Palliative Care Rounds

Role of Child Life Specialists in Pediatric Palliative Care

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Introduction

Each year, more than 500,000 children in the United States cope with life-threatening conditions.[1] Many are hospitalized for long periods for curative treatment, and some remain in the hospital for end-of-life care. Long inpatient stays lead to tremendous physical and emotional stress for both patients and their families, and the management of the burden associated with these periods may be improved by support provided by a comprehensive pediatric palliative care team. The team has a holistic approach, coordinates many interdisciplinary services, and addresses the physical, emotional, social, and spiritual issues that are often present at the end of life.[2,3] A study of terminally ill hospitalized children noted that they could have been provided with more palliative care services but access was limited by lack of awareness, resource constraints, or reluctance to establish goals for comfort care during a child's final days of life.[4]

An important member of the pediatric team or specialist palliative care providing care to the child and family is the child life specialist (CLS). The CLSs apply their training in child development to reduce distress and potentially gain insights into the child's thoughts. They may help children and their families navigate through the challenging and emotionally draining process of hospitalization, prepare children for upcoming procedures, and assist them in working through feelings about past and impending experiences. Their goal is to provide emotional and spiritual support in a developmentally appropriate way, educate, and advocate, while implementing a family-centered care model.[5] A CLS gently acquire information and fits it into an individualized family-centered care plan, which considers age, individual development, coping strategies, types of interventions, and other hospital stressors expected.[6]

CLSs deliver services in inpatient units, outpatient clinics, and at homes of terminally sick children.[7] Although CLSs work in many hospitals, the extent to which they are integrated with the palliative care teams varies.

CLS began as a profession in the 1920's as an effort to improve the experiences during hospitalization for pediatric patients and their families. In the United States, the field has grown exponentially as a career choice. The requirements include an undergraduate degree, with concentration on courses in child development, family systems, play therapy, and loss and bereavement.[2] These courses are approved in the United States by the Association of Child Life Professionals. A degree from an Association of Child Life Professionals–endorsed academic program is another path to a career as a CLS in the United States. After education, CLSs in the United States are expected to participate in a minimum of 600 hours of child life internship or fellowship under the direct supervision of a certified CLS. With this experience completed, a certification examination may be taken. For supervisors of CLSs, professional child life certification throughout the supervisory period with a minimum of 4000 hours of clinical experience is needed before the start of a supervisory role.

In the United States, CLSs work in both inpatient and outpatient pediatric settings including pediatric intensive care units, emergency departments, radiology units, specialty clinics, and behavioral and rehabilitation facilities. Some CLSs also work in private practices, hospice services, camps for children with health-care needs, dental offices, and at home hospices. Approximately 97% of pediatric departments in the hospitals of the United States have CLSs, with a ratio of one CLS to 15 patients.[2] The ratio may be

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adjusted to the severity and acuity of illness of the patients served.[2] Many hospitals have their own requirements based on their specific needs. Some hospitals prefer a master's degree, others require affiliation with a school, and yet others mandate additional training in specific areas, such as oncology.

We present a case that highlights the role of a CLS in helping both the pediatric team and the palliative care team manage a child who was at the end of life.

Case Description

A 14-year-old boy suffering from progressive ependymoma with hydrocephalus who was diagnosed more than 4 years ago was admitted with worsening respiratory distress, bulbar dysfunction, and evidence of multiorgan failure. He had multiple secondary metastases with impending herniation of the brain. He had undergone multiple surgeries and several rounds of chemotherapy, including treatment with experimental drugs for the last two years. His disease had progressed, and he was at the end of life. He was depressed, anxious, sullen, and refused to interact with staff. The family did not discuss his dying process, so an accurate assessment of the child's feelings was unavailable.

The palliative care team employed several strategies to address his distress. The plan of care involved social workers, the chaplain, and the CLS. The CLS took an inventory of the boy's interests to provide distraction and entertainment personalized for his age, development, temperament, and coping styles. Different child-friendly characters and electronic devices were offered, but he refused them. The CLS noticed that he had an interest in magic, and on day 7 of hospitalization, a magician, a volunteering medical student, was brought in to visit the patient. The child's reaction was positive, as he started interacting, smiling, and seemed to enjoy the visits. The magician visited him daily for two weeks to show him card tricks—and an act called "Magic Aid."

"Magic Aid" allowed the child to relax and bond with the magician, providing a sense of mastery and control in his last days of life. It allowed normalcy back into the child's life with an opportunity to temporarily escape the medical decisions and procedures. Perhaps, magic allowed him to believe that impossible things could be achieved and subsequently provided him with a subconscious feeling of hope for the future.

It was obvious that magic became a source of comfort for the patient and the family during his final days. The treating staff perceived "Magic Aid" as helping to preserve dignity and ameliorate suffering. It also helped the palliative care providers to address his symptoms because after each session with the magician, he was more receptive to treatments. It was also easier to counsel the parents because they relaxed and released their helplessness; they were better able to accept the downside of more aggressive treatment modalities.

After the patient died, the family expressed gratitude and acknowledged that the relationship with the CLS helped them to accept his death. It also helped the CLS to build legacy with the family and provide footprints for future life experiences.

Comment

This case is one of many which illustrate the approach that a CLS may seek in providing a child with advanced illness opportunities to engage in developmentally appropriate play and mastery through recreation. It highlights the ways that coordinated work by a CLS and a magician can be integrated into the plan of care pursued by both the pediatric team and the palliative care team during an inpatient stay for end-of-life care.

We expect children to outlive the adults in their life as they are still developing individuals with so much potential and experience ahead of them. To have a child with a terminal illness can be a devastating experience for a family. Health-care providers are similarly affected. When a child is admitted to a hospital for end-of-life care, a coordinated plan with input from a specialist palliative care team can have positive impact on both the child and family.[3,4] The interdisciplinary palliative care team works together to provide care focusing on the quality of life while respecting values and culture, traditions and religious customs as well as addressing the psychosocial needs.[8,9] The use of magic in our case underscores the range of coordinated approaches that CLSs may take in working with palliative care teams providing end-of-life care.

Our CLSs worked with other team members to help build rapport with the patient and family and provide support for the plan of care. They took into account many factors that can influence the ability to achieve rapport, including patient age, development, personality, temperament, diagnosis, and past medical experiences. This experience helped in strengthening the role of parents and other family members as partners with the health-care team in a family-centered care model. They worked with our patient at times that were convenient for the child, helped restructure the day, and prepared him for medical procedures.[10] They assisted in normalizing the environment and experience by decorating the hospital room to make it as comfortable and familiar as the home environment. They helped our patient to use electronic gadgets to stay in touch with his classmates. They brought in movies and played board games with the child. They encouraged families to continue traditions such as "Friday family game nights" to maintain a semblance of normal life in the hospital setting. CLSs used play because it allowed the child to take part in an activity that encourages self-expression

and engagement with friends and family. This technique helped the medical staff to build rapport with the child and allayed misconceptions about the dying process.[10] They acknowledged the child's and family's feelings and concerns about the illness and death and assured that it is normal to be fearful. They emphasized hope for a better day without pain and instilled courage and peace.[10] This helped the family achieve a sense of purpose in the last days of life. They also engaged with siblings, so that they were prepared for the future and were given the opportunity to attend the funeral.[10] Debriefing with the medical team was done routinely to keep all the members informed and help the team cope with the impending loss.

Our patient underwent several treatments during his formative years when children are enjoying school, sport, and having good times with their peers. Children between their ages of 10 to 12 years cope by regression, withdrawal, acting out, or feeling guilty—all which our patient experienced. Adolescents have different hospital stressors which include lack of trust, loss of independence, fear of death, lack of peer acceptance, and loss of bodily control. Teens often use defense mechanisms, nonconformity, or uncooperative behavior to combat stressors.[11] This negatively impacts parents, caregivers, and siblings. All these manifestations of the child's illness affect the physical and psychological well-being of parents and siblings.[12] The impact on siblings is determined by the age, development, temperament, involvement, and parental coping mechanisms.[13,14] Finally, the CLS assisted in building an end-of-life legacy by helping make a scrap-book, handprints, and T-shirts. These crafts were made by the child for their loved ones to remember them by and to have their legacy carried forward.[8,12] The parents appreciated the support offered by the CLS to make the end-of-life experience of their child a bearable one.[15]

Conclusion

Our patient's end-of-life journey was powerfully impacted and enriched as a result of the coordinated approach and involvement of the CLS. CLSs play an important role in the care of children with serious illnesses, including those children at the end of life. They should be considered as core members of the pediatric team and pediatric palliative care team, and their work should be integrated into the plan of care to ensure best outcome.

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