FEATURE ARTICLE

Transforming the Pediatric Experience: The Story of Child Life

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ABSTRACT

During the past century, child life programming has evolved into a standard of care for children experiencing life's most challenging events. From pediatric outpatient clinics and dentists' offices to funeral homes and courtrooms, children are now being provided access to professionals that relieve the anxiety and fear associated with emotional and physical pain. Recognized by the American Academy of Pediatrics, child life specialists focus on the "strengths and sense of well-being of children while promoting their optimal development and minimizing the adverse effects of children's experiences in health care or other potentially stressful settings." Armed with a strong background in child development, child life specialists provide therapeutic play experiences and developmentally appropriate language to promote normalcy within an unknown and potentially stressful environment, procedural education and emotional support, coping and pain management techniques, and grief and bereavement support. Child life programming plays an integral role in addressing the psychosocial concerns across the health care continuum and should be included in all general pediatric provider settings as a standard of quality care for young patients. [Pediatr Ann. 2017;46(9):e345-e351.]

Throughout the past few decades, there has been a rapidly expanding body of research in the neurobiological and behavioral sciences documenting the tremendous importance of optimal growth and development in the early years, not only for the child's later health and success as an adult, but also for the well-being of society. At the same time, it was becoming clear that the conditions for most children around the world, especially in a hospital setting, fell short of what medical science recommended.1

FROM "PLAY LADIES" TO CHILD LIFE SPECIALISTS

The story of child life programming begins in the 1920s when early child life professionals, formerly known as “play ladies,” identified play as a necessary means to promote optimal development during hospitalization while alleviating the anxieties and fears associated with medical procedures and treatment.2 Institutions like Mott’s Children’s Hospital in Michigan and Babies and Children’s Hospital of New York were among the first health care organizations to create play programs (in 1922 and 1929, respectively).2 It was through these play programs that developmentally appropriate education and preparation for procedures transformed the pediatric health care experience.

In 1965, these early play professionals in health care shared their experiences and challenges in the field with one another and recognized the need to develop a professional organization that supported the initiative to make pediatric environments more child-friendly while involving various disciplines in the process.2 Child life prevalence continued throughout the 1970s, resulting in the development of the accrediting organization, Child Life Council (CLC) in 1982.2

Using the title “child life” programming, specialists in this field worked in a multitude of settings that nurture the emotional and psychosocial care of children facing life's most challenging events.3,4 Almost 50 years later, child life specialists are recognized around the world for helping children not only in general pediatric facilities, but during natural disasters and in courtrooms, camps, and private practices.

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In 2015, the CLC undertook a process to rebrand in an effort to position the organization and its members for continued success. As a result of the rebranding efforts, in 2016 the Child Life Council officially changed its name to the Association of Child Life Professionals. Today, the role of the child life specialist has evolved to meet not only play and developmental needs, but also to focus on using play, alongside other medical professionals, to decrease pain and increase coping.

THE BENEFIT OF CHILD LIFE SERVICES: A MULTIDISCIPLINARY APPROACH

According to Cohen, when children are effectively prepared and feel emotionally supported, their cooperation increases, thus contributing to the successful completion of procedures and compliance with long-term treatment. In addition to promoting healthy development, child life specialists must work to be a cooperative member of the health care team through continual communication with all disciplines involved in the care of the child to determine each child’s unique emotional needs during a procedure. This helps to ameliorate stress and increase coping skills throughout the child’s health care experience.

To do this, it is also important that child life specialists co-treat with other disciplines to make sure the exchange of information and supportive techniques during the actual procedure are promoting the goals of the child’s medical treatment. Examples of this collaboration are working with nurses to increase compliance with medication, aiding a physical therapist in motivating physical movement through behavior modification tools and distraction techniques, and increasing cooperation during tests for vital signs, respiratory treatments, and physical examinations. When children are calm and cooperative, they are better equipped to heal emotionally and physically.

According to Dr. Vinod Havalad, a pediatric intensivist at Advocate Children’s Hospital in Park Ridge, IL “child life specialists have become indispensable members of the care team.” Havalad believes the child life services on his pediatric intensive care unit “have changed the way we practice pediatric critical care medicine by helping us to provide a more holistic and thoughtful approach to the wellness of children.”

A common misconception among pediatric staff is that child life specialists are the same as psychologists or social workers. Although similarities in clinical care exist, the difference is that child life specialists’ primary focus within health care is acute coping with hospitalization and illness issues based on the child’s developmental level, rather than the longer-term model used by psychology or the resource-based model sometimes favored by social work.

In addition to the priceless work of pediatric medical and nursing teams, and ancillary support members, child life specialists can limit unnecessary anxiety to the child and staff member by educating such hospital personnel in (1) a child’s development-specific reactions to strangers, novel medical equipment, and hospitalization (Table 1); (2) communication skills that offer explanations of events to children of all ages using minimally threatening, honest language (Table 2); and (3) the particular concerns of individual children by developmental age group.

Dr. Kezia Shirkey, a pediatric clinical health psychologist, feels that ancillary team members and child life specialists have complementary roles that allow them to work synergistically to provide emotional support for medically ill children. (written communication, April 2017). When asked what the difference between psychologists and child life specialists are, Shirkey reported “pediatric psychologists can offer assistance, tailored interventions, and support when children and adolescents have mental health issues or significant challenges coping; but by having a child life specialists on the unit more patients are covered and by collaborating with pediatric psychologists, those children in most distress or with atypical needs can receive increased and comprehensive supports. Efforts are not duplicated, instead they are enhanced by working collaboratively.”

Additionally, child life specialists are “valuable consultants about the physical environment of pediatric settings and the effect of the settings on the behavior and adaptation of children because they are keenly aware of the perspective and concerns of children and their families.” They offer a useful perspective on children’s developmentally appropriate language and healthy coping techniques, and provide important contributions to the organization’s efforts to meet the standards of medical care (Table 1 and Table 2). In addition to having a child life professional as an integral member of a pediatric health care team, indirect interventions can be used to support patients and families across the continuum of care. For example, posters (Figure 1) may be mounted in treatment areas to educate staff and parents about effective positioning or coping techniques to use with children of different ages. In some cases, a phone consultation conducted by a child life specialist can help parents prepare their child for an outpatient procedure such as allergy testing, blood draws, dental work, or any type of invasive and potentially stressful treatment.
Table 1 demonstrates the developmental stage and expected impact of the hospital experience. An understanding of illness across the developmental spectrum is an extremely valuable tool to a provider at the bedside of a critically ill patient. Table 2 gives examples of how a child may interpret common medical terminology as well as the best words
that could be used so that the child may have a clearer understanding of what is happening to them.\textsuperscript{13,14}

\section*{CHILD LIFE INTERVENTION STRATEGIES}

\subsection*{Procedural Education and Emotional Support}

Psychological preparation involves the communication of accurate, developmentally appropriate information in advance of a potentially frightening health care experience. Such information may include the reasons for the procedure or treatment, anticipated sequence of events, and potential sensations that accompany the experience. Children and their families are often exposed to medical and diagnostic jargon, but are not always provided with information that is specifically intended for them. Child life specialists have various resources to teach children about health care experiences, such as medical dolls, children’s literature, photos, and videos (Figure 2). These educational materials can also be modified to meet the patient’s developmental level and unique coping style, regardless of their age.\textsuperscript{10}

To incorporate family-centered care within the pediatric experience, it is extremely beneficial if a child life specialist has the time to assess the child’s involved siblings and/or caregivers understanding of a procedure by uncovering the actual plan of treatment with the medical team. This type of educational intervention can help to develop a cohesive coping plan that can be executed effectively prior to the procedure because the patient and family members feel well-prepared and possible misconceptions of the plan are clarified. A research study by Fassler\textsuperscript{15} examined the role of emotional support in preparation of children for procedures and found the combination of information to the family plus emotional support to be the most effective in reducing anxiety.\textsuperscript{10,16} Other circumstances benefiting from preparation include pre-surgery tours for children, siblings, and caregivers anticipating a significant surgery with a lengthy hospital stay; developing consistent coping plans for children with chronic illness resulting in repeated experiences; transitions to rehabilitation units, psychiatric units, or an inpatient stay from an emergency room or clinic setting; and preparing any young child before entering the hospital environment as a visiting guest.

Therefore, allowing time for educational preparation is optimal to minimize the child’s distress, and the consequent resistance and fear that may occur, which may lead to a preferred, and perhaps more efficient, outcome. In addition, this type of education can prevent unnecessary exposure to general anesthesia,\textsuperscript{17} especially if a child life specialist is able to provide relax-
ation techniques throughout a potentially stressful medical procedure.

**Nonpharmacological Pain Management and Coping Techniques**

Until the 1980s, many medical practices held the belief that children do not perceive pain.18 Now we know that children feel as much pain as adults, and perhaps even more.18 In fact, children are at risk of developing anticipatory fears of painful procedures and perhaps exposed to traumatic experiences if they are not provided with a supportive and understanding environment.18

One of the techniques most widely used by child life specialists is distraction, which is categorized as a “cognitive strategy” to pain management.19,20 The effectiveness of distraction is described by the gate control theory. When the patient’s attention is focused on the distraction rather than the pain, their gate for pain is closed.21 Characteristics of effective distraction are interventions that are interesting to the child, consistent with the child’s energy level, stimulate at least one of the major senses, and can change with the pain.19 Distraction techniques can include deep breathing, developmentally appropriate toys, electronic devices (Figure 3), and guided imagery. All distraction techniques are individualized to meet the child’s developmental and individualized needs.20

Hospitals are required to assess and effectively manage the patient’s pain based on clinical practice guidelines and evidence-based practices. Pain management is an ethical imperative, and child life specialists are a vital part of treating children’s acute procedural and chronic pain using nonpharmacological techniques. Although many pediatric health care professionals are committed to treating children’s pain, child life specialists are specially trained to advocate for and implement nonpharmacological techniques that complement other modalities such as topical analgesics and sedation. When a child is provided with pharmacological, physical, and psychological methods to relieve pain, they can develop a coping repertoire that aids them in recurring, ongoing pain, which in turn develops strong bonds between child, parent, and pediatric staff.20,22

**Grief and Bereavement Support**

Children experiencing grief and bereavement is a difficult topic that child life specialists try to teach pediatric professionals to overcome. Whether it is a child at end of life and or a child at the bedside of their dying caregiver, the thought of a young child experiencing loss can shake anyone to their emotional core. Child life specialists strive to teach other professionals and family members that children of all ages experience loss the minute they learn the feeling of love for something or someone; and because of this, child life specialists are specifically trained to understand and assess childhood grief phases and provide resources for the bereaved. As difficult and important as it is for health care providers to use the words “dead” and “dying” to parents of ill children, it is equally as important for child life specialists to do so with children.

Many child life specialists have developed a foundation for “grief culture” via academia; bereavement studies or grief counseling certifications are not uncommon. Topics like “the dying child,” “explaining parent illness,” or “communicating with the grieving child” are common courses and trainings within professional development studies and staff presentations. Throughout clinical services in pediatric health care, it is inevitable that child life will be involved in the treatment of children experiencing loss. Although there are many types of loss, two typically surface in the pediatric health care setting: (1) ambiguous loss, which is physical absence with psychological presence or psychological absence with physical presence, and (2) physical loss. Ambiguous loss is when children experience a
situation in which someone they knew goes missing without understanding or closure, and physical loss is experiencing amnesia or a family member with Alzheimer’s disease (the person is living but has cognitive deficits). Physical loss can also represent a child experiencing the loss of a body part, object, or person. For example, this could be a child undergoing an amputation, the death of a friend or family member, or experiencing parents divorcing. Grief comes in all shapes, but does not specifically mean a child enduring death. For example, anticipatory grief may be a byproduct of a child experiencing their caregiver or sibling being diagnosed with a terminal illness, and bereavement support is continued after the loved one dies.9,23,24

Child life specialists have a solid foundation and understanding of childhood grief phases, the types of losses children may face throughout their lives, and a plethora of tools to help children heal throughout the loss. Examples of grief and bereavement work include educational interventions in explaining death and dying to a child, memory-making activities such as cast molds, fingerprint charms, and legacy videos, as well as in-person support during memorial events. Although child life specialists often support children through grief and bereavement within a pediatric setting, it is becoming increasingly common to use child life services for this type of work beyond hospital walls.

**CHILD LIFE OUTSIDE OF THE HOSPITAL SETTING**

As child life programming within the hospital setting has become better established, many specialists have expanded their practices outside hospital walls into new areas.25 The possibilities for implementing child life services are endless due to the applicability of child life core competencies to nonhospital settings.

In recent years, child life specialists have acted as consultants for a plethora of agencies and organizations for children needing specialized interventions. Consultative services can now reach school re-entry programming after a child has been hospitalized, help children feel more comfortable on the witness stand in a courtroom, facilitate activities in disease-specific camps, and work with children of adult patients in palliative and hospice care centers.

Although child life specialists routinely provide this support in pediatric settings to hospitalized children as well as their siblings and parents and are the standard of care in pediatrics, child life private practices have expanded to the care of children of adults with serious illness.

Child life consultants are now being used for families struggling to talk about and cope with a parent’s life-threatening illness and potential death.9 Clinical health psychologist, Dr. Stephanie Ross, an assistant professor in the Department of Psychiatry at Northwestern University Feinberg School of Medicine and founder of Illness Navigation Resources (a private practice that routinely integrates child life specialists when supporting adults with chronic or life-limiting conditions) believes that child life specialists can “ease suffering and provide concrete resources—particularly when ill parents’ overarching concern is for their children’s ongoing emotional adjustment” (written communication, April 2017).

**FUTURE IMPLICATIONS FOR PEDIATRIC PROVIDERS**

The evaluation of experimental studies and several program models has shown that the presence of a child life specialist has a significant positive effect on children. One study showed children experience less emotional distress, better overall coping during stressful events, a clearer understanding of procedures, and a more satisfactory adjustment and physical recovery when
given the opportunity to use this service. However, it is evident that more empirical data are needed to explore the ongoing effort to justify the cost of child life services, especially as health care costs continue to escalate.

Child life programming has the capacity to transform the pediatric experience and should be included in all pediatric practices as a fundamental standard of care, and when not available, child life consultations are best used to provide an extra layer of support to families and staff.

REFERENCES