery. Parenting stress among mothers fluctuates with the condition of the child, and interventions to decrease parenting stress can also be helpful [19]. These interventions can be personalised and administered by Child Life Specialists. Child life specialists can also design effective non-pharmacological interventions that involve toys, games, clowns, puppets,

cartoons, and colouring books. Pre-operative visits by the specialist benefit children undergoing treatment [20]. Child life specialists can also help communicate unfavourable news to the parents in a socially appropriate way and provide compassionate professional support [21]. Explaining procedures, interventions, and treatments to the children in an age-appropriate manner will help them understand and relieve their stress.

In India, CLS was initiated for the first time under Dr Chetan Ginigeri, Program Head, Paediatrics, Aster CMI Bangalore, and is headed by Dr Sushma Gopalan.

This article highlights the nature of CLS in Aster CMI, a hospital in Bengaluru, Karnataka. This descriptive study focuses on the interaction between a Child Life Intern and several paediatric patients. The article aims to showcase the interventions that can be provided for children in distress.

Materials and methods

The intern facilitated social interactions with hospitalised paediatric patients by visiting patients in their rooms, interacting with them, understanding their problems from a psychosocial perspective, and providing them with various games to engage themselves. In addition, rapport had to be built with the parents/caregivers to create a supportive environment and help the patient adapt to the hospital surroundings.

Dr Sushma Gopalan, the Child Life Specialist and a psychologist, supervised them. The Child Life Specialist had to oversee the services for kids and family, meet with the parents/caregivers to assess, plan, build a supportive rapport and aid in psychological preparation. The intern's duties aligned with those of a Child Life assistant, wherein they facilitated the coordination of play activities and interactions. Therefore, the article will address the intern as a Child Life assistant.

A daily roster with the names of kids admitted to the hospital was handed out, and the Child Life Assistant would have to visit the rooms on the roster and build rapport with the kids. Questions were asked to understand the child's current situation and observe the progress. This would then be followed by playing with the child or interacting with them. In many cases, in addition to building a rapport with the patient, a rapport had to be made with the parents/caregivers. Key points were noted down to understand the progress of the patient. The Child Life assistant would discuss the key events and happenings of the day at the end of her shift with the Child Life Specialist and seek her input for the strategies that can be utilised.

The Child Life Assistant interacted with the patients in the General Wards, Paediatric Intensive Care Unit (PICU), Oncology day-care and in very few cases, in the Bone Marrow Transplant unit (BMTU) and Emergency room (ER). The tools used were play, micro-skills and macro-skills established in the counselling framework, and age-appropriate communication.

The data that has been represented was collected from 1st October 2022 to 17th December 2022. The intern worked four hours as a Child Life Assistant on Fridays and Saturdays. The demographic information and the departments she visited were part of the internship requirement, and she submitted it to the child life specialist at the end of the internship.

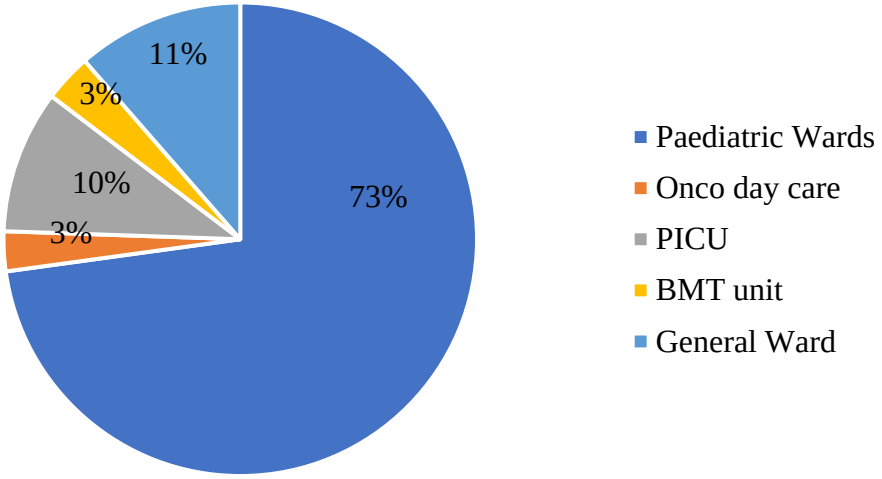
Results

Child Life Assistants: Hospital Settings

As a child life assistant throughout the internship, she was required to visit paediatric patients in various departments. These departments included the General Wards, Paediatric Intensive Care Unit (PICU), Oncology Day Care, and, in some instances, the Bone Marrow Transplant Unit. Most of the time was spent

in the third-floor Paediatric wards (73%), followed by the first-floor general wards (11%), the PICU (10%), the BMT unit and the oncology day care unit (3%) (see Figure 1).

Figure 1: Pie chart depicting the percentage of time spent in various departments of the hospital as a Child Life Assistant



The gender of the paediatric patients affected the way the assistant interacted with them. Throughout the internship, it was observed that more boys were admitted to the hospital than girls. This led to interaction with more boys than girls. Child and parent support involves meaningful interaction and using micro and macro skills in counselling to engage in conversations with patients and their caregivers/parents. It was inferred that girls and boys generally preferred interacting and conversing to playing word games and puzzles. The charts below depict the distribution of patients based on gender and the activities they preferred (see Figure 2 and Figure 3).

Figure 2: Pie chart illustrating the distribution of Paediatric Patients based on Gender

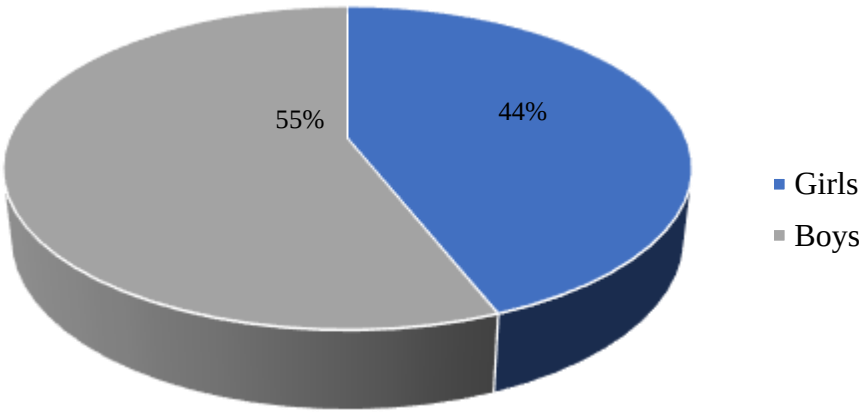
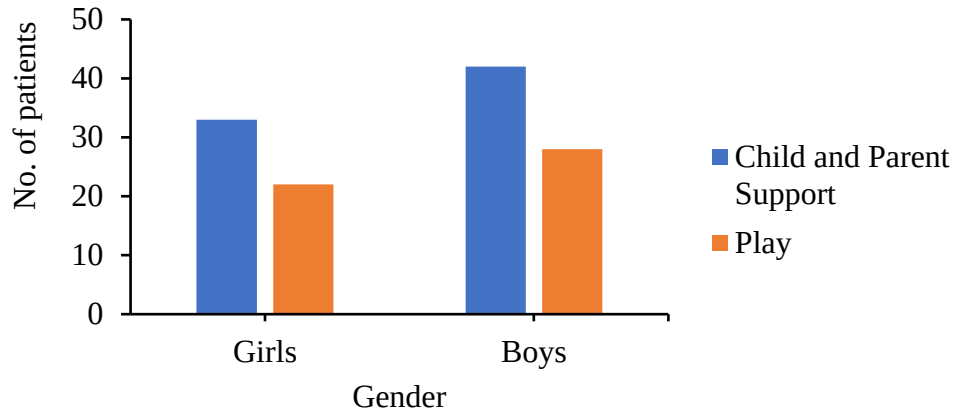
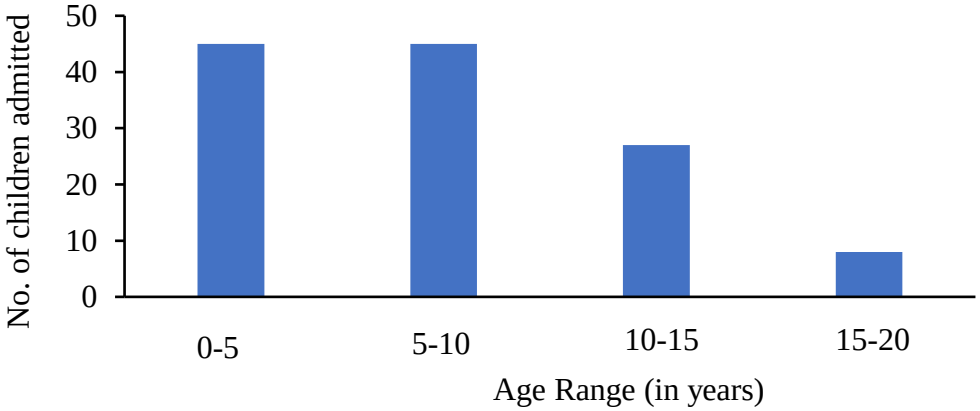


Figure 3: Column chart representing the preferred activity among boys and girls during their hospitalisation.



The assistant had to interact with kids of different ages. The ages of the children ranged from 0.33 to 20 years. The average age of the paediatric patients was 7.74 years. The chart below depicts the age distribution of the children she visited during the internship. There were 45 kids in the age range of 0-5 and 5-10 years. This was followed by 26 kids in the age range of 10-15 years and eight in the age range of 15-20 years (see Figure 4).

Figure 4: Column chart illustrating the age distribution of Paediatric patients who visited the hospital during the internship period.



The primary interaction methods were Normative Play and parent and child support through interaction and participation. Interacting with the babies was difficult, so parental support was provided to the toddlers' parents. Normative play, child support, and interaction were the most often used strategies to build rapport with paediatric patients between 0 and 5 years and 5 and 10 years (see Figure 5). Connect-4, 12-piece puzzles, animal puzzles, phrase recognition games, Ludo, Snakes and Ladders, and colouring

books were among the most popular games. However, not all children were comfortable playing; instead, they preferred Child Support. Paediatric patients between 10-15 and 15-20 years sought conversation and engagement to feel relieved. Paediatric patients in this age group were at ease discussing obscure and popular topics like schoolwork and academic stress, series and shows, music and hopes and dreams for one's career, indicating a change in the support required by these patients (see Figure 5).

When the Child Life Assistant visited paediatric patients for a follow-up, they preferred interaction and support more frequently over child play. This suggests that talk-based interventions are a vital intervention strategy that must be incorporated for adolescent patients (see Figure 6).

Figure 5: Column chart illustrating the preferred activity among Paediatric patients of various age ranges.

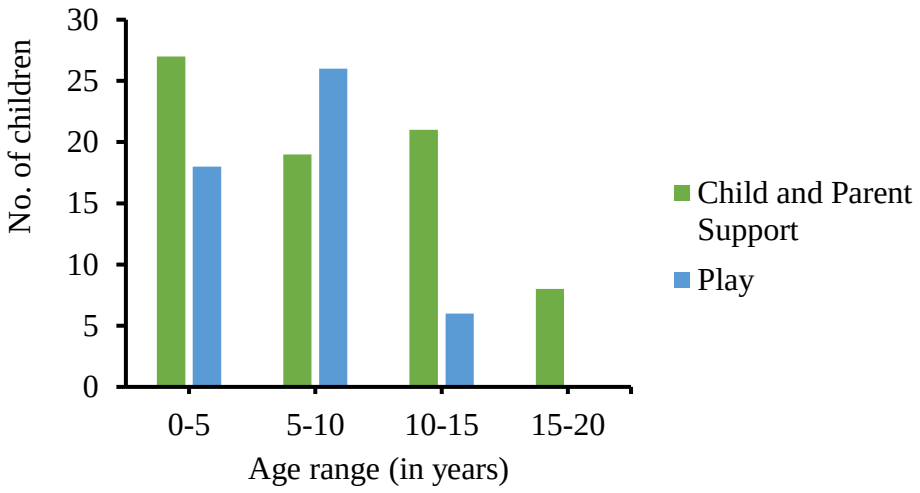
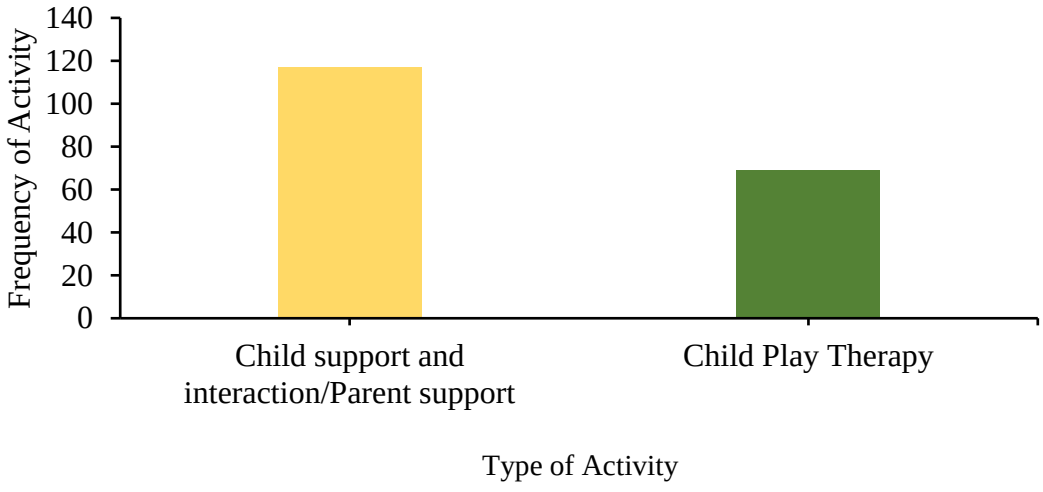


Figure 6: Bar graph depicting the frequency of interventions implemented among Paediatric patients of various age ranges.



Additionally, it was observed that the use of the screen could be a potential diversionary strategy. Infants preferred to watch videos and listen to music on the screen, and it was noted that paediatric patients use screens as distractions. This was specifically useful when infants were reluctant to have their meals. Parents displayed screens as effective distractions, and screen usage by paediatric patients gives them temporary relief. Adolescents use a screen to view their favourite series on TV. Future interventions can include using the screen for a limited time to enhance the well-being of paediatric patients.

Discussion

Child Life Programs involving children, parents, and families can be implemented in various healthcare sectors to cope with stress. This could be a part of the Paediatric Intensive Care Unit (PICU) [22], Medical wards [23], Paediatrics Outpatient Department (OPD) [24], Neonatal Intensive Care Unit (NICU) [25] and Paediatric Emergency services [26]. Children suffering from various diseases, from biological to psychosocial illnesses, can also be the focus of Child Life Specialists [27]. Psychological and psychosocial interventions in children with diverse diseases and conditions have proven favourable [28-31].

To provide these interventions to children, a multidisciplinary team can collaborate with children, including doctors, nurses, dietitians, specialised psychologists, social workers, pharmacists and Child Life Specialists [32]. It is imperative that Child Life specialists also have a team to ensure effective and efficient care and treatment of the children in the hospital. Since India must yet develop a framework for Child Life Programs, inspiration can be drawn from the Western world.

During her training, the assistant observed that Aster CMI employs a hierarchical-systematic model of child life specialists and assistants to benefit hospitalised children and their families. The model followed can be illustrated below [33]: -

1. **Certified Child Life Specialists: -** They are the primary decision-makers in organising CLS for each kid and family. Currently, the Child Life Specialist at Aster CMI helps with the following duties: (a) patient admission and evaluation; (b) stress vulnerability and evaluation; (c) ongoing evaluation and activity planning; (d) developmental enhancement; (e) psychological preparation; (f) post-procedural play; (g) family involvement; and (h) supportive relationship. This also involves meeting with the patients to assess, plan, and build a supportive rapport.
2. **Child Life Assistants: -** These helpers will report to the Child Life Specialist and facilitate the coordination of play activities and interactions between the kids and different family members. This involves deciding what kind of play should be given to children of various age groups, providing child and parental support, and receiving feedback to improve these approaches and procedures.
3. **Volunteers/Interns: -** They can additionally help Child Life Assistants and play an instrumental role in planning activities and interacting with children.

From the observation made by the assistant during her internship, it can be inferred that CLS can be incorporated into various hospital units to alleviate fear and distress among paediatric patients and their families. There is a particular need for assistants in the General ward, which has the highest number of paediatric patients.

While child life assistants will be trained to employ various other techniques, play is the most essential tool for a child life assistant in hospital settings. Play helps children between 0 and 10 years old cope with stressful and anxious situations. It is a coping strategy that distracts them from anxious thoughts and allows them to express certain feelings by recreating events in their life [5]. This, in turn, makes the healthcare experience more reassuring and familiar for the child, enabling faster adaptation to the hospital

environment [6]. Various play strategies can be incorporated into a child's treatment. The play strategy the Child Life Assistant used to interact with children was Normative play. Normative play activities are those that children engage in outside of hospital settings, which promote the child's normal development. This can include board games, video games, puzzles, pretend play, and arts and crafts, and it can take place at any time. While meeting the children, games such as Connect 4, 12-piece puzzles, animal puzzles, word recognition games and colouring books helped her initiate a relationship with the children. This kind of play is pleasurable, has no extrinsic goals, and allows the children to pass their time. The routine can also incorporate other play activities like Medical and Therapeutic play. Medical play can be used to ease children's anxiety and help them deal with operations, hospital stays, and check-ups. Children can play with everyday medical tools (such as thermometers, stethoscopes, etc.), which will lessen their anxiety when medical equipment is used. Children engaging in therapeutic play are encouraged to express their emotions, which benefits their expected growth, psychological well-being, and coping mechanisms. Expressive arts, doll play, puppet shows, and sticker charts are all examples of therapeutic play [5].

It was observed that the type of games children choose also depends on their gender, wherein during the period of her internship, in the children of ages 0-10 years, boys chose puzzles, word recognition and Connect-4 more frequently, and girls chose games which included vocabulary and word usage. While play is an effective tool, its usage for adolescents must be considered. Adolescents did not prefer play and were comfortable with conversations. This could have been because of the type of games that the Child Life Assistant provided. These games would have been more appealing to children than to adolescents. Games that are challenging, like chess, which involves a lot more cognitive faculties, might be better for adolescents.

Age-appropriate communication is a crucial ability that aids the child's life assistant in connecting with the child. Effective communication can establish therapeutic relationships with children and parents, educate patients about their prognosis, encourage optimal development, plan and practice helpful coping mechanisms for medical events or procedures, work through feelings about recent or upcoming experiences, and educate patients about their prognosis. Additionally, it helps with the patient's psychological preparation [6]. While the patients were initially apprehensive about connecting with the assistant, they became more receptive when a rapport was established. This requires communication skills and the use of various other linguistic tools. The assistant used age-appropriate questions to engage with children.

An example is asking kids between the ages of 5 and 12 about their favourite shows, families, and schools. Children eagerly discussed their favourite cartoons, friends, and school life. Since it was noticed that stress is a prevalent element among adolescents (12 years and above), questions about school and academic issues were raised to better understand the problems that adolescents encounter. Adolescents were more amenable to abstract ideas about stress, hardships, and academic challenges than younger children. This helps us understand the importance of communication skills within the counselling framework.

To establish a relationship with the kids and comprehend their circumstances, the child life assistant employed a variety of macro-skills, including focusing and self-disclosure and micro-skills, including attending behaviour, basic listening sequence, and empathy. Being multilingual is an additional skill that can help the child life assistant interact with various parents in a diverse country like India. The assistant had to frequently use English, Hindi, Malayalam, Kannada, and Tamil while interacting with parents and paediatric patients. Thus, a child life assistant is vital in bridging the gap in engaging with paediatric patients and supporting parents. They also help the Child Life Specialist with their routines and bridge the

interactions between the parents of paediatric patients and the Child Life Specialist.

This descriptive study shows that CLS aims to provide a nurturing environment for the child to get better, facilitate the child's development and help children gain control of the world in hospital settings, contributing to their socioemotional development. It investigates issues related to the child's experiences in the hospital and reduces the intensity of negative apprehension accompanying a child's hospital admission [34, 35]. Certified child life specialists use a multifaceted approach to meet the needs of paediatric patients and their families. They considerably lower the expenses of discomfort and anguish that last well past each episode of care on a financial, developmental, and psychological level [36]. Child Life Specialists and Child Life Assistants together can play a role in spreading awareness about child life practices and discussing family-based strategies and interventions for the children's speedy recovery. It is known that parents' stress and anxiety, especially mothers', fluctuate with their child's health condition. The support from spouses and family, specific guidance and appropriate information from hospital staff about their children positively affect the mother's interaction with the child and the mother's well-being [19]. The Child Life team can also help provide interventions to decrease parenting stress. The child life team can also design non-pharmacological interventions that involve toys, games, magic tricks, clowns, puppets, bubbles, cartoons, and colouring books, which are effective methods. Pre-operative visits, which the specialist can do, may benefit children undergoing treatment [20]. Child life specialists can also help communicate unfavourable news to the parents in a socially appropriate way and provide compassionate professional support [21].

While many hospitals in developed and developing nations implement child life programmes, CLS is critical in India, where 697 million of the country's 1.3 billion population are children and adolescents. To support our growing economy, which is currently the fifth-largest, we must reduce the physical, psychological, and social burdens that affect children and adolescents [37]. Only a few facilities in India, including Aster, Manipal, and Rainbow Children's Hospital, strongly emphasise the children's overall health. There can also be programmes and courses tailored to this, even within India, that help students interested in this work to join hospitals for the same as an intern and support the present healthcare system. While the Western world has eligibility criteria for students to enrol in the CLS programme within the hospital [38], the scenario is not the same in India. A wide gap must be filled to recruit more students interested in improving India's paediatric healthcare system. Therefore, there is great potential for implementing child life programmes at multiple chains of hospitals in India.

Conclusion

The present article focuses on the importance of CLS in hospital settings. CLS caters to paediatric patients and their parents, providing support through various interventions. The article described the role of the Child Life Specialists and Child Life Assistants in CLS of Aster CMI, Bengaluru, through the lens of an intern trained as a Child Life Assistant. Various tools such as play, communication and counselling skills have been focused upon, along with the employment of different techniques for children and adolescents of other age groups. This article also highlights the need for further programmes that can enable the implementation of Child Life Programs in multiple hospitals within India.

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