

4 I is for Industry
versus Inferiority

8 2017 Distinguished
Service Award

10 Child Life in a
Refugee Camp

13 Integrating a Humanoid
Robot into Child Life

ACLP Bulletin

A PUBLICATION OF THE ASSOCIATION OF CHILD LIFE PROFESSIONALS

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All Heart

**Animal-Assisted Interventions with
Hospitalized Children with Cancer**

PAGE 20

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TABLE OF CONTENTS

IN THIS ISSUE:

- 1 You Tend to Find What You're Looking For
- 2 Consistency and Progress Through Times of Change and Transition
- 4 I is for Industry versus Inferiority
- 8 Extraordinary Service Lived Every Day: Anita Pumphrey Honored with the 2017 Distinguished Service Award
- 10 Child Life in a Refugee Camp: When Two Worlds Collide
- 13 Integrating a Humanoid Robot into Child Life
- 18 How To Be a Child Life Detective in Your Hospital
- 26 Filling the Gaps: Bringing Music into Critical Care Rooms
- 28 The Protection Paradox
- 30 EBP, One Step at a Time
- 32 The Quest: Uncovering Educational Technology Tools for Child Life Specialists
- 34 Book Review: The Healing Power of the Breath
- 36 Advocacy: What I Learned in My Internship
- 37 Supporting Well Children in a Critically Ill Adult's World



PAGE 10



PAGE 13

CHILD LIFE FOCUS:

- 20 "All Heart" Animal-Assisted Interventions with Hospitalized Children with Cancer: A Case Description





from the **Executive Editor**
Katherine L. Bennett, MEd, CCLS

You Tend to Find What You're Looking For

I have an estate sale problem. Actually, if I'm being completely truthful, my "problem" isn't limited to estate sales only. Flea markets, antique stores, and even those where the merchandise skirts the line between junk and antiques all can cause me to stop in my tracks, reconfigure my schedule, and do U-turns in places they're probably not legal.

Sometimes, I'm looking for something specific. I love to search out things for others, kind of like a private picker. The more obscure the item for which I'm searching, the better. I usually turn away from sales and shops that look a little too curated. In fact, I actually seem to prefer digging through things that may have been forgotten for a time or even through a pile of things that could give me tetanus. Old barns, piles of wood and metal items, glass jars and orbs? These are just a few of my favorite things. For instance, I've located a tin bank in the shape of a globe, vintage plastic Christmas decorations, a gavel, and a fiberglass marlin. More often, though, I'm just looking to see what I can find. Before I go "flea marketing" or "estate selling" (those are both verbs, right?), someone will inevitably ask, "What are you looking for today?" Unless I truly have a list, my answer is usually, "I never know what I'm looking for until I find it." How else would I be the proud owner of a stranger's vintage, handmade wedding dress?

I am not alone in this drive to hunt and gather. I tend to run into some of the same people on "the circuit." At the monthly flea market here in town many of the vendors know me, my husband, and especially my daughters. The question of nature or nurture is clearly answered in this aspect of development. My children went to flea markets before they were born and have been frequent visitors ever since. Several of the vendors will hold things back for them based on what they know they are collecting. Vintage Little People? E.T. earrings? Some of them even enjoy letting my children haggle with them over prices. Insider tip: Children almost always get better deals than adults.

What is the attraction to all this seeking and collecting? I suppose I simply can not resist the idea of undiscovered treasures or the potential of finding something I've yet to realize I need. This issue of *ACLP Bulletin* holds similar potential with a variety of topics to browse through and then consider for your own practice. A fascination with child development is what ultimately turned me towards a career in child life. When I read this issue's Alphabet 2.0 column ("I is for Industry vs. Inferiority") I felt my appreciation for the value and relevance of developmental theory be refreshed. The column articulates a more in-depth, yet practical, perspective of a very common term we talk about almost daily. Whether you are a student or a seasoned professional, you are sure to take away some jewels from this article. Reading about the work of Anita Pumphrey, the 2017 Distinguished Service Award winner, is so inspiring! Someone with that clear of a professional direction and drive encourages me. Learning about the use of play in refugee camps and the way child life specialists advocate for the needs of children and families, both in and out of the hospital walls, will broaden your perspectives of how foundational child life skills can be translated into new settings. Seeing a case unfold in this issue's *Focus* piece will deepen your understanding of animal-assisted interventions with children and teens experiencing chronic illness and treatment. Working with animals in the health care setting is certain to pique the interest of many.

I am a collector of many tangible things, but I am also an avid collector of concepts and novel perspectives. Consider this column your little sign on the side of the road inviting you to pause and explore the contents of this fresh Spring 2017 issue. Hopefully, you won't have to dig too much, haggle for a deal, or risk a scratch with a rusty old piece of metal to find something you did not even know you needed! ✨



President's Perspective

Kristin Maier, MS, CCLS

Consistency and Progress Through Times of Change and Transition

By nature or nurture, most child life specialists are flexible people, and this trait has been greatly appreciated as our organization evolves and changes. With the departure of the executive director comes a search for our new leader, one who will inspire us toward our vision and our future. The Association of Child Life Professionals is extremely fortunate to have an amazing staff supporting our profession every day and in everything we do. Their resiliency and dedication to our mission has been incredible and has enabled the continuity of our work during this time of transition. Jennifer Lipsey, MA, who stepped into the role of interim executive director, has been especially deserving of accolades for her desire to lead us through this change. The strength of any organization is dependent upon its members and staff, and I have no doubts that ACLP will continue to be a robust and dynamic organization. When you read the summaries below of a sampling of the current endeavors underway within the organization, I think you'll agree!

The data center will be a repository of program details and metrics that allow us to benchmark and compare the work of hundreds of child life programs.

Work on the benchmarking project has ramped up since I wrote about it in my last column, and I'm eager to share our progress on this important project. Through a partnership with Dynamic Benchmarking, we will be officially launching the Child Life Professional Data Center (CLPDC) this month. The data center will be a repository of program details and metrics that allow us to benchmark and compare the work of hundreds of child life programs. The data collected will provide much-needed evidence to help define the capacity for patient and family impact based on child life staffing, and will enable data-driven decision making by child life leaders and hospital administrators. This undertaking, which will provide

enormous value to the child life profession, would not be possible without the dedicated work of the Benchmarking Subcommittee of the Scientific Advancement of Professional Practice Committee, especially the tireless "fabulous five" leaders of this project: Kate Shamszad, MS, MPH, CCLS, Quinn Franklin, MS, CCLS, Patrice Brylske, MPA, CCLS, Michael Towne, MS, CCLS, and Anne Claire Hickman, MA, CCLS. We will continue to provide updates as we move ahead with this work.

There are many other committees working to benefit members, too. One new committee that's off to a rousing start is the Technology Integration Committee. One of several exciting projects on their docket is a ground-level exploration of the use of virtual reality (VR) in child life practice. Their task to learn more about VR came as a result of an inquiry on the directors' forum, which resulted in a lively discussion of over 100 posts—clearly, there's an interest in the topic! Amanda Moatz, MEd, CCLS and Meghan Kelly, MEd, CCLS, committee chairs, were invited to brainstorm about how to capture and evaluate the interest in VR, and they've created a survey to help ACLP explore the potential and logistics of employing this technology in child life and to understand the risks and rewards of its use. Many thanks to this committee for their work to help child life professionals stay up to date in an ever-changing technological world.

The Leadership Development Committee, led by Stephanie Hopkinson, MA, CCLS, and Kellye Carroll, MS, CCLS, and its Mentor Program Subcommittee, led by co-chairs Cristie Suzukawa Clancy, MS, CCLS, and Jennifer Fieten, MA, CCLS, are proud of the enthusiasm generated within this year's Mentor Program, which began in January and will run through June. The program, which is in its third year, has matched 45 mentor/mentee pairs, the largest group to date. In addition to one-on-one conversations designed to support mentees in working toward self-defined goals, the program brings all participants together for a series of webinars on leadership topics. The relation-

ships that are built through this program will enable mentors and mentees alike to develop the skills that our profession needs to lead us into the future. This annual program is open to all ACLP members, who are encouraged to look for emails about the application process in the fall.

There's news to share on the academic front as well. Curriculum mapping, which allows graduate programs the freedom to design their own unique courses of study while still ensuring that students are exposed to the knowledge and skills outlined in the [Child Life Competencies](#), has been completed, and the endorsement process will be underway soon. The exciting news is that there are more child life graduate programs than we knew of when we began planning accreditation. As of August 2016, we are aware of 26 graduate programs offering a degree in child life or a degree in a related field with a concentration in child life, and it is our hope that many of these will continue to pursue excellence as we navigate the many academic changes in the coming years.

The big news from the office early this year was the launch of the new ACLP website, and our new look has generated a lot of interest. We appreciate all of the feedback we've received, and it's been especially helpful to learn about areas where we can continue to enhance the functionality and content of this platform. We encourage you to invite families, colleagues, and administrators to the website—it's not just for child life specialists anymore! If you've had a unique opportunity to share the website, please continue to tell us about it. Please know that staff continues to devote time and energy to perfecting the website, and we appreciate your patience as broken links are corrected and pages that weren't activated in the initial phase are rolled out.

Finally, with volunteers and staff continuing the hard work of planning the 2017 conference—our first as ACLP—we're now to the point where anticipation is building daily. It's hard to decide what to highlight in this small space: the excitement of an auditorium packed with child life professionals for the opening session; the powerful educational presentations (and accumulation of PDUs for attending them); the

As of August 2016, we are aware of 26 graduate programs offering a degree in child life or a degree in a related field with a concentration in child life, and it is our hope that many of these will continue to pursue excellence as we navigate the many academic changes in the coming years.

countless opportunities for networking, laughing with old friends and making new connections; the creative meals and assortment of vendors in the exhibit hall; exploring the town from our home base at the Paris Las Vegas Hotel; or the inspirational send-off that invariably moves us as we wrap things up during the closing session. The energy throughout conference is incredible! Kicking it off with the Emma Plank Keynote Address is Kevin Spencer, an illusionist and strong advocate for the arts, who will inspire us with his message about the impact of art in multiple venues and throughout every phase of life. After our full days of celebrating everything child life together, Shola Richards will speak about our professional needs during the Closing General Session, encouraging us with his wisdom about making the workplace a more positive environment. Those who have been to conference know that the many moments of inspiration, motivation, camaraderie, and affirmation make this one of the best weekends you can experience each year. You can become part of this experience by [registering](#) today.

As you can tell, this time of transition for our organization has not been a time of rest. We continue to work toward the goals of the strategic plan and to make progress on the many projects that we've identified as priorities. With the strong corps of ACLP staff and volunteers, the work to support you—our membership—and through you, the patients and families you serve, has continued unabated. ✨



ALPHABET 2.0



I is for Industry versus Inferiority

Jessika C. Boles, PhD, CCLS

MONROE CARELL JR. CHILDREN'S HOSPITAL AT VANDERBILT, NASHVILLE, TN

Most can recite Erikson's (1950) "Eight Ages of Man" from start to finish with some level of depth, whether for an interview, in-service, term paper, or intern. Since their inception and publication, his ideas have built upon and driven forward the fields of developmental psychology, psychoanalysis, child life, and many others focused on the coping and development of children and their families throughout the lifespan. Yet even until his death, Erikson was "surprised at the popular interest [his theories] have generated, and [was] a little troubled about the possibility of being misunderstood and misinterpreted" (Elkind, 1970, para. 9). Although only occasionally misunderstood, his work on psychosocial development has largely been diluted by the progression of time and (unanticipated) accumulation of fame; therefore, it is our professional responsibility to preserve Erikson's (1950) legacy, to return to his very words to guide our interventions with children and families.

As child life specialists and helping professionals, industry reminds us of the importance of opportunities for production and socialization, whether through playroom activities, arts and crafts, or maintaining connections to peers, family, and community members.

Of Erikson's (1950) eight linear, universal, and continuous stages of development (which he termed "crises" due to the inherent conflict in each between one's psychological desires and society's rules and expectations), perhaps the

most well-known and applied crisis is industry versus inferiority. This conflict between one's developing sense of self and norms established by social peer groups is associated with a broad age range: 6- to 11-year-olds. As child life specialists and helping professionals, industry reminds us of the importance of opportunities for production and socialization, whether through playroom activities, arts and crafts, or maintaining connections to peers, family, and community members (Rollins, Bolig, & Mahan, 2005). On the other hand, Erikson (1950) encourages us to be wary of these activities and their potential to negatively influence the child, cautioning that "the child's danger, at this stage, lies in a sense of inadequacy and inferiority" (Erikson, 1950, p. 260).

An industrious child, according to Erikson, "...adjusts himself to the inorganic laws of the tool world. He can become an eager and absorbed unit of a productive situation. To bring a productive situation to completion is an aim which gradually supersedes the whims and wishes of play..." (Erikson, 1950, p. 259).

The "tool world" here refers to the fundamental definition of technology, most generally meaning the creation and use of symbols, tools, and tactics to influence one's environment or activities. Typically these skills are mastered through systematic education, "whether school is field or jungle or classroom" (Erikson, 1950, p. 258), or even a nontraditional setting such as a hospital, hospice, or orphanage. In these structured and formalized settings, the child "now learns to win recognition by producing things," (Erikson, 1950, p. 259). As children interact with tools to produce outcomes (whether tangible, interpersonal, or intrapersonal), they find meaning and success in their accomplishments, which translate into a sense of confidence and competence.

Industry, in this vein, may feel like a threat to the process-oriented pleasures of play, art, creativity, and sport. Erikson (1950) emphasizes that children facing this crisis must prioritize new information and skills, cast aside imagination and fantasy, and focus on the joy of labor and the mastery of both cultural tools and one's own work ethic. It could be argued that this mirrors many of the pressures around standardized testing that currently plague the American education system: prioritization of work over play, cognitive development over social-emotional skills, and product over process. Similarly, stress-inducing environments and situations such as hospitalization, illness, or trauma further complicate this dynamic between work, play, and a child's sense of self.

Mechanical and cold as it may seem, the concept of industry is likely related to Erikson's personal experiences of balancing his own desires for creativity and pride with rigid social expectations about responsibility and productivity from his family and community (Elkind, 1970). Against his father's wishes, Erikson became an artist rather than a physician. As time went on, he accepted a teaching appointment at an American school of psychiatry in Vienna, studied psychoanalysis, became certified as a Montessori teacher, married an artist, and moved to Boston to practice psychoanalysis and then lecture on human development at Harvard. Amidst these accomplishments, Erikson conducted anthropological research with the Oglala Sioux of South Dakota and the Yurok of Northern California; he also worked at a veterans' rehabilitation center to help veterans address the crises of industry and identity after returning from war (Elkind, 1970).

Erikson was, in every direction, industrious throughout his lifetime. He found competence and confidence in what he was able to produce while balancing competing social pressures with personal interests. Some of his products were tangible writings and academic posts, and others were intrapersonal psychotherapy outcomes, prestige, or theoretical developments. School-aged children instead create art projects, win awards, earn grades, build friendships, take up hobbies, and learn new skills that begin to shape self-concept (Harter, 1986), which then grounds identity development in the next psychosocial crisis.

Social comparison information (the insights that children gain from comparing themselves and their work to others or from being compared to other children by adults; Nicholls &



Within play, however, there are small accommodations that child life specialists and other professionals can implement to buffer a child's self-efficacy and self-concept through both the process and product of the play experience.

Miller, 1984), provides the basis for judgments of self-efficacy (one's beliefs about their ability to complete a specific task; Bandura, 1977), both of which contribute not only to self-concept, but also self-esteem (Rosenberg, 1979). It is clear to see how each of these levels—social comparison information, self-efficacy, self-concept, and self-esteem—can be significantly impacted by the stress of hospitalization, illness, or injury within the family system. The hospitalized 6- to 11-year-old child is caught between a proverbial rock and a hard place: Productivity is primary, yet health and wellness are impediments to productivity. Opportunities for play can then be limited by demands for productivity, yet play may be a valuable avenue for gaining the mastery, control, intrinsic pleasure, and self-compassion (Allen & Leary, 2010) that all children, whether ill or typically developing, need to cope with social pressures to achieve.

[continued on page 6](#)

I is for Industry versus Inferiority

Furthermore, a child's personal history of success, failure, or somewhere in between accompanies them into the hospital, through an illness or injury, and upon their return to a community, home, or hospital-based school system and community participation. How can we ensure an experience of production, completion, and perseverance for children across these settings? Most immediately obvious is the use of play, whether therapeutic, developmental, medical, self-expressive, or vicarious, to create opportunities for success that translate into improved immediate and long-term self-concept and coping skills. Within play, however, there are small accommodations that child life specialists and other

Likewise, normalizing feelings of failure or inadequacy is also essential for promoting the resilience children need to face the vulnerabilities that come with social comparison and self-judgments.



professionals can implement to buffer a child's self-efficacy and self-concept through both the process and product of the play experience.

First, it is important to praise children for their efforts rather than outcomes, both in their coping efforts and in their play activities and achievements. In addition, as efforts are praised, child life specialists, peers, and other adults should capitalize on opportunities to recognize and highlight the child's individual strengths. Since self-concept is actively developing, deliberately pointing out and valuing the child's strengths can ward off potential feelings of inferiority. As school-age children learn to compare themselves with others, it is also helpful to model (and normalize) imperfections, disappointments, rejections, or failures in the playroom or bedside play setting. Those who have seen me try to draw things know that, with a pencil in my hand, all I can do is display imperfection and failure! Likewise, normalizing feelings of failure or inadequacy is also essential for promoting the resilience children need to face the vulnerabilities that come with social comparison and self-judgments.

Given the limitations of our roles as child life specialists within the child's expansive social context, there remains the potential for the development of inferiority in the face of a stressful health care experience. Or, on the other end of the spectrum, a child may enter into a medical situation with pre-existing feelings of inferiority, which can further challenge our work to promote coping and development. It is crucial then to be able to recognize the warning signs of inferiority as we continually assess and reassess the child's needs and coping.

Classic inferiority can manifest as a sort of learned helplessness, or a lack of engagement in one's own illness and activities. If a child "despairs of his tools and skills or of his status among his tool partners, he may be discouraged from identification with them and with a section of the tool world" (Erikson, 1950, p. 260). For the child life specialist, this may look like avoidance, denial, or other types of passive coping mechanisms. In addition, inferiority can range from "hidden" clues, such as statements like "I'm not very good

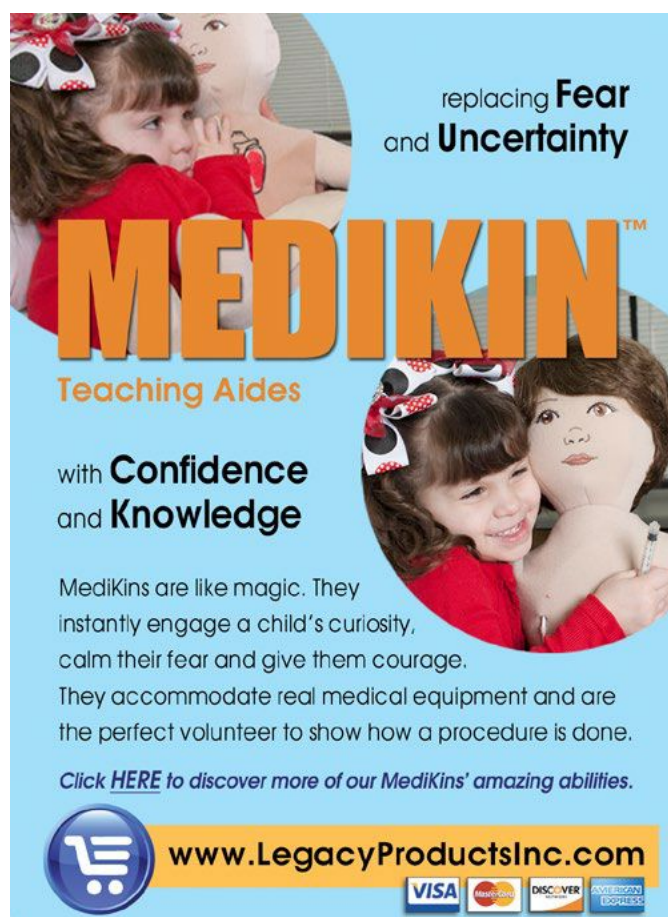
at that,” or “I won’t be able to ‘get it,’” to more overt tactics such as “hiding” behind an iPad, or “escaping” into headphones or sunglasses to resist engagement in one’s medical or psychosocial care (Boles, 2016). Less typically, inferiority can take the form of selective mutism, anxious-avoidant disorders, or other behavioral health diagnoses which would indicate the need for appropriate referrals and services.

Erikson’s (1950) essay on the psychosocial crises of human development largely reflects his own personal struggles with “lifelong feelings of inadequacy” (Bloland, 2004, p. 12), per his own daughter, particularly in a time where psychology was preoccupied with pathology and abnor-

mality rather than strength and resilience. As documented in his later work, Erikson explained his perspective, saying “if we know what can go wrong in each stage, can we say what should have gone and can go right?” (cited in Roazan, 1997, p. 595). When children and their families are experiencing the stress of illness, injury, or hospitalization, practitioners are aware of the many challenges to coping and development that may lie ahead. By deepening our insights into our theoretical foundations and deconstructing the infamous crisis of “industry versus inferiority,” we can see new opportunities to engage in daily play practices that promote a balanced sense of industry and a cautious awareness of inferiority in the patients and families that we serve. ✨

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Extraordinary Service Lived Every Day

Anita Pumphrey Honored with the 2017 Distinguished Service Award

Stephanie Hopkinson, MA, CCLS

KUWAIT ASSOCIATION OF THE CARE OF CHILDREN IN HOSPITAL, KUWAIT



Extraordinary people have blazed the trails of our field for over three decades, paving the path of vision and innovation to bring us to where we are today. These people have been celebrated and honored as the Distinguished Service Awardees for their work in representing unwavering commitment and profound dedication and service to child life. This year, 2017, we honor the next recipient of the Distinguished Service Award, Anita Pumphrey, MS, CCLS. Reflecting on her path to and within child life, Anita acknowledges the model of her parents, who demonstrated the value of helping other people and treating them with kindness and respect in their everyday life as a family. She

shares with a wonderful sense of love that “they were my first teachers and role models for showing God’s love through service to others.”

Anita is an incredible, dynamic model of distinguished service for child life. Early in her career, in 1993, she started the first child life program at St. Francis Medical Center in Monroe, Louisiana. She then moved into academic education in the fall of 1995, teaching in Family and Child Studies at Louisiana Tech University in the School of Human Ecology. During this time, the child life program was not yet offered at the university, and Anita was instrumental in developing the program to be the thriving and dynamic course of study that it is today. To date she has developed and delivered over ten courses and has reached thousands of students who are making a difference in the lives of children and families. She has received numerous awards and accolades for her teaching and work at the university, including the Outstanding Faculty Advisor Award and the F. Jay Taylor Undergraduate Teaching Award, both high honors from the university.

Her past students credit her for preparing them for what life in the professional world will bring. They speak with love, conviction, and passion about how she has supported them, both as students and as emerging professionals.

Anita’s dedication to the field truly centers around being a voice for students. When speaking about the defining moments of her career and what drives her, Anita always comes back to the students. Early on in her path she connected to the insight that growing the field of child life needed to begin with the students. Her belief in the academic training of students and setting them up for success is what she humbly does year by year. Her past students credit her with preparing them for what life in the professional world will bring. They speak with love, conviction, and passion about how she has supported them, both as students and as emerging professionals. Anita’s students have shared that she has a “crying” chair in her office, where many tears of challenge and success have been expressed. The true heart of a child life specialist in an academic role is illustrated in Anita, respectfully known to her students as Mrs. Pumphrey.

For the past 20 years, Anita has been highly involved and actively engaged in the work of the Child Life Council (CLC; now known as the Association of Child Life Professionals [ACLP]). To date she has served on 11 committees, served twice on the executive board of directors, participated in three strategic planning sessions, authored several publications, and presented many innovative sessions at conference. One of the milestones of her work in the association was marked by her involvement in the early stages of the endorsement of child life academic and internship programs,

initiated by the CLC board of directors over 16 years ago. Anita was actively involved in the collaborative development of these documents and processes, and brought a consistent and visionary voice to these initial steps. She honored the collaborative nature of the process and helped to guide others' understanding of the academic setting. This history and her steadfastness is significant in the current development of this process as the Association of Child Life Professionals moves into the accreditation and endorsement of both academic and internship programs, where Anita has continued to share her wisdom and expertise of the academic world in child life. Moreover, she co-represented CLC on a site visit to Spain where she helped to guide, coach, and mentor the design of a child life master's program being developed at the University of Barcelona.

When asked about her network and engagement in ACLP, Anita expresses that "it is a place that is boundless—it is a place where I find my energy!" She credits ACLP as a place to use her skills and talents. With profound gratitude, she celebrates all those who were there to mentor her during her tenure in the field, and those who took the time to listen to the vision she shared early on about the importance and value of student preparation. She expresses, "I love my work, the colleagues I work with, the network of child life professionals, and the opportunities I have had with ACLP!"

"I love my work, the colleagues I work with, the network of child life professionals, and the opportunities I have had with ACLP!"

To this day, ACLP and her students are what drive Anita in her professional work. This drive is supported by her incredible husband, sons, and family. Anita's reflective and thoughtful presence has been experienced by many around the world. She brings a wealth of knowledge and experience to each aspect of the association she is involved in. Her dedication, perseverance, and pure passion for the growth and integrity of child life work are truly among the hallmarks of who Anita is. The Distinguished Service Award will be presented to Anita at the Closing General Session of the ACLP conference on Sunday, May 28th. Join us in congratulating Anita Pumphrey as a courageous servant-leader who continues her extraordinary work and vision in child life—a great model of distinguished service and this year's Distinguished Service Award winner! 🌟



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Children in the refugee camp during free play.

CHILD LIFE IN A REFUGEE CAMP: When Two Worlds Collide

Marais Pletsch, MA, CCLS

REFUGEE TRAUMA INITIATIVE, THESSALONIKI, GREECE

Although I began my career as most child life specialists do, working in a hospital, I now use my skills to provide services in an unusual setting and to a different population than most child life professionals imagine. My previous experience as a child life specialist in the emergency department has taught me many valuable lessons about working with children experiencing trauma and providing opportunities for play in challenging situations.

I draw on this experience on a daily basis in my work as the early childhood development program manager at my small grassroots organization: Refugee Trauma Initiative (RTI). While completing a master's degree studying child studies in London, I had the opportunity to intern with this organization and was then recruited to manage psychosocial programs on the ground in Greece. Our mission is to increase resilience and enhance well-being in

refugee camps by offering culturally sensitive psychosocial support to the most vulnerable refugees, particularly children, on an individual, group, and family basis.

Allow me to set the scene of the refugee camps in Northern Greece: Typically held in abandoned, isolated warehouses with limited ventilation and light; hundreds, sometimes thousands of predominantly Syrian refugees are

crowded in rows of small tents holding only the possessions they carried with them on their journey. Some swam for hours before being rescued. Others watched family members drown on the journey. Children of all ages run around the camp and surrounding areas playing with anything they can find, from rusty nails to stray dogs. There is a dense fog of hopelessness and fear that floats through the camp. For these reasons and many more, psycho-

social support services are vital while families wait for an unknown amount of time to be granted asylum.

Instead of introducing services and making rounds from hospital room to hospital room, I now go from tent to tent. Here I am not validating feelings regarding hospital frustrations such as annoying monitor sounds and waiting times; instead I am validating feelings of anxiety regarding the lack of heating in the camps during winter and lack of adequate nutrition for children under two. Each family has been through their own horror; whether it be during the war, on the journey, or inside the refugee camp. Everyone here is vulnerable, especially children whose development has suffered immensely.

In collaboration with other organizations, my work helps fill the gaps to provide support to children. Instead of a playroom, I have access to an old shipping container that has been converted to a comfortable space with books and toys. When I feel overwhelmed by the challenges of providing services in this setting, I remember that play is a universal language. These children are desperate for structure, for stimulating and imaginary play that will take them out of the camp and into a better place. Our early childhood development program focuses on providing psychosocial support and early learning to children ages 0-6 and their caregivers. The program is family-centered and provides sessions for parents to alleviate their stress and address their trauma, but also to support them in keeping their children safe and healthy in transient and uncertain times. I teach the families how to utilize guided imagery and therapeutic activities that give their children opportunities for self-expression and help to normalize their experiences. This program gives mothers an opportunity to engage with their infants and work to form secure attachments that have been hindered by the difficult circumstances. Similar to the teen groups I facilitated for hospitalized adolescents, we have teen groups focused on

normalization activities such as nail painting, dancing to traditional music, yoga, and arts and crafts activities. I have observed children who had not spoken since arriving in Greece speak after attending our sessions. I have celebrated with families who felt empowered by being able to calm their child back to sleep after night terrors. I have been moved to tears hearing of previously-isolated teenagers from different cultural backgrounds connecting after attending our teen groups. I have praised children who after much practice have learned how to place trash in the trash can and how to share with other children. Although these children and adolescents have a long way to go to be able to assimilate into their future societies, I am thrilled to have played a small part of making this excruciatingly painful journey more tolerable.

Instead of advocating for children at multidisciplinary rounds, I now



Children in the refugee camp during free play.

advocate at camp coordination meetings, regional meetings, and to the government and United Nations to ensure that the needs of the children and families we work with are being recognized. Similar to my work in

[*Continued on page 12*](#)

Working with Refugee Children and Families in the Hospital Setting

It is of utmost importance to understand the cultural norms of the child and family you are working with, and it is equally significant to recognize that the attachment between parent and child may be disrupted due to the trauma they have likely experienced. Among refugee children, hospitals or sick people may trigger memories of conflict and suffering. Similarly, being separated from parents may trigger immense anxiety. It would be helpful to have an in-depth understanding of PTSD to be able to support the children and families who suffer from it. Some of the children I work with are developmentally delayed and have behavioral difficulties and lower socio-emotional intelligence. Many of the children I work with have difficulty expressing emotions appropriately and can be particularly aggressive. Because they have been in a refugee camp environment for so long they are often not able to sit still for extended periods and need extra encouragement to complete basic tasks. But most importantly, these children are resilient. They have been treated 'differently' for so long. They desire to be understood as humans, not as refugees. They crave normalcy, structure, and play. As these children and families adjust into their new societies, it will be particularly important to give them opportunities to process and express their emotions. Doing so will help alleviate barriers to successful coping with experiences such as hospitalization.

continued from page 11

Child Life in a Refugee Camp

the hospital, my current role is fast-paced, unpredictable, challenging, and deeply rewarding. While my two worlds of hospital and refugee camps can feel very different, they also feel exceptionally close. Ultimately, I am working toward the same goal: to provide support for vulnerable children and families undergoing challenging experiences. By facilitating opportunities for these groups to come together and share stories, process trauma, and breathe, we are giving them an opportunity to come alive again. And that is something incredible to be a part of. ✨

Follow and support the work of RTI on Facebook (Refugee Trauma Initiative) or on the RTI website at www.refugeetrauma.org. Marais can be contacted directly at marais@refugeetrauma.org



Children in the refugee camp practicing how to be calm sleeping animals.

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MEDi and patients after preparation for EEG testing.

Integrating a Humanoid Robot into Child Life

Jacqueline Reynolds Pearson, MA, CCLS

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If robots are the future, then the future is here, even in child life. Although I have been working with MEDi, Alberta Children's Hospital's humanoid robot, for almost two years now, I still find it incredible that a singing, dancing, walking, talking robot has become part of the daily practice of a child life team.

History

MEDi is a Nao robot built by Aldebaran and programmed for pain management by Dr. Tanya Beran, a professor and the founder of RxRobots. In 2011, Dr. Beran and a team of physicians and researchers from Alberta Children's Hospital and University of Calgary began to explore the impact of a small humanoid robot programmed to implement cognitive-behavioral strategies to reduce distress and pain with children receiving flu vaccinations (Beran, Ramirez-Serrano, Vanderkooi, & Kuhn, 2013). Based on evidence

from the growing field of pain management literature of strategies that have been shown to help children through needle procedures (Uman, Chambers, McGrath, & Kisely, 2008), the researchers designed a repertoire of behaviors for the robot. They hypothesized that given children's intrigue with technology and robots, a socially engaging and entertaining robot could provide a means of distraction during vaccinations and that children who received this intervention would experience lower levels of pain and distress than children without such support.

The study yielded clinically significant results: Participants experienced a 50% reduction in both pain and distress. A subsequent unpublished study at the same site during bloodwork found similarly positive results.

In support of this cutting-edge initiative, Alberta Children's Hospital purchased four robots under the umbrella of the Vi Riddell Pain and Rehabilitation Centre. Alberta Children's Hospital also agreed to be the official test site for the robots and

[Continued on page 14](#)

Integrating a Humanoid Robot into Child Life

became the first hospital in the world to have the opportunity to work with humanoid robots in this way.

When the robots, all named MEDi, arrived in February 2015, they were pre-installed with a few apps, including the two for procedural support that Dr. Beran had previously studied. Ideas for the development of additional apps for

key. Child life was a natural fit for the study's focus on supporting children in coping with medical procedures, and as a longtime Certified Child Life Specialist with expertise in technological applications to child life, in June 2015, I was assigned to lead the implementation of the robots and coordinate the quality improvement study.

We quickly discovered that there are numerous practical considerations to have in place to successfully integrate humanoid robots into hospital practice.

a wide variety of medical procedures quickly emerged. Dr. Beran worked alongside several nurses and child life specialists, observing the steps of the procedures and the psychological support strategies utilized. Apps were programmed in ways that could complement therapeutic interventions and align with pain management research evidence (Chambers, Taddio, Uman, McMurty, & HELPiNKIDS, 2009). Specific strategies were embedded within the apps: affirmation, deep breathing, encouragement, guided imagery, humor, positive reinforcement, preparation, reframing, relaxation training, role modeling, and storytelling.

The Practical Side of Integration

Given the robots' potential, demonstrated by the vaccination and bloodwork studies, it was posited that the robots could also improve pain management for children undergoing other medical procedures in the inpatient area. A quality improvement research team was assembled to explore the possibilities. Due to the magnitude of beginning a study of this nature in a diverse and dynamic inpatient environment, appointing a project leader was

We quickly discovered that there are numerous practical considerations to have in place to successfully integrate humanoid robots into hospital practice. These include: enabling frequent charging, finding a means of transportation throughout the hospital for robots and other necessary equipment, ensuring the safety of children, securing expensive pieces of equipment, developing an infection control protocol, and establishing as well as maintaining robot-router-tablet connections.

Learning how to operate the robots was initially viewed as a formidable challenge, but as we have worked through the start-up phase, this process has become much easier. Development and programming of the applications was pioneered by Dr. Beran and has now evolved into a multidisciplinary and multisite collaboration. RxRobots programs the apps and makes them available to all hospitals. Everyone using the robots is encouraged to build on each other's ideas. Troubleshooting is a joint effort between RxRobots, Aldebaran, child life specialists, and the project leader. We are now in the final stage of the quality improvement study and plan to publish the findings in the near future.

Current Uses of the Robots

Presently at the Alberta Children's Hospital, the robots are used as tools to enhance the service child life provides with the typical outcome goals of child life interventions in mind:

Procedural Support – MEDi guides the child through the various steps of a medical procedure, reframing medical language in a child-friendly way and providing alternative focus (often referred to in the pain management literature as distraction) by telling jokes or doing a dance at key times. The challenge with this approach is synchronizing MEDi to the procedure. Nurses in a few treatment areas have tried to operate the robot during medical procedures but they have found it very difficult to simultaneously manage the hands-on requirements of the robot while performing the procedure. We have found it most effective to use MEDi as one part of a child life specialist's procedural support intervention.

Alternative Focus – Attentional capacity theory explains that a child's attention will be drawn to the strongest stimulus (Beran, Ramirez-Serran, Vanderkooi, & Kuhn, 2013). A novel, highly engaging robot singing and dancing to "Gangnam Style," for example, often appears to provide a stronger stimulus than a needle.

MEDi has also recently been part of a multidisciplinary approach to using alternative focus in lieu of sedation during minor surgery. In the past few months, child life specialists have been invited to regularly provide support during the minor surgery clinic, a service in which child life had rarely been involved prior to MEDi's introduction. A child life specialist operates the robot in effort to engage the patient's attention away from an invasive procedure, but this is just one important piece of



a team approach to ensure the child's optimal comfort.

Deep Breathing Support – In reviewing the literature, we found evidence that an effective strategy for coping with pain associated with injections is breathing/blowing (Chambers, Taddio, Uman, McMurtry, & HELPinKIDS, 2009). MEDi has been programmed to explain the concept of deep or belly breathing to children and their parents and encourage them in a fun way to use this strategy. We have observed that children are very receptive to MEDi's instruction and have seen some use the strategy taught by the robot even when MEDi wasn't there during the procedure.

Preparation – MEDi has been programmed with an app that provides information in a playful manner about what a child will see, do, hear, smell,

and touch when coming to the hospital for surgery, including demonstrations of how real medical equipment is used.

Medical Play – We have successfully used MEDi during medical play to help children prepare for, gain mastery of, and play through health care experiences including diagnostic tests such as EEG. MEDi has been used in a similar manner to a doll or stuffed animal with the advantages that the robot is programmed to speak and demonstrate friendly human qualities. Children may use medical equipment and treat MEDi as the patient, taking care of the robot in the same way they have been taken care of. When MEDi tells them they are being gentle and caring, we hope this reassures children that health care staff use the same care, and believe this fosters cooperation and confidence to face their health challenges.

Play Partner – We have noted that children appear to relax when playing with MEDi pre-procedure, therefore potentially reducing anticipatory anxiety in the waiting room and possibly decreasing overall distress. For several children, MEDi has played a large role in combatting the social isolation and boredom that are often part of a hospital stay. We have also explored the use of MEDi in our mental health program, assisting patients in identifying and regulating their intense emotions to help them develop peer and family relationships and adapt to the school environment. Patients in this area have contributed ideas to the creation of an app focused on the theme of "feeling left out". MEDi conveys a story about being rejected and encourages empathy and a discussion of their own feelings. Based

[Continued on page 16](#)

Integrating a Humanoid Robot into Child Life



on the children's recommendations, MEDi completes the interaction with an empowering song about being brave.

Movement Motivator – We have used MEDi to engage patients in developmentally appropriate play involving movement and physiotherapy, particularly after surgery or long periods of rest and weakness. In one example, health care professionals were having difficulty encouraging a 5-year-old to move or even get out of bed. One of the child life specialists set up MEDi on a mat on the floor and prepared the robot to invite the child to play “Simon Says.” To everyone's surprise, the child readily agreed, allowed the nurses to lift her to MEDi's side, and began following the robot's lead in moving her entire body, playing and doing physiotherapy without realizing it. Physiotherapists in Australia are

also exploring the use of a Nao robot to perform rehabilitation exercises with patients (Butchart, 2016).

Hospital Tour Book – MEDi appears as the main character in a hospital tour book designed as an orientation to Alberta Children's Hospital for preschool and early school-age children (Bell-Graham, Gregson, & Pearson, 2016). Children are thrilled to see that the character in the book actually exists and is available to interact with them and provide support during their hospital experience.

Referral and Assessment

There was tremendous excitement about MEDi when the robot was first introduced. Our team tried to build on this by offering in-services to staff and physicians in various program

areas to discuss the therapeutic use of the robots and outline the appropriate referral process. Hospital personnel were encouraged to “not promise” robot encounters, rather to submit a referral to child life for support. Once referrals are received, they are triaged, and individual child life specialists then assess and determine whether MEDi will be used during their intervention. Type of procedure or concern, location, timing, child's developmental level, prior health care experiences, coping skills, and preferences are all factors for consideration. Most referrals are discussed with other health care professionals and within the child life team so as to implement MEDi in the best possible way for each individual child.

Often child life specialists show children a photo or short video in advance of introducing MEDi, as some children, especially those under 4 years of age, may be afraid of robots. Originally, the upper age limit for use of the robot was thought to be 12 years, but we have noticed that some children even a little younger than 12 may reject the apps as childish, but still find the technology fascinating. Due to wide variation in children's preferences, it is difficult to predict which children will be interested in MEDi.

Ethics and Learning

Prior to my experiences with MEDi, I thought of robots and their purpose in society as replacements of humans, often in predictable repetitive tasks. Although a child life specialist's day is typically anything but predictable or repetitive, the replacement piece did cause concern. Our initial fear was that the robot could be perceived as a convenient substitute to child life assessment and intervention. We wondered how we could possibly champion the use of a robot to meet what the

Association of Child Life Professionals Code of Ethical Responsibility (child-life.org) states as our goals:

- Maximizing the physical and emotional health as well as the social, cognitive and developmental abilities of children.
- Minimizing the potential stress and trauma that children and their families may experience.

One of my first experiences with MEDi was with a 4-year-old boy. His mother saw me in the hallway and mentioned that it would make her child's day to see a robot. When I brought the robot into the room, the boy, who had apparently been very withdrawn while awaiting surgery for skin grafting, was immediately engaged in play, passing toys to MEDi and cheering as the robot kicked a soccer ball. The child life team has a long list of many such stories, and we are just beginning to understand how humanoid robots can inspire play and joy, help children cope with stress and trauma, and enhance the health care experience.

Early in the project we were fortunate to have an undergraduate student on a summer scholarship assist us in gaining comfort with learning the basic operations of the robot. When summer ended, I took on the role of "robot expert" and worked with each individual child life specialist to support them

When I brought the robot into the room, the boy, who had apparently been very withdrawn while awaiting surgery for skin grafting, was immediately engaged in play, passing toys to MEDi and cheering as the robot kicked a soccer ball.

in their learning in new situations. Through imagination, risk-taking, and creatively weaving MEDi into our therapeutic interventions, we have come to see that a robot can be a very positive complement to a child life specialist's approach. Many of the ways in which the robots are programmed and used are supported by current evidence in the pain management literature (Birnie et al., 2015).

Learning has been an ongoing process of trial and error, characterized by both success and failure, but we adapt with humour, patience, and constant critical reflection. When incorporating MEDi into an intervention, child life specialists also bring additional teaching and alternative focus tools along to ensure the best possible outcome in the event that the robot is not the best tool for the situation.

An unexpected benefit of MEDi has been a noticeable increase in awareness of child life in our hospital. The exposure generated by a robot has led to increased referrals for support and

better relationships with multidisciplinary team members throughout many areas of the hospital including anesthesia, lab, minor surgery clinic, and vision clinic.

As for the concern about robots replacing child life specialists, in my opinion, robot substitutes are still a long way off. Attention to individual differences and the intricacies of each medical situation are just not possible for even the most autonomous humanoid robots. Our hope is that we can support children in better ways through robots' integration into health care. Based on my experience, integrating humanoid robots into child life practice will only increase the demand for child life specialists' unique—and fully human—expertise and care. ✨

A video of MEDi in action is available on the [Alberta Children's Hospital](#) website. The child life team is more than willing to share our experiences with others. Please feel free to contact us with your thoughts and questions.

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How To Be a Child Life Detective in Your Hospital

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One of the most important assets that successful child life specialists possess is the ability to use critical thinking and emotional intelligence to make positive changes within their units. Being on the front line of patient and family care, child life specialists often perceive health care through a unique lens, noticing ways providers can improve care for patients. In a hospital, implementing change sometimes can be challenging—the bureaucratic structure of a hospital consists of many tiers of management, and a change often needs approval from a number of disciplines and senior-level administration. However, with an open mind, it can be worth it in the end.

As child life specialists, our coursework prepares us to be attuned to ways to improve children's understanding and capacity for coping. Since we are trained to focus on the emotional needs of patients and families, we have a keen awareness when a protocol is causing a patient or family distress or dissatisfaction. When this happens, we need to be committed to voicing the need for modification and become involved in quality improvement projects. Quality improvement projects consist of measurable actions that examine the best way to improve patient care, and improving the quality of care for patients is an obligation for hospital employees (The Children's Hospital of Philadelphia Research Institute, 2015). According to the American Hospital Association (2012), a quality improvement project generally involves five steps:

1. Identify target areas for improvement.

2. Determine what processes can be modified to improve outcomes.
3. Develop and execute effective strategies to improve quality.
4. Track performance outcomes.
5. Disseminate results to spur broad quality improvement (p.1).

It is important to note some differences between quality improvement projects and research projects. The goal of a research project is to prove or disprove a hypothesis, whereas the goal of a quality improvement project is to use the results of previous research to develop a project that improves the quality of patient care (The Children's Hospital of Philadelphia Research Institute, 2015). Hospitals are always seeking to improve the quality of patient care, and the metaphor of being a detective can be used to explain how child life specialists can be part of this process. Table 1 illustrates the similarities between the actions of a police detective and a child life specialist undertaking a quality improvement project.

In my experience working on a surgery unit, I have learned to think like a detective, keeping an open mind and attempting to see things from an objective perspective. I have used my assessment, observational, and critical thinking skills to implement positive changes that have improved our care for pediatric patients. A case about parental presence in the post-anesthesia care unit (PACU) illustrates this model and the steps that a child life specialist, working like a detective, would take to solve a problem.

- 1. Hear a complaint, notice a problem,**

or see something that can be done better.

Every time I assessed my patients in the PACU, I kept hearing the same complaint from parents: "I wish I could have been there when my child first woke up after surgery." I knew that these parents had a point. Both children and parents could possibly have a much better surgery experience if they could be together for that potentially frightening moment when children first wake up from surgery and want to be comforted by their caregiver.

- 2. Investigate the problem, talk to nurses and doctors, and try to figure out why things are being done the way they are.**

I spent time watching the process of children leaving the OR and arriving in the PACU. I learned that the process was as follows:

1. OR nurse calls the PACU and tells them the patient will be arriving in 10 minutes.
2. After 10 minutes, patient leaves the OR and arrives in PACU.
3. A staff member notices a pediatric patient in the PACU and calls the family lounge to get the parents.
4. Parents begin to make their way back to the PACU.
5. By the time the parents arrive in the PACU, the child had often awoken from surgery without his/her parents there.

- 3. Identify a better way of doing things.**

As I thought about the problem, it seemed like it would be logistically easy to fix. Instead of calling the family lounge after the patient arrived in the

PACU, the PACU could call the family lounge at the 10-minute warning. This way, parents would have time to walk to the PACU and arrive just before their child. Although this was logistically possible, I didn't know if there were medical risks or other reasons that this process would not be a good idea to implement.

4. Gather evidence to prove that change is needed.

I started by floating the idea by a couple of PACU nurses. I learned that nurses were afraid the parents would get in the way or distract them from doing their job. They were also uncomfortable with the thought that parents would be judging them as they provided care. Next, I reached out to child life colleagues in other surgery units, both in my hospital and other hospitals. I learned that it was standard practice in many PACUs for parents to be present as their child awoke from surgery. I did a literature review and found articles on topics such as separation anxiety, how parents can best support their children when they're in pain, and the positive effects of parental presence in a postanesthetic unit. Additionally, I kept track of statistics. I kept track of the number of patients that would wake up in the PACU without their parents and the amount of time it would take for parents to arrive there, which averaged about 15 minutes. After doing all of my research, I had relevant evidence to support my advocacy for change.

5. Convince superiors and colleagues that change would make outcomes better.

Now came the hard part: Who was I going to have to convince and what obstacles would I have to face? I scheduled a meeting with the patient care director of the PACU. Knowing her, I considered that she was a concrete thinker and that it would be best to present her with facts and figures. I presented my evidence for why a change was needed, a concrete plan of how this would be accomplished, and

TABLE 1
Comparison of the Work of a Detective and Child Life Specialist

| WHAT DOES A DETECTIVE DO? | WHAT DOES A CHILD LIFE SPECIALIST DO? |
|---|---|
| Hears a complaint, notices a crime, or sees something suspicious | Hears a complaint, notices a problem, or sees something that can be done better |
| Investigates the crime scene, talks to witnesses, tries to piece together what has happened | Investigates the problem, talks to nurses and doctors, tries to figure out why things are being done the way they are |
| Identifies the suspect | Identifies a better way of doing things |
| Gathers evidence to prove suspect is guilty | Gathers evidence to prove change is needed |
| Convinces superiors and colleagues to take the case to trial | Convinces superiors and colleagues that change would make outcomes better |
| Works with attorneys and testifies to put suspect in jail | Works with the interdisciplinary team to implement the changes |

focused the message on the fact that it could improve patient satisfaction numbers. I showed her research that demonstrated the benefits of having parents at bedside when children first woke up from surgery (Lardner, Dick, & Crawford 2010) and the statistics I had gathered. I suggested that we make a brochure for parents to review in the waiting area to inform them of what to expect in the PACU. She told me I would have to get this approved by surgeons, anesthesiologists, and more senior administration.

6. Work with the interdisciplinary team to implement the change.

My next steps were setting up more meetings and sending out more emails. I came to each meeting with an agenda and specific goals in mind. I provided an in-service to the PACU nurses addressing their concerns about feeling judged or parents getting in the way of the patient's care. I finalized the brochure that would be offered to parents. Once everyone agreed to implement the change, I followed up to make sure the new procedure was being implemented and continued monitoring for challenges. Today, parents are more frequently by their children's bedside when they wake up from surgery.

Making any change can seem like a scary and daunting task. However,

child life specialists may see things through a lens that others may not, and need to feel empowered with our ability to influence change. Many employees in the hospital setting have a responsibility to focus on a patient's medical needs, while child life specialists have a responsibility to focus on patients' and families' emotional needs. This allows us to make observations that someone focused on the physical needs of patients may overlook. Child life specialists have voices that need to be heard, and by using our detective skills and becoming involved in quality improvement projects, we can make a difference. It takes a lot of patience and persistence, but the end results can be extremely rewarding. 🌟

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Child Life Focus



“All Heart”

Animal-Assisted Interventions with Hospitalized Children with Cancer:
A Case Description

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Each year, 13,500 children are diagnosed with cancer, while over 40,000 undergo cancer treatment in the United States (Children's Oncology Group [COG], 2016). While survivorship from childhood cancer has improved greatly over the years, psychological and physical complications may linger and negatively impact children and their families (National Cancer Institute, 2016).

Quality of life for these children remains a concern (COG, 2016). Strategies to address the challenges incumbent with a cancer diagnosis vary, but animal-assisted interventions (AAI) provide one example of a potentially effective initiative (Gilmer, Baudino, Goddard, Vickers, & Akard, 2016; Gilmer et al., 2015). The basis for the title of this article is included as a sidebar, demonstrating the etymology of the word for *dog* in Hebrew and

the crucial place of the human-animal bond in the healing process. This case study begins with an overview of the research related to the therapeutic benefits of animal-assisted interventions, describes the experiences of an adolescent patient, Grace, related to AAI, and concludes with practical suggestions for child life specialists.

Relevant Evidence

Efforts to improve psychosocial outcomes for children diagnosed with cancer or other serious illnesses have existed for decades. From the days of not allowing parents to visit their children to the current incorporation of essential child life specialists into the health care team, tremendous strides are being made. Child life specialists are able to include play as an integral element in psychosocial care for children.

The construct of play has many different facets, but when defined by Rubin, Fein, and Vandenburg (1983), play refers to activities that are intrinsically motivated, focused on means rather than ends, nonliteral or symbolic, free from external rules, and actively engaging. Especially for children who are experiencing stressful circumstances and struggling to cope with a new diagnosis or procedure, play may be beneficial, as it is developmentally supportive as a normalizing activity (American Academy of Pediatrics Committee on Hospital Care & Child Life Council, 2014). Play is essential for children's growth and development, as it provides children a means to build competence, become empowered, and promote positive affect (Rollins, Bolig, Mahan, 2005, p. 83). It can decrease anxiety (Power, 2000) and increase the child's sense of control (Rollins, Bolig, & Mahan, 2005, p. 92). Burns-Nader and Hernandez-Reif (2016) remind readers that "children learn about their world" (p. 4) and "safely explore stressful or unfamiliar themes" (p. 4) through play.

One type of play, animal-assisted play, helps to normalize a hospital environment, improve mood, increase children's socialization, and decrease fears (Urbanski & Lazenby, 2012). Animal-assisted play provides opportunities for children to interact with animals in a safe environment. This may include petting a dog, snuggling with a dog, talking to a dog, or taking a dog for a walk. Animal-assisted play can particularly help children living with cancer

as they are at especially high risk for distress related to numerous negative experiences and/or stressors (Chubak & Hawkes, 2015).

In the literature, animal-assisted play is described in a variety of ways: AAI, animal-assisted therapy, and animal-assisted activities (Gilmer et al., 2016). Pet Partners (2016), one of the certifying bodies that trains and evaluates volunteers for animal programs, describes the umbrella term of AAI as goal-oriented and structured interventions which incorporate animals in health, education, and human service to improve health and wellness. AAI include walking a dog, petting a dog, socializing with the owner of a dog, talking to a dog, and conversing about the patient's own pet at home. To distinguish the other commonly heard terms, animal-assisted therapy as a specific type of intervention is planned and directed by health care professionals to meet a specific therapeutic goal, while animal-assisted activities are more informal and provide opportunities for motivational, educational and/or recreational benefits to enhance quality of life (Pet Partners, 2016). Sessions with an animal are generally delivered by specially trained professionals or volunteers, in partnership with a certified animal that meets specific criteria. For example, certified dogs can walk through a crowd of people or past a table full of food without being distracted. They are friendly with strangers and obedient. The animal may be owned by a volunteer and working under the supervision of a health care professional or owned by the professional.

Animals have been used therapeutically to help address symptom distress for thousands of years (Stanley-Hermanns & Miller, 2002). Even Florence Nightingale noted how beneficial small pets could be as companions for the sick and disabled (Nightingale, 1898). Sigmund Freud speculated that dogs could judge the character of people (Fine, 2010). He allowed one of his own dogs, Jo-Fi, to attend psychotherapy sessions because of his calming presence. A child psychologist in the 1960s, Dr. Boris Levinson, observed that children were less anxious and resistant to therapy when his dog, Jingles, was present (Levinson, 1965).

The Association of Child Life Professionals (Child Life Council, 2014) attests that those children who are less fearful of their hospitalization experience less psychological distress

and improved well-being. Providing experiences with animals in the hospital setting may be one way to decrease fear (Gilmer et al., 2016; Gilmer et al., 2015). Many children have pets at home and the role of animals in

[Continued on page 22](#)



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Continued from page 21

society has shifted from primarily a means of food, labor, and transportation to include an increased role for domesticated pets throughout the last century (Hines, 2003). Pets provide companionship to people across the world, and the relationships among animals and their owners are widely recognized in current psychological science (Audrestch et al., 2015). The human-animal bond is often studied in clinical settings, with an emphasis on the importance of animal interactions in human health and well-being. Certified animal teams volunteering in the hospital setting can provide an additional means of play, as the choice is given to the child to participate in a session with an animal, the sessions provide active engagement, and they focus on the act of play (Rubin, Fein, & Vandenberg, 1983).

The Human-Animal Bond. Studies have documented the positive implications of the human-animal bond for human psychological, emotional, and even physical health (Chandler, Fernando, Barrio Minton, & Portrie-Bethke, 2015; Maharaj, Kazanjian, & Haney, 2016; Sable, 1995; Wells, 2009). Sable (1995) suggested that the attachment an owner has with a pet provides comfort and reduces loneliness during times of social and emotional stress. Another study found that dogs promote their owners' health, mood, and emotional satisfaction (Maharaj et al., 2016). In evaluating pets as a valuable means of therapeutic intervention, Wells (2009) concluded that animals contribute to both long- and short-term physical health by alleviating mood, relieving stress, and reducing anxiety. Chandler and colleagues (2015) described eight domains of human wellness that are affected by the pet-owner bond, including "emotional and physical nurturance, sense of family, sense of responsibility and purpose, friendship or companionship, social interaction and connections, personal values and spiritual meaning, fun and play, and physical health" (Chandler et al., 2015, p. 268).

Attachment Theory. The effectiveness of this human-animal bond in promoting health and wellness has often been explored using the conceptual framework of Bowlby's theory of human attachment (Bretherton, 1992). Bowlby explained attachment as a lasting emotional bond that connects one person to another and is important for human social, emotional, and cognitive development (Bowl-



by, 1975). Attachment in the context of a parent-child relationship begins with the premise that parents responding appropriately to their children's needs allow the child to form secure attachments. He described programmed behaviors, such as crying, clinging, and search behavior, which begin to develop in the first few months of life and are designed to keep the infant and caregiver close. These behaviors often manifest themselves when pain, fatigue, or frightening experiences occur. Bowlby (1975) stated that when a child is distressed or anxious, a prolonged cuddle will often eradicate the behaviors.

Although this theory of attachment is commonly used to understand relationships with friends and families, in 2008, Beck and Madresh used attachment as a framework to explore human-animal relationships. Beck

and Madresh (2008) found evidence that attachment measures are useful in evaluating human relationships with pets, as animals are often viewed as integral members of a family. Subsequent studies focused on attachment when investigating the human-animal bond. Maharaj et al. (2016) noted that a goal of most humans is to make sense out of their everyday lives, and the significance of the human-animal bond contributes to that end. Qualitative analyses of focus groups in the study revealed three themes: 1) the human-animal bond is a sacred relationship, 2) all we have is today, and 3) the human-animal bond can help. These findings are beneficial in moving toward a deeper understanding of the reciprocal attachment bond between humans and their pets, which may contribute to fulfilling owners' psychosocial needs (Maharaj et al., 2016). A study

conducted with college students found attachment to dogs comparable to some extent to the attachment the students felt to other humans (Kurdek, 2008). Julius and colleagues discussed how social interactions among humans and pets incorporate concepts of attachment and caregiving. Such interactions trigger the release of oxytocin, a neurotransmitter that results in reduced anxiety, and have been suggested to be beneficial in a therapeutic setting (Julius, Betz, Kotrschal, & Turner, 2015).

Many studies have demonstrated evidence to support the value of the human-animal bond and its benefits in mitigating physical and psychological symptoms in clinical settings, but few studies have focused on children with cancer or other life-threatening conditions. One intervention used short-term interactions between therapy animals and maltreated youth (Terpin, 2004). While these interactions failed to improve socio-emotional functioning, they resulted in increased socialization and self-esteem in participants. Another study examined the effects of animals on stress and pain experienced by children post-surgery (Calcaterra et al., 2015). AAI resulted in more rapid recovery in activity levels and concentration following anesthesia, coupled with decreased perceptions of pain.

As we recognize the importance of play throughout childhood and its benefits when a child is hospitalized, we realize the important role children's hospital team members have as they incorporate play into a child's care. Likewise, a child's choice to participate in AAI in the hospital can increase normalization and fun, giving child life specialists a tool to add to their list of offerings designed to meet the psychosocial needs of children in the health care environment.

A Cancer Patient's Journey

Grace, a 17-year-old female, noticed a non-tender swollen mass in her left anterior neck and had few other symptoms. When the mass persisted, she and her parents decided to seek medical attention. A biopsy of the lymph node showed Hodgkin's lymphoma, and doctors shared the news the diagnosis was stage IV. Intensive chemotherapy started two days later.

A diagnosis of cancer can create feelings of tension, loss, fear, and powerlessness (Long & Marsland, 2011) and it is the role of the

health care team, including psychosocial health care staff, to assess and provide support to promote optimal growth and development, reduce stress and anxiety, and encourage resiliency (Rollins et al., 2005). Child life specialists are key team members who realize that the unfamiliarity of the hospital setting frequently reduces opportunities for developmentally appropriate play, and they provide opportunities to reduce the stress that children often experience (Burns-Nader

& Hernandez-Reif 2016).

A child life specialist met with Grace to introduce services, provide support, and assess psychological needs. As an adolescent, Grace was at risk for typical stresses that teens experience: separation from peers, feeling different, loss of privacy, dependence on caregivers, physical changes such as loss of hair, and even fear of potential death, particularly with a stage IV diagnosis (Rollins et al., 2005). Grace received a visit from a certified dog each time she came to the clinic for chemotherapy, and the family was very open to this complementary therapy. Thus, part of Grace's treatment included scheduled visits with a dog certified by a national certifying organization whose mission is to improve human health and well-being through the human-animal bond. These visits occurred at the beginning of each visit to the pediatric hematology/oncology clinic. During the animal-assisted interventions, Grace spent about 15 minutes sitting with the dog beside her, or sometimes in her lap. She seemed to relax while petting the dog and often talked to the dog. Grace's mother's shared her impressions and insight:

Grace has told me over and over that her journey was not typical. Grace is a fighter. She goes into each situation with a positive outlook and from the very beginning totally rejected any 'woe is me' feelings. She did not allow negative thoughts to find root in her heart. She carried this outlook into her fight with cancer. Hers is not a typical journey... I admit. BUT, hers is a journey worth sharing. She just wanted no part of pity.

Grace did VERY much look forward to seeing the dogs. The dog visits DID make those chemotherapy days easier. It was a tangible way that helped her to take the focus off of her immediate situation and to move her attention onto the dog. Grace very much looked forward to 'the dog visit' and so was not just focused on the treatment. The dogs' visits, in a way, encouraged each of us to look past 'just us.' The focus of the day was not JUST the treatment looming ahead. The dogs each have a heart to befriend immediately with no explanations needed. They are just there to be themselves. No expectations, just a big heart and a wagging happy tail. They encourage a forward outward focus. There is a hope and a future.

[Continued on page 24](#)

WHY A DOG? ETYMOLOGY AS EVIDENCE

Interactions with dogs are frequently very meaningful to children and their parents and reflect the Hebrew characters in the word for dog. Hebrew is an ancient Semitic language that has existed for over 3 millennia. One of the prominent features of Hebrew words is a central element called its *base* or *root* (Shimron, 2006). The significance of the bond between humans and canines involves investigating the root meaning of the word 'dog'. One such analysis can be completed through the breakdown of בלע, pronounced *Kelev*, which is the Hebrew word for "dog." Hebrew words often paint pictures, and are designed to be meaningful on the page as well as through the spoken word. Hebrew word meanings can be seen as well as heard. Reading Hebrew involves tracking from right to left. On the right side, the first half of the Hebrew word of dog, *Kel*, contains the Hebrew characters that compose the word "all." The second half of the word *lev*, contains the Hebrew characters that compose the word "heart." Thus, in considering the etymology of the Hebrew word for dog, one will notice that, since antiquity, in Hebrew the word "dog" means "all heart." Throughout this paper, this Hebrew word for dog is evident in the research on the human-canine bond and the impact the "all heart" nature of a dog is having in a variety of settings, particularly through AAI.

Shimron, J. (2006). *Reading Hebrew: The language and the psychology of reading it*. Mahway, NJ: Erlbaum.

Continued from page 23

Implications for practice

As Grace's story exemplifies, entering the hospital can be a frightening experience when new faces, uncertain plans, pain, and even life-threatening diagnoses may present themselves (Burns-Nader & Hernandez-Reif, 2016). Children are especially vulnerable to anxiety and stress caused by the hospital (Rollins et al., 2005). Grace's experiences were not typical of many children in the pediatric hematology/oncology clinic as she was an older adolescent, mature for her age, very self-confident with a positive outlook, and enjoyed tremendous family support. While all experiences are unique, Grace's mother's comments about how the dogs made chemotherapy days easier provide anecdotal support for use of AAI. Other children in the hematology/oncology clinic also commented on the benefits of AAI: A 14-year-old boy maintained that seeing a dog in the clinic made him "forget (he) was sick." Such anecdotes further assist us in our understanding of the individualized benefits of AAI.

For child life programs interested in establishing an AAI program, Table 1 provides an outline of suggestions for partnering with other organizations and strategies to ensure success in creating a program that fits within a hospital's established volunteer program. For additional comprehensive information regarding certification standards or ideas for beginning an AAI program, visit a therapy dog certification site.

Children may benefit from the introduction of AAI in hospital settings due to the resulting normalization of the hospital environment and improvement of mood, but rigorous research is needed to document potential benefits such as decreased anxiety and enhanced quality of life.

Summary

Children may benefit from the introduction of AAI in hospital settings due to the resulting normalization of the hospital environment and improvement of mood, but rigorous research is needed to document potential benefits such as decreased anxiety and enhanced quality of life. Opportunities exist for cost-effective compassionate care through AAI with families of children with cancer and

TABLE 1
Strategies for a Successful Animal-Assisted Intervention Program

| | |
|---|---|
| Establish a relationship with a local certification program (Pet Partners, Therapy Arc) | <ul style="list-style-type: none"> • Visit website • Contact representative • Set up a meeting |
| Create volunteer service description (requirement of Joint Commission) | <ul style="list-style-type: none"> • Where teams will visit • Hours of visit • Expectations of visit |
| Create an application for volunteers | <ul style="list-style-type: none"> • Experience with children • Experience in the health care field • Strengths/areas of growth to identify during interview |
| Define interview process | <ul style="list-style-type: none"> • On-site interview recommended to assess dog's behavior • Shadowing first visit to be sure owner and dog demonstrate appropriate, therapeutic behaviors |
| Educate staff | <ul style="list-style-type: none"> • Safety standards • Certification • Infection control |
| Orient pet team | <ul style="list-style-type: none"> • Certification includes: accepting friendly strangers, sitting during petting, controlling reactions to other dogs or distractions • Recommend shadowing another team if possible |

other life-threatening childhood conditions. In our example, Grace navigated the challenging journey through treatment for a stage IV cancer diagnosis. She remained strong and resolute and often expressed her appreciation for the visits from a canine. She said that while she did not look forward to coming to

beneficial. More research is needed to evaluate characteristics of children most amenable to AAI. A study currently underway at Monroe Carell Jr. Children's Hospital at Vanderbilt is examining the role of AAI in reducing anxiety and enhancing quality of life in children ages 3 to 17 years newly diagnosed with cancer, and their parents. Researchers hypothesize that children with cancer who receive AAI will experience less anxiety and stress than children who do not receive AAI.

Although existing research supports the potential healing effects of human-animal bonds in clinical settings, more rigorously designed research is required to test the limitations of these bonds and gain a better understanding of the mechanisms under which the bonds operate. Child life specialists and health care providers continue to learn strategies to address the needs of children and their families during challenging and stressful experiences in acute care settings. AAI can be another tool to add to the repertoire of child life specialists. Providing AAI is a cost-effective way to address the needs of hospitalized children by using innovative strategies to minimize detrimental effects of serious illness and its treatment to increase child well-being and enhance quality of life. 🌟

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Filling the Gaps:

Bringing Music Into Critical Care Rooms

Suzanne Lee

Each member of the health care team plays an important role in providing quality care to patients and families. Whether it be the doctor who has identified the cause of the patient's illness, the housekeeper who has cleaned the patient room, the nurse who has attended to the patient's daily needs, or the child life specialist who has provided normalization for the patient during a hospital stay, each role is vital to the delivery of high quality care. In some hospitals, the child life assistant is the person who checks in with families to fulfill patients' developmental play needs and carries out activity sessions with patients. As a child life assistant in the Pediatric Intensive Care Unit (PICU) at Dell Children's Medical Center, this role also enabled me to see opportunities for comfort to be enhanced. One such measure that I identified as a needed resource was the use of sound machines to offer timed music and white noise options to calm patients' fears, allay anxiety, or to just provide stimulation in a room where no one else was present, if appropriate. Since the rooms did not have a music or sound machine,

I carried out a quality improvement project that would provide parents with regular music or sound options.

I began by investigating what pediatric research had to say about the benefits of sound or music machines, for PICU patients in particular. According to Hugh et al. (2014) "too much noise can lead to disturbances in sleep and arousal in infants, and acoustic disturbance can have direct physiologic effects on infants that can negatively influence the quality and quantity of their sleep" (p. 2), as well as affect healthy speech intelligibility (Saint Louis, 2014). Because hearing loss has been known to be induced at high levels, conservative noise limits are advised for infants (Hugh et al., 2014). The resonance properties of the infant's smaller ear canal amplify higher-frequency sounds in the ear canal, and with continued exposure, these higher-frequency sounds can damage the developing ear canal (Hugh et al., 2014). In fact, when Hugh and colleagues tested 14 commercially available sleep machines at maximum volume and close distance, three exceeded workplace safety limit for adults, one significantly (Hugh et al., 2014).

Given the physiological and auditory effects that too much noise can have on the hospitalized infant, the study by Hugh and colleagues attempted to better understand the risks associated with infant sound machines and develop recommendations for caregivers on the maximum output levels of these machines for the ear canals of a 6-month-old infant. In acknowledging that infant sound machines can oftentimes be overused—playing continuously and at maximum sound levels, which can be dangerous to an infant's ear canal development and provide disruptions in sleep—the study concludes with the following recommendations:

1. Place the infant sound machine as far away from infants as possible (at least 200 cm away from the infant).
2. Set the volume as low as possible. Specifically, a 50-dBA equivalent noise level averaged over 1 hour is recommended as maximum safe exposure for infants in hospital nurseries and NICUs.
3. Limit the duration of use with timed shut-off.

Discussing the Hugh et al., study, Dr. Blake Papsin, chief otolaryngologist at the Hospital for Sick Children in Toronto and one of the authors, summarizes, “Farther away is less dangerous, a lower volume is better and shorter durations of time, all things that deliver less sound pressure to the baby” (Saint Louis, 2014, para 8).

With this information as guidance, a pilot test was undertaken with a single patient: a critical care, cardiac 6-month-old infant in the PICU at Dell Children’s Hospital. The Munchkin Nursery Projector and Sound System, identified as being the most economical and usable machine with the highest consumer ratings, was installed on a countertop 200 cm from the patient’s head. In addition to providing music/sounds (heartbeat, ocean, rain, lullabies, Mozart, and white noise), the machine also had the option to project images (fish in the sea, a tropical bird in the rainforest, and a sheep in the sky at night) onto the ceiling above the patient’s bed. For nine days, each assigned day shift nurse used the sound machine when they identified that the infant required calming, playing a selected choice of one of the 10 sound options for no longer than 60 minutes at one time (based on the machine’s timer). At the end of their shift the patient’s assigned nurse completed a short questionnaire that asked for feedback on the ease of use of the machine and its perceived usefulness as a sound tool. When nurses worked more than one day during the nine days, they completed a questionnaire at the end of each shift. A total of seven different nurses completed the questionnaire over the nine days. Findings from this questionnaire were:

Ease of use: 43% of the nurses found the sound machine “very easy” to use, with more than half of the nurses noting it was “easy” to use. Supporting comments included:

- “Seems like a therapeutic exercise that is easy to use and it is readily available.”
- “I like it.”

- “Soothing, helps block out the noise from the unit.”
- “Calming.”

Of the three nurses who used the projector, two thought it might not be located close enough for this patient to see it on the ceiling.

Usefulness: 6 of the 7 nurses found the different sound options to be “more useful” for this patient than a crib mobile or white noise machine. The 7th nurse found the different options to be “equally useful.” Supporting comments from these nurses included:

- “Patient seemed to calm easy and stay calm.”
- “Volume control good! More options for sounds and more variety of stimulation for long-term patients—applies to a larger age range!”
- “More options.”

All 7 nurses were unanimous in indicating that they would like this projector/sound machine in each room of the PICU. Conclusions of this pilot were provided to the child life department and formed the basis of a funding request for music/sound machines for each PICU room. These conclusions were as follows:

- The ease of use and usability of the Munchkin Nursery Projector and Sound System were found to be “easy” to “very easy” to use by nurses who used the sound machine during their day shift.
- The location of the installation of the sound machine in the room needs to take into consideration the auditory development of the infant’s ear canal and the recommendations of Hugh et al. (2014) on the use of sound machines.
- The majority of nurses found the different sound options to be “more useful” for this patient than a mobile or white noise machine.

Taking the time to learn what research says about music at bedside for infants

changed the primary way the needs of infants in the PICU are met at Dell Children’s. As a result of this pilot, the child life department purchased and installed a Munchkin Sound Machine in each room in the PICU and the child life assistant presented the pilot results and recommendations of Hugh and colleagues (2014) to all PICU nurses at a weekly meeting. The child life specialist helped ensure that any education follow-up questions by nurses during use were addressed.

Further, because so many patients move from the PICU to the intermediate care unit (IMC), the IMC nurses found that they were being asked by parents whose children had transferred from PICU rooms if they could use the music/sound machine that they had in their previous rooms. As a result, the IMC nurse manager purchased and installed the same sound machines in each IMC room according to the guidelines. Prior to the use of the sound machines, the IMC nurse manager shared findings from the PICU pilot study as well as the recommendations from Hugh et al. (2014) with IMC nurses.

Note by note, these music/sound machines are enhancing the child life care of the critical care infants at Dell Children’s Medical Center. In acting on a need that was identified during activity visits to patient rooms and play sessions with infants, music and calming sounds have been brought into a silent space with a simple quality improvement project. ✨

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The Protection Paradox:

How the Desire to Protect Influences Communication

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Communication is how we connect with others. Words, more often than not, are the tools we use to communicate, express ourselves, and make sense of ourselves and our world. Lev Vygotsky once stated that “The child begins to perceive the world not only through his [or her] eyes but also through his [or her] speech” (1978, p. 32). Speech and language allow us to perceive, understand, connect, and communicate. But what happens when we fail to communicate? What happens when we fear a certain word or phrase? What happens when we cannot bear to speak certain words? What causes these communication failures, and what do they mean for those of us working with children and families?

My curiosity surrounding these questions first emerged during my time as an undergraduate student at Wheelock College in Boston, MA. I was taking a class on helping children cope with grief and loss, and my professor shared a story about a family that chose not to tell their 10-year-old child about his cancer that would likely end his life. I will admit that when I first heard this story, I was quick to judge; I could not understand why the child’s parents chose not to share this information with their son, a 10-year-old child who would likely be able to read the hospital signage, hear what was being said around him, and in the end, understand what had never been shared. My desire to understand this family’s decision followed me for some time and eventually inspired me to conduct an independent inquiry examining communication with seriously ill children.

During the course of my inquiry, I spoke with numerous experienced child life specialists and read as much literature as I could find on the topic of communication during end of life. This research revealed that most families viewed talking about death as taboo. Caregivers did not want to speak openly with their children about death and dying, and children did not want to speak openly with their caregivers about these subjects. Once again, I asked “why?” Why did children and families choose not to communicate honestly with each other during such sensitive and emotional times? As I explored this question further, a theme emerged: Children and families seemed to avoid open conversations about death and dying to protect one another. Judd (1995) explains this “mutually protective falsehood” (p. 37) and references a study conducted by Bluebond-Lagner (1978) that found that children with leukemia at end-of-life often neglected to communicate openly with their caregivers about their anxieties in an attempt to protect their caregivers. Spinetta, Rigler, & Karon (1974) also explored patterns of communication between children with cancer and their families by asking children at end of life and chronically ill children to place four dolls (nurse, doctor, father, and mother) somewhere within a replica of a hospital. They found that children at end of life repeatedly placed the four figures at significantly greater distances from each other than the chronically ill children did. These researchers concluded that the tendency of the children at end of life to separate the figures with such large distances reflected the children’s growing sense of psychological separation and isolation from their caregivers.

Judd (1995) further emphasizes: “children sense that their illness is serious, even if they are not told explicitly. . . children need to be given the opportunity to speak ‘about their concerns so that they can receive support in their struggles’” (Spinetta, 1982 as cited in Judd, 1995, p. 37).

It appears that this lack of communication related to protection leads to increased feelings of isolation, anxiety, and fear among children and families, and studies suggest that children and families who engage in open communication surrounding illness and prognosis experience a greater degree of closeness compared to those who do not engage in open communication (Beale, Baile, & Aaron, 2005; Lansdown 1988; Spinetta, Rigler, & Karon, 1974). This discovery led me to coin the term the “protection paradox,” and I soon realized this phenomenon occurs not only during end-of-life communication, but also in situations where communicating sensitive information could be life changing.

The protection paradox is notable in a variety of encounters with children and families, including our own daily interpersonal interactions. It exists in our decisions not to communicate openly about a new diagnosis, an overheard conversation, politics, and “bad things” seen on television. We find ourselves in the protection paradox because talking about them makes difficult topics real. The belief that voicing an idea makes it a reality exists in many cultures, and although Western cultures tend to value veracity and sharing age-appropriate information with children, Western families still fall into the protection paradox, especially during traumatic or life-changing events



sion screen with their child, they must address the reality of the causes and impacts of that violence. When we say we are scared—when we admit to our deepest fears, insecurities, and anxieties—we must face the circumstances surrounding our emotions and vulnerabilities, and this confrontation can be overwhelming, tempting us to avoid speaking about the uncomfortable things, the sad things, the painful things.

We keep the weight of our emotions to ourselves, guided by a belief that doing so will protect our loved ones and ourselves, but failing to speak openly about the realities we face will only burden us more in the long run. Like most hard things, communicating openly is easier said than done, but we cannot avoid things because they are difficult. Difficulties strengthen us in ways we never imagined. Words are constructs drenched with the meanings of past experiences, knowledge, definitions, expectations, and emotions, which is why we often struggle to find the right words, to say these words out loud, and to accept the reality that these words reveal. However, we owe it to ourselves, our loved ones, and the children and families we care for in our professional lives to remain aware of the motives behind our communication and recognize the value of open communication. Communication is the basis of human connection, and speaking honestly with each other about all subjects, no matter how traumatic, forges the connections that keep us going. ✨

(Wiener, McConnell, Latella, & Ludi, 2013).

The protection paradox illuminates the power of our words. When we say something out loud, we can no longer deny its existence. When we speak about the things we fear, they

become real in a way that they were not before. When a caregiver has the courage to use the word “cancer” and tell their child of their diagnosis, they confront the realities of that diagnosis. When a parent discusses the violence being shown on a loop on the televi-

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PATHWAYS TO EBP

EBP, One Step at a Time

STEP 3: Search for Evidence

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After developing the clinical question, the next step in evidence-based practice is to search for evidence that informs or answers the clinical question. This is done by conducting a literature search, which includes four general steps: (1) identify the search terms from your clinical question, (2) perform electronic literature searches using relevant databases, (3) review the titles and abstracts of the search results to determine which articles to eliminate and include, and (4) review the remaining full text articles to determine if they answer the clinical question (Cincinnati Children's Hospital Medical Center Evidence Collaboration [CCHMCEC], 2015). Each of these steps is described in detail below.

The first step is to **identify the search terms** that will be used when conducting the electronic literature search. These search terms are typically keywords from the clinical (or PICO) question (CCHMCEC, 2015). Be sure to consider synonyms, related terms, variant spellings, and truncating the search terms to maximize the search results (Child Life Council

Evidence-Based Practice Committee [CLC EBP Committee], 2012). In addition, identify the limits, filters, and search date parameters that may help to appropriately narrow or broaden the search results.

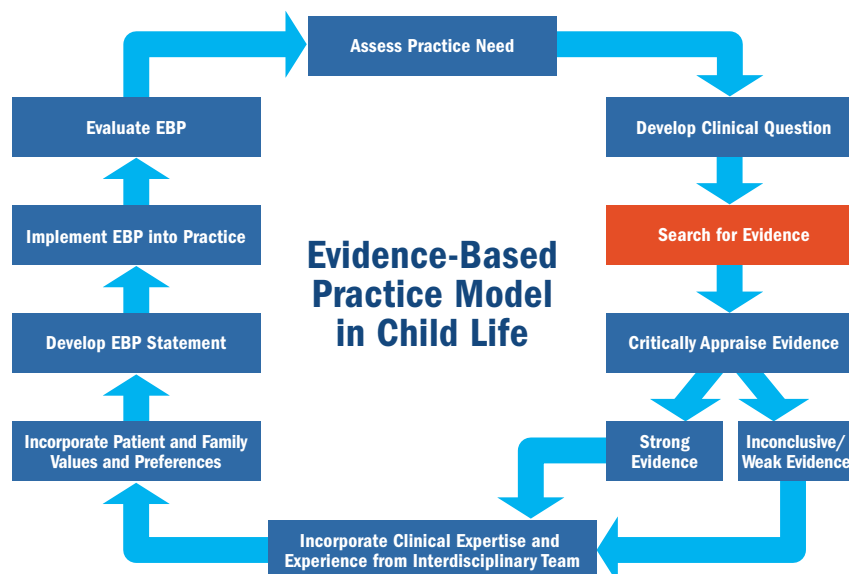
The second step is to **perform electronic literature searches** using relevant databases. This step will

include three topics: (a) a description of the relevant databases used to perform electronic literature searches, (b) how to conduct electronic literature searches, and (c) the types of article references retrieved from literature searches.

There are several relevant databases for child life professionals to use when conducting electronic literature searches.

- The Cumulative Index to Nursing and Allied Health Literature (CINAHL) database includes nursing journals from the National League for Nursing, American Nurses Association, and 17 allied health disciplines (EBSCO Health, 2017). *A subscription is required to access the CINAHL database.*

- The Cochrane Database of Systematic Reviews (CDSR) is considered the leading resource for systematic reviews in health care because of the structure in which reviews are consistently updated with emerging evidence (Cochrane, 2017). *Cochrane is a free database.*



- The PsycINFO database, housed by the American Psychological Association, is an interdisciplinary database that includes references and abstracts for the behavioral and social sciences (American Psychological Association, 2016). *A subscription is required to access the PsycINFO database.*
- The PubMed database includes the MEDLINE and PubMed Central databases, as well as additional citations from the National Center for Biotechnology Information (NCBI) Bookshelf (National Institutes of Health [NIH], 2016). The PubMed database provides access to references and abstracts in the field of medicine, nursing, dentistry, health care systems, and life sciences (NIH, 2016). *PubMed is a free database.*

In addition to the databases, clinical practice guidelines can be searched through the National Guideline Clearinghouse (for free) and relevant professional associations (professional associations may require membership to access documents; CCHMCEC, 2015). For example, clinical practice guidelines for child life specialists can be found within the Association of Child Life Professionals' (ACLP) Evidence-Based Practice Statements.

To complete an electronic literature search, access the database webpage and enter the search terms previously selected. Typically, there is an "Advanced Search" link that can be clicked to include limits and filters for the search (e.g., articles written in English only) and the search date parameters (e.g., articles published within the last 10 years). This is especially helpful if initial searches return a large number of results. Now, it's time to generate results for the literature search! Results will consist of article titles and abstracts—depending

TABLE 1
Example of Spreadsheet of Electronic Literature Searches

| | SEARCH TERMS | LIMITS, FILTERS | DATE OF SEARCH |
|--------|--|--|----------------|
| PubMed | <ul style="list-style-type: none"> • pediatric • tablet-based interactive distraction • standard of care • coping during PIV placement | <ul style="list-style-type: none"> • English only • articles published from 2007 to 2017 | 1/1/2017 |

on the database subscription. Literature searches are typically conducted on each of the previously mentioned databases to assure all evidence on the clinical question is found.

To keep the electronic literature searches organized and efficient, be sure to document the search strategy used with a spreadsheet (See Table 1). Important information to include in the spreadsheet are the databases searched, each search term used, and the limits, filters and search data parameters that were applied to each search (CCHMCEC, 2015). Also, include the date of the most recent search for each database.

When electronic literature searches are performed, several types of articles may appear in the search results (Galvan, 2014). One type of article is an *empirical article* (also termed "original research" or "research article"). Empirical articles are original research investigations conducted to advance the understanding of a topic or problem. Another type of article is a review article, which includes both systematic and meta-analytic reviews. Both types of reviews include empirical articles published on a specified topic within a certain time frame. A *systematic review* synthesizes the findings from the empirical articles to answer a clinical question (Higgins & Green, 2011; Haidich, 2010). A *meta-analytic review* is a type of systematic review

that combines and analyzes the data (using a common measure) from the empirical articles to answer a clinical question (Haidich, 2010). If either of these reviews are retrieved during your literature search and are relevant to your clinical question, it will save a lot of time when searching for evidence! Additional types of articles include theoretical articles, anecdotal reports, and reports on professional practices and standards (Galvan, 2014); however, medical professionals typically focus on empirical and review articles, as well as reports on professional practices and standards (e.g., ACLP's Evidence-Based Practice Statements) when searching for evidence to answer a clinical question.

One inevitable question that occurs when conducting a literature search is how child life specialists gain access to these databases, especially when the full text articles are needed. One place to access these databases is through your hospital institution's online medical library (CLC EBP Committee, 2012). If a medical librarian is on staff at your institution, they will be able to assist in accessing the databases and full text articles. Another place for free access to the databases is through a public library, where a research librarian may be able to help navigate database searches (CLC EBP Committee, 2012). In addition,

Continued on page 33



BITS AND BYTES

System Updates from the Technology Integration Committee

The Quest: Uncovering Educational Technology tools for Child Life Specialists

Kristen Beckler, CCLS, CTRS

STANFORD CHILDREN'S HOSPITAL, PALO ALTO, CA

The Technology Integration Committee is on a quest: a quest to find and utilize the most innovative technology to benefit pediatric patients and their families. Our mission is to evaluate the integration of technology in clinical practice, develop original technology solutions, and support child life professionals' knowledge of technology-based applications. As part of this quest, the Technology Integration Committee has evaluated how existing educational technology programs and resources, designed for teachers and schools, can be adapted to support child life practice.

Virtual Field Trips

There are virtual field trip tools available that allow pediatric patients to have innovative and positive experiences with family or friends in the comfort of their own room. These tools can be used to provide opportunities for engagement for patients in isolation, offer alternative focus as non-pharmacological pain control for invasive procedures and tests, or provide educational opportunities to help patients learn about their bodies or complete school assignments. Two popular tools that allow you to use a tablet to lead patients on a 1:1 adventure anywhere in the world are

Google Expeditions and Discovery Education Virtual Field Trips. Neither app requires virtual reality, but the experience is enhanced if that option is available to you.

Legacy Building with Digital Media

Using technology, you can teach patients to edit their own photography, make their own family crest digitally, or create a video or sound bites for family and friends. If you are thinking, "I have no idea how to do that," there are easy, free programs to teach you. KQED Teach is a free online learning platform that supports educators' growing media literacy needs by helping them develop the media skills necessary to bring media production to their learning environments. They offer courses on photography, digital storytelling, podcasting, and digital media basics that enable teachers to use these tools in their classrooms. Adobe Education Exchange offers a variety of free professional development opportunities, including self-paced workshops, as well as live events and webinars, which are all free to educators. The programs for Adobe can be expensive, but child life specialists can request a non-profit or educators price (between \$19.99 and \$34.99 per month) by calling Adobe customer service.

Learn a Universal Language

Learning to code can help children communicate across the world, be creative, and solve problems. Coding is what makes it possible to create computer software, games, apps, and websites. Coding can empower children, provide opportunities for life skills while in the hospital, and be something to share with friends (either in conversation or to teach them). Coding games can be fun and can spark an interest in a new hobby or help pass the time. Child life specialists can provide an in-hospital Hour of Code, a one-hour introduction to computer science using games, which takes place each year during National Computer Science Week in December. Patients can also learn how to code through the free program at Code Academy, which offers a web-based program that teaches programming in an interactive and fun online environment while the participant earns points and badges along the way.

Online Writing

There are so many benefits to vlogging (video logs, i.e. YouTube channels), blogging, and journaling. First and foremost, these practices connect patients to the outside world. Furthermore, writing stories can provide reflection for patients. What did they do each day? What were their successes

and what was challenging? Online writing can provide a space to share ideas and experiences, and to empower the next patient with the tools they need to do well in the hospital environment. It can generate dialogue and help children find the words to have difficult conversations with their care team. There are several sites for blogging. Most students use Google programs in school and may be familiar with Google Sites, while others may need more structure and can use sites like Edublog or Weebly Education, which provide students with administrative support.

Online Tools to Connect with Friends and Family

Being away from home, school, friends, and family can be difficult. To support

coping during separation from home and community, child life specialists can encourage schools to include a hospitalized student in events and activities. Google Hangouts, FaceTime, and Skype are all programs that allow children to be in their classroom via video. Patients can watch class performances, plays, and art activities while in the hospital. Patients can read stories with friends and family from afar using Readeo, a Skype-type program that allows children to “book chat” and stay connected. Programs like Monkey in my Chair for oncology patients are fun tools that inspire an ongoing classroom connection with the absent child, giving the patient access to an online program that allows pictures and documents to be shared between the patient and the classroom.

There is a plethora of educational tools for teachers. The Technology Integration Committee has just started to tap into what is available for child life practice. We look forward to sharing helpful tools we uncover in several ways: in research/evidence-based literature we review in *ACLP Monthly* emails, in our blog, and in this new regular feature in *ACLP Bulletin*. Keep a lookout for noteworthy information from the members of the Technology Integration Committee as we continue on the quest to find the most innovative and creative programs for children in the hospital. ✨

Continued from page 31

EBP: Search for Evidence

many universities provide access to the databases and full text articles for students, as well as members of their alumni associations. Some professional associations also provide free access to databases, so it is best to explore the resources that may be available.

The third step in the search for evidence is to **review the titles and abstracts** that were retrieved during the electronic literature searches to determine which articles need to be eliminated and included (CCHMCEC, 2015). Eliminate any duplicate articles and articles

irrelevant to the clinical question, and include articles relevant to the clinical question. It is easy to get caught up reviewing new and interesting literature, so make sure to only include studies that specifically answer the clinical question.

After the titles and abstracts are reviewed, the final step in the search for evidence is to retrieve and **review the full text articles** (CCHMCEC, 2015). Like the previous step, eliminate the articles that do not answer the specific clinical question and include the articles that answer the specific clinical

question. Then, on the spreadsheet used for documenting the literature search strategy, include the entire APA article citation. (A great resource on APA, MLA, or AMA styles is the Owl Purdue Online Writing Lab). Now, you are ready to move into step 4—critically appraise evidence. Our next *ACLP Bulletin* article will explore this step.

Continue to follow this series as we dig deeper into each step of the EBP process! Past articles are available on the [ACLP Website](#). ✨

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BOOK REVIEW

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The Healing Power of the Breath

By Richard Brown, MD and Patricia Gerbarg, MD

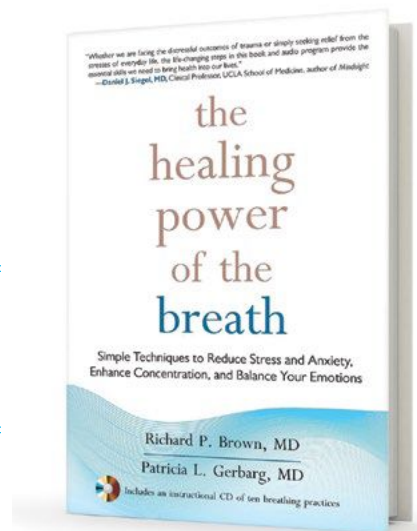
A recent survey by the National Institutes of Health revealed a clear rise in children's use of complementary health practices, such as yoga, in the treatment of anxiety and chronic pain (Black, Clarke, Barnes, Stussman, and Nahin, 2015). Yoga, which incorporates both meditation and deep breathing, is low cost and can be incorporated into a child's routine at a time that is flexible and convenient. Data also supports the use of purposeful, mindful breathing as a complementary health practice, as evidenced by children's self-reports that consistent breathing exercises led to decreased anxiety and increased physiological wellness (Chiang, Ma, Huang, Tseng, & Hsueh 2009; Black et al., 2015). In their book and accompanying CD, *The Healing Power of the Breath*, Richard Brown, MD, and Patricia Gerbarg, MD, introduce readers to breathing exercises in simple, concrete language that can easily be integrated into daily life. Child life specialists can incorporate the exercises and resources presented in this book in both clinical work and self-care routines.

Dr. Brown is an Associate Clinical Professor of Psychiatry at Columbia University and leads Breath-Body-Mind workshops that focus on using integrative treatments to address mental health conditions. Dr. Gerbarg is an Assistant Clinical Professor in Psychiatry at New York Medical College, maintains a private practice, and facilitates research on mind-body

treatments for stress-related medical conditions. Both authors have experience working with individuals dealing with common mental health conditions, including anxiety, ADHD, PTSD, and depression; as well as with survivors of stressful situations, including victims of mass disasters, war and genocide, and sexual assault survivors.

Brown and Gerbarg divide the book into two sections, first providing readers with steps to learning some basic breathing techniques: coherent breathing, resistance breathing, body scan and breath moving. Coherent breathing, as defined by the authors, sets the pace and rhythm for the exercises to five or six breaths per minute and readers are instructed to breathe in and out through the nose while comfortably seated and with eyes closed. Tracks on the CD assist with pacing by sounding chimes that prompt readers to breathe. Resistance breathing is used to augment coherent breathing and is accomplished by breathing in through the nose and out through pursed lips making an "ocean" sound, to induce relaxation. Body scan and breath moving use the imagination to move the breath and bring awareness to individual parts of the body, beginning at the toes and moving up to the crown of the head, to improve circulation. In combination, these breathing techniques flow together as a total breathing circuit.

The second section focuses on how and when to apply these exercises and shares additional breathing exercises for specific use, such as healing trauma, building relationships, and dealing with



insomnia. There is little pressure put on the reader to perfect these breathing techniques and adaptations are suggested for readers who struggle with pacing breaths or mastering the exercises. On several occasions, the authors stress the potential benefits of only partially incorporating breathing practices based on physical limitations or time permitting in one's daily routine. While there is a connection made to origins of these breathing techniques in Eastern medicine, it is presented in a way that is not cumbersome or unrelatable to the reader. There was certainly a potential for this work to be heavy or overly academic; however, Brown and Gerbarg were able to use anecdotal evidence and concrete examples to make *The Healing Power of the Breath* an easy read.

The "train the trainer" style writing employed in this book allows readers to apply individual basic breathing techniques or the total breathing circuit throughout their clinical work. Applications indicated by the authors aimed at decreasing anxiety clearly fit within the scope of child life practice. Brown and Gerbarg claim that their coherent and resistance breathing strategies trigger a parasympathetic nervous system (PSNS) response, leading to emotional regulation. The PSNS response, sometimes referred to as a "rest and digest" response, helps the body achieve a state of equilibrium or calm. The authors explain that the "worry centers" of the brain are turned off by deep breathing, promoting a calming response, thereby

reducing negative thoughts. The book seeks to support these theories with the inclusion of the authors' research using psychological assessment scales, as well as anecdotal evidence from patients to whom they have taught this practice. An example of the effectiveness of these techniques is shared by Gerbarg herself, who utilized her own breathing methods to overcome anxiety surrounding public speaking.

Every method discussed in this book may not be completely available for implementation within the scope of child life practice. Two practical applications for child life specialists do present themselves, however: integration of deep breathing to enhance patient coping and child life specialists' own self-care needs. The authors' deep breathing tips and coaching via their CD can easily be relayed to the anxious child or patient dealing with pain. Coherent breathing appears to be as easy to teach as it is for the practitioner to master, allowing child life specialists to implement these exercises at the bedside to help children breathe away their worries and pain. Breathing interventions could be especially useful for child life specialists working in chronic care, as they may be able to achieve greater benefit by building on these breathing routines over the long term. Additionally, the body scan technique is a tool that would fit nicely into child life practice as a guided imagery journey for patients dealing with pain control issues, during invasive procedures, or undergoing conscious sedation.

Another relevant use of the breathing practices presented in this book is for child life specialists' own well-being. There is much importance given to the idea of self-care in the health care field and the impact of compassion fatigue on clinicians across disciplines. As child life specialists, we strive to balance our personal lives with the

emotionally taxing work of building therapeutic relationships with patients and families and our often demanding professional work, including a push to involve ourselves in research and other academic pursuits. For this reason, readers of *The Healing Power of the Breath* may find themselves breathing along with the tutorials and may quickly realize benefits in stress reduction through deep breathing.

Overall, I would recommend *The Healing Power of the Breath* to readers looking to enhance their knowledge of deep breathing practices and to learn practical breathing exercises to enhance one's clinical practice or self-care needs. *The Healing Power of the Breath* is an easy read and the basic deep breathing techniques could integrate into and enhance child life specialists' practice. ★

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BEYOND THE CLASSROOM

Views of Emerging Professionals

Advocacy: What I Learned in My Internship

Alexandria Friesen, CCLS

Like any other aspiring child life specialist, obtaining the coveted Certified Child Life Specialist (CCLS) designation was not just any goal, but possibly the most important goal I had set out for myself. I knew the basics, understood the environment, was confident in the skill set I had, and was excited to build upon it. The majority of my clinical internship took place in a community-based child life private practice and it has been through this experience that I learned the value and sheer importance of advocacy in the role of a child life specialist.

As child life specialists, we know and understand the importance of advocating for ourselves, our patients and their families, and for our role as health care professionals in general. Advocacy is crucial to our work, and I observed this every day working in the community. Child life specialists are taught the importance of listening to patients and their families, making their voices heard, and making change happen where possible. All of these things are action-oriented—we work with a purpose. An advocate is more than just a team member; an advocate is also a confidante, an ally, and a person who provides guidance during and after a medical journey.

Similar to the way child life specialists in hospitals need to advocate for their presence, child life specialists in the community need to do the same. I learned that this is done not only through education on what child life is, but through specific explanation on how our presence provides direct support and enhances coping, whatever the patient's situation may be. I have

been interested in a career in child life since I was a child myself, so I am no stranger to explaining what child life specialists are. So while this form of advocacy was not necessarily something I was unfamiliar with, it was a new experience explaining it from the perspective of the working child life specialist—it made me feel like a professional, not just a student.

Much of the work I experienced during my internship required me to provide patient and family support once active medical treatment had been completed. In many instances, my supervisor and I conducted home visits for children and teens who had been in motor vehicle accidents and had suffered a brain injury as a result. Due to the nature of the injury, families were often in the midst of a lengthy legal battle that caused immense stress and strain on family members and their relationships with one another. I learned from these situations how to advocate on behalf of the patient to the legal team when the patient and family had questions, concerns, or wanted things done differently. I truly saw the versatility of child life and the complexities associated with an injury that had often taken place many years prior. While remaining within the child life scope of practice, advocacy ensures patient and family understanding while helping restore a sense of normalcy during such a trying time. The therapeutic relationship formed between child life specialist and patient provides an inside look at the way life events affect the patient and family, allowing us to provide support in legal situations, ensuring their needs are being met in the appropriate way.

I also advocated for self care and family relationship building. There were many families in which a parental illness was the reason for our visit, and we provided these families opportunities to go on community outings to take a “break” from their illness and treatment and to take advantage of chances for quality family time. These families typically had children or spouses acting as caregivers, and it was through our support of these outings in which we advocated for those caregivers who needed a break but were either unsure of how to ask for one, or didn't know if asking for one was appropriate. We also advocated for the ill parent by ensuring that the outing was an activity that was enjoyable, and not something that would cause further undue stress. Providing a positive and fun experience on community outings is crucial and to do this we took a leadership role in making sure families received the best care possible, wherever we went.

Throughout the course of my internship, I witnessed advocacy in a variety of ways. It was through hearing my supervisor describe our work as child life specialists to others, standing up for patient rights, and making certain that families were well cared for that I began to see how versatile child life is and how critical our role as advocates really can be. I learned that advocacy means listening and understanding, but most importantly, I learned that it also means taking thoughtful and purposeful action. ✨



Supporting Well Children in a Critically Ill Adult's World

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BAYLOR SCOTT & WHITE HEALTH-NORTH TEXAS,
DALLAS-FORT WORTH, TX

Supportive and palliative care is a growing specialty within the field of adult medicine. While these services typically focus on supporting the needs of patients with a serious, life-limiting condition and their families, it is not uncommon for the youngest family members to go unacknowledged in adult hospital settings (Sutter and Reid, 2012). Whether it is for the patient's child, grandchild, niece, nephew, or even a sibling, access to professionals offering developmentally appropriate psychosocial support for children is crucial for families coping with a serious illness (Christ and Christ, 2006; Rollins, Bolig, & Mahan, 2005; Sutter and Reid, 2012; Thompson, 1981; Thompson, 2009).

As the field of child life continues to grow, the need for child life specialists in adult medicine has become increasingly evi-

dent. Adult supportive and palliative care teams are evolving as they've recognized that the children of their patients have unique needs that should be addressed. As a result, many are expanding their programs to include child life services. The supportive and palliative care teams of Baylor Scott & White Health are helping to lead the way and are fighting to shine a light on the diverse needs of children loved by adult patients with any serious medical condition, including organ transplants, traumatic brain injuries, gunshot wounds, autoimmune diseases, and more. The child life specialists working with the supportive and palliative care service line have become core team members who provide psychosocial support *exclusively* to well children of adult patients facing a serious illness or traumatic injury. Child life services are available during inpatient admission, outpatient treatment, and even after the patient's death. People are often surprised to learn that about 50% of the child life visits are actually *only* with the adults involved in the child's life, educating and equipping them with the appropriate language and techniques to support the children they love through these difficult situations. Though the child life team is equipped

[*Continued on page 38*](#)

Supporting Well Children in a Critically Ill Adult's World



with a traditional skillset, their role encompasses a different approach than that of child life specialists in pediatric settings.

While utilizing the traditional mantra of reducing stress and anxiety and promoting normal growth and development, child life specialists in this role also make sure to discuss the three most common concerns children may have when they have a loved one with a serious illness. Those common concerns are: (1) can I catch it? (2) did I cause it? and (3) who is going to do the 'daddy things'? (McCue, 2011). It is important to address the unique stressors that children face when they have a loved one with a serious illness. Those stressors can include misconceptions about a loved one's illness and/or hospitalization, breakdown in communication between the children and adult(s), behavioral, emotional, or physical changes, and the loved one's death (Barnes, Kroll, Burke, Lee, Jones, & Stein, 2000; Winch, 2001; Sutter & Reid, 2012; McCue, 2011). Below are five vignettes that illustrate some of the ways this program supports the unique needs of well children of seriously ill adults.

Adult Education

Barnes et al. (2000) found that mothers with breast cancer benefitted from having a health care professional provide support and guidance on

ways to inform their children of their diagnosis. As child life specialists, we often support children we haven't yet met by providing information to their caregivers and advocating for what the children may need.

Suzanne was a 49-year-old woman who had acute, end-stage renal failure. Her sister, Nicole, expressed concern for Suzanne's daughters, ages 13 and 16, when she visited with the child life specialist. As Suzanne's condition rapidly declined, Nicole encouraged Suzanne's ex-husband, the girls' father, to be open and honest about the situation with their daughters. Up to that point, he had not allowed them to visit and had only told them that their mom's kidneys were sick. Nicole felt strongly that they should be told that their mom would likely die soon, but their father disagreed. As the situation grew dire, the child life specialist explained how adolescents typically understand and react to a parent's life-threatening illness, and stressed the importance of being truthful with the girls about their mom's imminent death so they would have the opportunity to say goodbye. Nicole took notes during their conversation and shared the information with Suzanne's ex-husband. They were able to come together to establish a plan for a bedside visit after telling the girls about Suzanne's poor prognosis. Ultimately, the girls were able to say goodbye to their mom shortly before support was withdrawn. Empowered with information from the child life specialist, Nicole was able to work with the girls' father to provide the love and support the children needed as they were not only grieving the loss of their mother, but navigating their new normal.

Addressing Misconceptions

As child life specialists, we know there are benefits to open, honest, developmentally-appropriate explanations when a child or loved one is facing a serious illness (Barnes et al., 2000; McCue, 2011). When children remain uninformed, it is not uncommon for us to see their imaginations take over and create misconceptions about what is really going on, and sometimes these misconceptions can be worse than reality (McCue, 2011).

Brock was Diane's 5-year-old grandson and, more

than anything, he loved playing pretend with “Meme” every afternoon. Diane and her husband Jack had assumed full custody of Brock when he was 18 months old. Diane, age 55, was sedated and on a ventilator when Jack asked the child life specialist about bringing Brock to visit. Brock had only been told that Meme was in the hospital. Although the child life specialist discussed the importance of talking with Brock about Meme’s condition, Jack continued to want to protect Brock by only giving him minimal information. When Diane was weaned from the ventilator and found out Brock was not informed about her situation, they both understood that Brock needed to know the truth and asked the child life specialist to meet with him. After a visit with Diane, Brock met with the child life specialist. When asked what he knew about Meme being in the hospital, he quickly blurted out, “Meme died!” Jack was in disbelief upon hearing Brock’s statement. The child life specialist reminded Brock they had just seen Meme and she was breathing, talking, and eating, thereby clarifying his misconception. She said people can’t do these things when they’re dead, and that Meme is alive. She explained that Meme has a “big sick” and it’s different from the “little sick” he gets, like a tummy ache. The child life specialist and Jack reassured Brock that he didn’t do anything to cause Meme’s “big sick” and that he couldn’t catch it like a cold. Following the child life specialist’s cue, Jack told Brock that he would do his best to handle all the ‘Meme things’ while she’s in the hospital. In the days following this visit, Jack reported continuing to be open and honest with Brock to avoid any additional misconceptions he could have developed otherwise.

Bridging Communication

Children want to protect their parents, just as much as parents want to protect their children. When children are grieving the loss of a parent, it is not uncommon for emotions and fears to be internalized as a way to protect the remaining parent (Dyregrov, 2008). As child life specialists, we strive to help children and parents become more open with one another, empowering them to appropriately support each other during life’s most challenging events.

Reading the story aloud helped Caitlin openly express her thoughts about her new life without her dad, and open up to her mom about her biggest fear—that her mom could die, too.

Caitlin was the 10-year-old daughter of 40-year-old Sam, who died following a motorcycle collision. During a meeting with the child life specialist after Sam had died, Caitlin’s mom, Danielle, expressed worry that Caitlin wasn’t coping well. Danielle explained that Caitlin had been very “matter-of-fact” shortly after the accident, walking up to others and telling them, “My dad is 40 years old and he died.” The child life specialist discussed the importance of Caitlin wanting to share her story and needing validation and someone to empathize with her situation. Danielle had difficulty talking to Caitlin about what had happened with Sam because her own life role had changed; she was learning to be a single mom while also filling her husband’s role as dad. This change made it difficult for Caitlin to talk with Danielle about Sam and thus, Caitlin often avoided talking about her dad and kept worries to herself. The child life specialist encouraged Caitlin to write her story and to share it with Danielle once it was completed. Caitlin had expressed worry that her mom might cry when she heard her story, and thought she might always be too sad to talk about dad. The goal of writing and sharing her story was offering Caitlin an opportunity to acknowledge what happened to her dad on the day he died, while validating a concern she was worried about: “Who will take care of me now that Daddy is gone?” Reading the story aloud helped Caitlin openly express her thoughts about her new life without her dad, and open up to her mom about her biggest fear—that her mom could die, too. Caitlin expressed her deep-seated concern about injuries, or even deaths, that might happen when people don’t wear helmets on bikes or motorcycles, and Danielle addressed this by emphasizing that she and Caitlin would always wear their helmets. Although Danielle couldn’t

[Continued on page 40](#)

Supporting Well Children in a Critically Ill Adult's World

extinguish Caitlin's fear that Danielle might die, she did reassure Caitlin that even if that were to happen, there would always be someone there to love and care for her. By providing a voice for Caitlin to share with her mom, the child life specialist allowed Caitlin to gain some control over the situation and empowered her to share her feelings honestly, mastering a novel situation.

Coping Responses to a Loved One's Serious Illness

As many child life specialists know, it is not uncommon for a teen to exhibit a variety of responses to illness, including internalizing feelings, seeking out support from peers, and wanting to maintain their routine away from the family (McCue, 2011).

During a bedside visit, Matthew talked with the child life specialist about feeling "pitied" by his peers and how he did not like the sympathy.

Fourteen-year-old Matthew was no different. His dad, 47-year-old Patrick, had metastatic bladder cancer, and had recently experienced several multifocal strokes. The strokes resulted in some loss of function in his extremities, and it had become clear to him and his family that he likely had only weeks to live. His wife, Karen, was interested in learning more about child life services for their four children, but was most concerned about Matthew. Karen expressed concern that Matthew was "withdrawn and didn't seem to care about his dad." She explained that he didn't want to spend time at the hospital and refused to stay overnight at Patrick's bedside. Karen said he just wanted to hang out with friends and constantly used music to "tune everything out." She pressured Matthew to visit his dad and admitted that she tried to make him feel guilty by telling him how much "his dad needed him to be there." The child life specialist strongly encouraged Karen to keep Matthew informed, but to also allow him a choice of when he wanted to visit. She explained that Matthew was exhibiting common coping responses seen in teenagers, as they often turn to their peers

for support, and he was possibly hurting so much that it was hard for him to be around his dad (Rollins, Bolig, & Mahan, 2005), and that by allowing Matthew to choose when he wanted to be with his dad, he could gain a sense of control in an out-of-control situation. Karen was very appreciative of the information. In rounds the following week, medical staff commented on how Karen was honoring Matthew's choices, allowing him to visit when he wanted and for as long as he wanted. During a bedside visit, Matthew talked with the child life specialist about feeling "pitied" by his peers and how he did not like the sympathy. They discussed ways of politely expressing this feeling and responding to friends who were reaching out to support him, while still maintaining his privacy. Matthew also opened up to the child life specialist about having a vision where he saw his healthy dad standing with his deceased grandparents, and expressed that this brought him peace because he knew his dad "would be going to heaven." The child life specialist continued to support Karen, validating that the adaptations she made had appeared to be helpful for Matthew as Patrick neared death. Karen told her that Matthew had "said his goodbyes" and didn't plan to return to the hospital, and reported that she believed that she and Matthew had "really turned a corner" and their relationship felt much stronger than it ever had before.

End-of-Life Support

Death is often an unexplored experience for children, which frequently leads to a child life specialist providing psychosocial support for both the children and their parents in these critical moments (Parvin & Dickinson, 2010). Christ and Christ (2006) note the importance of adequate support for children and teens facing a parental loss, as these children are at an increased risk for negative psychosocial outcomes.

Mitch was a 38-year-old man with end-stage cystic fibrosis. After a lifetime of treatment, he had exhausted all curative options. The child life specialist met with Mitch and his wife, Jan, and helped them identify their most pressing concerns for their children, ages 7, 10, and 16. The child life specialist offered options for language to explain

Mitch's imminent death, and shared information about common physical, behavioral, and emotional responses that children may exhibit when a parent is at end of life, including "red flag" behaviors they may observe. The child life specialist also discussed the unique aspects of childhood grief, and provided family with handouts on children's grief and bereavement for future reference. During child life visits, the children verbalized how they felt mad because their dad kept saying "everything will be the same" after he was gone. The 10-year-old even said he wished his dad would die quicker so he wouldn't have to feel so sad. The child life specialist validated these feelings to normalize their emotions. The children asked, "Why are people sad when they talk about how great it will be in heaven?" This sparked discussion about anticipatory grief and their beliefs about afterlife. Following Mitch's death, the child life specialist met with the children three more times for bereavement support. These visits included helping the children process each of their own unique grief responses. While the 7-year-old was struggling with cognitively understanding her dad's death, she also expressed fear of dad's upcoming funeral. The child life specialist helped prepare her for the funeral by addressing the 'who, what, when, where, why, and how' of the funeral, and utilized play to help her understand what she would see. The 10-year-old discussed his difficulty with feeling "weighted" by his sadness and grief. He informed the child life specialist of his frustration when his teacher said she understood his feelings

because her dad had also died (at age 80). His response to her was, "That's not fair, my dad was only 38!" They discussed others' well-intentioned statements, but validated how they can be hurtful and explored ways to respond in challenging situations. After their last visit, Jan graciously thanked the child life specialist for helping make what could have been a traumatizing experience a beautiful one. She revealed that the family was utilizing the movie *Inside Out* to continue addressing and processing their emotions, and stated "You can't always be happy. There are times were you have to let sadness in and you can blend those together."

These vignettes demonstrate what child life specialists have long proclaimed, that child life services can be of great benefit for well children of adult patients facing a serious, life-limiting illness or injury. Because of their ability to provide support to adults and children alike, child life specialists are a valued member of this interdisciplinary team. Child life specialists bring benefit in being able to utilize the child life model: increasing understanding and assisting in immediate coping skills in the medical setting (Rollins, Bolig, & Mahan, 2005; Sutter & Reid, 2012; Thompson, 1981; Thompson, 2009). In being able to assess needs and provide appropriate interventions to these children and families, child life specialists are able to enrich understanding, promote coping, and reduce stress (Leeuwenburgh & Sanzari, 2007; Rollins, Bolig, & Mahan, 2005; Thompson, 1981; Thompson, 2009). ✨

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ACLP Calendar

MAY

25-28 [35th Annual Conference](#) in Las Vegas, NV

JUNE

16 – Abstract submission for 2018 36th Annual
JULY 24 Conference in Washington, D.C. Metro area

JULY

- 1** Submission deadline for [ACLP Bulletin and Focus articles](#) for consideration for the Fall 2017 issue

AUGUST

- 7** Initial [Mary Barkey Clinical Excellence Award](#) nominations due
- 10** Deadline to apply for the August administration of the [Child Life Professional Certification Exam](#)
- 15-30** [Child Life Professional Certification Exam](#) Administration testing window

SEPTEMBER

- 5** Supporting documentation for [Mary Barkey Clinical Excellence Award](#) nominations due

OCTOBER

- 1** Submission deadline for [ACLP Bulletin and Focus](#) articles for consideration for the Winter 2018 issue



Webinars

The schedule of presentations for 2017 is coming together, and webinars on a wide variety of topics are planned, including sessions fulfilling the requirements for PDUs in ethics and assessment. For details of each session and to register for a webinar, see the [webinar page on the ACLP website](#). Check back often, as the schedule will be updated as new sessions are added!

Unless otherwise noted, ACLP webinars are scheduled on Wednesday afternoons from 2:30 to 4:00 pm Eastern time. Attendees earn 1.5 PDUs for each webinar. Individual and group rates are available.

For your convenience, several OnDemand webinars are now available! See the ACLP website for details.

APRIL 12

Child Life and Ethics: How to Ignite a Fire without Getting Burned

MAY 3

“Squad Goals”: Building Therapeutic Relationships With Adolescent Patients

JUNE 7

Recognizing Physiological and Psychological Signs of Stress in Parents and Facilitating Parent Interventions for Positive Coping Strategies in the Hospital

JUNE 14

Removing Restraint: How Child Life Specialist-Clinician Partnerships can Eliminate Procedural Suffering and Change the Culture of Pediatric Emergency Medicine

JULY 26

Supporting Patients Who Identify as Transgender Within the Health Care Setting

AUGUST 2

Infants, Toddlers and Parents . . . Oh My! Weaving the Threads of Infant/Toddler Preparation: Helping Parents Become their Child's Advocate



Upcoming Events

APRIL 19-21, 2017

**Association of Pediatric Oncology Social Work
41st Annual Conference
Chicago, IL**

Visit the [APOSW website](#) for more information.

APRIL 21, 2017

**Great Lakes Association of Child Life Professionals
Child Life Assistant Summit
Grand Rapids, MI**

Visit the [GLACLP website](#) for more information.

JULY 26-27, 2017

**National Hospice and Palliative Care Organization
2017 Virtual Conference**

Visit the [NHPCO website](#) for more information.

SEPTEMBER 9-12, 2017

**American Therapeutic Recreation Association Annual Conference
Orlando, FL**

Visit the [ATRA website](#) for more information.

SEPTEMBER 16-19, 2017

**American Academy of Pediatrics
2017 National Conference & Exhibition
Chicago, IL**

Visit the [AAP website](#) for more information.



Child's Play

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MOMENTS FROM THE PAST

Cassettes and Contents: Human Needs and Political Realities, 1978

Joan Turner, PhD, CCLS

ARCHIVES MANAGEMENT GROUP

The late 1970s represented a period in history when questions addressing the need for humanizing health care were at the forefront of discourse in the Association of the Care of Children in Hospitals (ACCH). A box of cassette tapes of recordings of the conference, located at the ACLP Archives at Utica College, Utica, NY, indicate the lead advanced by ACCH as political advocates. The labels on the tapes are compelling...

“Is there a national conspiracy against children in the United States” — MICHAEL B. ROTHENBERG

“Legislating Health Care”
— EDWARD M. KENNEDY, U.S. SENATOR

“From Policy to Practice Makes Perfect”
— B.J. SEABURY

Digging deeper into the archives, I discovered the 1978 ACCH conference proceedings published in full text. *Human Needs and Political Realities* features child life pioneer and ACCH President B. J. Seabury promoting the advancement of children at the top of the National agenda. She opens her remarks with a review of her personal experience testifying on Capitol Hill to the Committee on Child Care in the 1960s. She relates that the congressmen for the later Committee on Comprehensive Child Development and Day Care felt unsupported and had anticipated greater numbers of teachers and child care workers to support the agenda. Further, she discovered that the justification material and testimony received by the Committee for the Center for Disease Control on Health Education Programs were “neither useful nor convincing” (Seabury, p. 1).

In reviewing the available research and materials, Seabury

was driven to ask the question, “How can ACCH advocate for children in health care settings?” The answer: “We must develop grass roots advocacy and make the Central Office strengthen the grass roots by feeding them current information and news” (p. 3).

Listen for the powerful voice of B. J. Seabury as she presents the ACCH president’s keynote address in 1978, recognizing twelve “hard facts” required for effective advocacy in placing children nearer to the top of the national agenda:

1. Nobody is going to give us anything.
2. We cannot accomplish everything at once.
3. We must be specific.
4. We should be ready.
5. We should ask ourselves the right questions.
6. We should know what our objectives are and use our energy to move forward.
7. The ground rules and roles of advocates have changed.
8. We must take the offense.
9. We must coalesce around some key issues before it’s too late.
10. We must establish a powerful, flexible political network that can get things done for children.
11. We must stop falling over each other doing the same things.
12. We must become hardnosed and tough!

— SEABURY, 1978, P. 3-4

Though the date on this address is almost 40 years old, the similarities to the current political and social climate is hard to deny. History can often clarify our perspectives on the present. What would our list of “hard facts” include in 2017 as we work to advocate for the needs of children?

For further research

Pearson, L. (2014). “Play as a right” in J. Turner and C. Brown (Eds.), *The Pips of Child Life: Early Play Programs in Hospitals*. Dubuque IA: Kendall Hunt.

Seabury, B.J. (1978, June). “Human needs and political realities” in Association for the Care of Children in Hospitals 13th Annual Conference Proceedings. (Utica College, Utica, New York: ACLP Archives).



Photograph courtesy of Zbigniew Kowalewski, 2014



2018 CALL FOR ABSTRACTS

Association of Child Life Professionals (ACLP) 36th Annual Conference

MAY 2–6, 2018 • GAYLORD NATIONAL HARBOR, MARYLAND • WASHINGTON, DC METRO AREA

The 2018 Conference Program Committee is seeking submissions of presentation proposals for the Association of Child Life Professionals (ACLP) 36th Annual Conference at Gaylord National Harbor, Maryland in the Washington, DC Metro Area, May 2–6, 2018.

The Annual Conference is designed for and attracts representatives at every level of the child life profession in hospital, physician practice, and academic settings. Of the more than 1,100 attendees at the 2016 conference, 35% had 10 or more years of experience in child life, 24% had 5 to less than ten years of experience, 33% had less than 5 years of experience, and 8% were new to the field.

The committee is seeking all forms of professional development with an emphasis on interactive, experiential learning:

- Sessions;
- Workshops;
- Full-Day Intensives;
- Half Day Intensives; and
- Poster presentations

The committee is particularly interested in proposals of advanced level workshops developed for attendees with more than 10 years of experience in child life – thirty-five percent of the attendees at the 2016 conference.

To assist attendees in meeting their certification requirements, we encourage submissions in the domains of **Professional Responsibility, Assessment, and Intervention.**

BENEFITS OF PRESENTING:

- Improve the child life profession
- Share creative ideas and best practices
- Demonstrate your leadership
- Expand your industry recognition
- Network with your peers
- Receive discounted full conference registration
- Earn PDUs

ACLP will accept abstract submissions for the 36th Annual Conference through the website June 16–July 24, 2017.

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Suggested presentation topics for 2018 include innovative ideas and best practices in the following areas:

- Academic & Clinical Preparation
- Age-specific
- Bereavement/Grief
- Community-based child life
- Cultural Competency
- Diversity
- Diagnosis-specific (i.e., Autism, Sickle Cell, etc.)
- Documentation
- Evidence Based Practice
- Ethics
- Families
- Interdisciplinary Collaboration
- Leadership Development
- Management Strategies
- Medical Play
- Palliative Care
- Play
- Preparation
- Program Development
- Research (Completed)
- School Issues
- Self-Care/Personal Development
- Specialty Areas (i.e., Emergency, Oncology, etc.)
- Technology
- Therapeutic Play
- Other

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Attendees work at every level of the child life profession in hospitals, community outreach, private practice, and academic settings. Of the more than 1,000 attendees, 35% have 10 or more years of experience working in child life, 24% have 5-10 years, and 41% have 0-5 years.*

*Source: 2016 annual conference exhibitor survey

OPENING SESSION KEYNOTE SPEAKER

Kevin Spencer

*Kevin is the Founder of the **Healing of Magic** program, widely considered the leading authority on the therapeutic use of magic tricks in physical and psychosocial rehabilitation. Kevin believes strongly in the power of the arts to impact the quality of people's lives.*



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