Diane Hart to Receive Distinguished Service Award

Allison Sohanlal, MSc, CCLS
McMaster University, Hamilton, ON, Canada

Growing up in a small northern town in British Columbia, Canada, Diane Hart always knew she wanted to work with children and youth. When she first learned about child life in high school, sitting in on classes at the University of Victoria’s Child and Youth Care program, she never imagined that the field she chose would one day pay tribute to her with one of its most prestigious honors, the Child Life Council’s Distinguished Service Award.

After graduating from the University of Victoria’s School of Child and Youth Care with a specialization in child life in 1988, Diane immediately started her career as a child life specialist at BC Children’s Hospital (BCCH) on the adolescent unit. Her career has flourished at BCCH where she has transformed services for children and families from her days as a child life specialist to her current position as director of patient- and family-centered care.

Diane credits her long tenure at BCCH to the amazing opportunities to be involved with community and special projects and her organization’s support for her work on these endeavors. Taking advantage of the many opportunities that presented themselves is what has allowed Diane to rise to the top, gaining valuable experiences and increasing her skill set with each experience. Beginning early in her career, Diane was able to spearhead the creation of the ON TRAC transition program;

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E is for Essential Oils: Benefits and Cautionary Advice for the Child Life Specialist’s Tool Kit

Rebekah Teller, BA
Graduate Student, University of Missouri, Columbia, MO

E

ssential oils (EOs), distilled from plants, are liquid properties that have fragrance, vaporize easily, and have therapeutic value (Buckle, 2002; Essential Science Publishing, 2009). Aromatherapy, by its very definition, uses EOs as therapeutic stimulants through the sense of smell, typically through inhalation of scented vapors in the air, or in mediums such as massage oil or bath salts (Buckle, 2002; Edge, 2003). Rayburn (2014) discusses benefits of using different methods of EOs with children for colic, infant massage, and emotional well-being, and other studies have demonstrated EOs applications for children and families with anxiety, pain, and symptom relief (Chamblis, Heggen, Copelan & Pettignano, 2002; Kim, S. Kim, Yeo, Hong, Lee, & Jeon, 2011; Sadathosseini, Negarandeh, & Movahedi, 2013).

The most likely ways that child life specialists might use EOs are through diffusion and infant massage. Inhalation and/or diffusion of EOs into the air can not only calm and relax the patient, but can promote a more soothing environment for the family, more effective pain management, lower anxiety, and decrease depressive symptoms for chronic patients vulnerable to psychological distress (Chamblis et al., 2002; Kim et al., 2011; Mein, 2015; Rollins, 2005). Those certified in infant massage may apply pure therapeutic grade EOs with carrier oil, which is fattier oil such

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President’s Perspective

Implementing the Transformation of the Child Life Council into the Association of Child Life Professionals

Sheri A. Mosely, MS, CCLS

It’s an exciting time to be a member of the Child Life Council. The field is growing and CLC is adapting to meet the changing needs of members and society at large. We want to increase the professional acknowledgement and recognition of the important work that all of us do as child life specialists. It is also very rewarding to hear the enthusiasm expressed by so many of our members for the recent announcement that the Child Life Council is now becoming the Association of Child Life Professionals.

The news has generated thoughts about the future and prompted many questions as to how and when these groundbreaking changes will occur. Some members have already started to refer to the organization as the Association of Child Life Professionals, or ACLP, which speaks to the excitement that many have. Though the decision to change the name has been made, it is only one part of the much larger endeavor to rebrand the organization. There is work to be done before the Child Life Council’s new identity is fully realized, as the rebranding of the organization is an evolving process that will take some time to fully implement.

First, a new logo needs to be designed and brand standards need to be developed identifying the new corporate color palette, fonts, and usage of the new logo. Our new name needs to be accompanied by a new “look” to reduce confusion that seeing a new name with an old logo would cause for members and other stakeholders, especially when it comes to printed materials. For that reason, all changes will be finalized before being rolled out and utilized. Once these are in place, the website will be redesigned to reflect the new name, standards, and corporate identity. Until the rebranding is complete, please continue referring to the organization as the Child Life Council, or CLC.

As of right now, the new logo design is in progress. Several designs have been submitted, and feedback has been sought from various member constituents through a survey and the leadership forum. Once the final logo selection has been made, a sub logo—an embellished version of the main logo, adding an extra visual component that speaks to an ‘extra step’ taken for education and training—will be created for child life certification.

The new color palette and fonts that are chosen will be incorporated into all of the organization’s communications materials to reflect the new identity. You will see these new brand standards everywhere: the website, letterhead, publication covers, Bulletin, membership materials, and marketing materials, just to name a few.

The website will be redesigned not only with the new branding, but also with content targeted toward a wider variety of child life audiences—active child life specialists, those interested in becoming child life specialists, parents and families, hospital administrators, and corporate sponsors that may have an interest in funding child life initiatives.

Throughout all of this branding evolution, new messaging will also be developed to communicate more effectively with the identified external target audiences such as parents and hospital administrators. Messaging will include things like new association tag lines and short written descriptions about the work of child life (the infamous ‘elevator speech’). Expanding this professional reach and recognition of the organization has been identified as an important component in the Child Life Council’s 2015-2018 strategic plan.

In summary, we are envisioning a three-part approach to the new brand implementation. The first phase will be a logo and brand standards reveal to attendees at the Child Life Council’s 34th Annual Conference on Professional Issues in Orlando, FL. A larger marketing campaign will occur during March 2017, Child Life Month. And finally, the new identity will be fully implemented at the 35th anniversary Annual Conference in Las Vegas, NV, in May 2017.

I am honored to be a part of this transition, which I believe will make our organization even stronger in the coming months and years, and will ensure that as a profession, child life professionals have the backing and support that we need to best meet the psychosocial needs of pediatric patients and their families.
When Theory Hits Home

Jessika Boles, MEd, CCLS

I only knew it was Christmas when an old man with weathered skin, dark eyes, and a thick graying moustache started handing out foil-wrapped snacks to the small crowd in the ICU waiting room. Tamales, I could tell by the smell, a symbol of the joys and fruits of the holiday season. For once in my life, I wasn’t hungry, and neither was my dad. We were sitting in silence in the corner of the room, the only outsiders to the family celebration taking place around us. There was nothing for us to celebrate in those moments. In fact, we were each stoically trying to convince the other that we weren’t falling apart...by not looking at each other, not talking to each other, and even being careful not to bump elbows on the painfully uncomfortable arm rest signifying the emotional wall between us.

Three days of coughing had become respiratory distress overnight. My dad rushed her to the emergency room, and within 24 hours, I held my mother’s hand while she anxiously and tearfully awaited intubation. Her lungs were failing, without explanation, and the only choice was to ventilate and sedate her in hopes that her lungs would start to fight more desperately for life. I watched her sob and cry, asking me to stay with her for the procedure, and to tell her that everything would be okay, and I did. My dad couldn’t do it, couldn’t watch that part, and waited from the hallway. I stayed with her until she was asleep, the tube was placed, and her heart and respiration rates were stable.

When I stepped into the hallway, where I could pretend that my mother was comfortably sleeping instead of mechanically supported, I felt the air rush back into my own lungs again. Just as quickly I had the breath knocked out of me by a physician who shared with us that “things aren’t looking good.” He (inappropriately) told us his wife had died of the same circumstances last year, as if we were supposed to feel sorry for HIS loss in the matter. My dad looked down and said nothing. I looked down and cried, trying to hold back a burning desire to just run away from it all.

The car ride home was awful. What would we tell my brothers? Kody was the most sensitive one – how would we tell him in the gentlest way possible? Was there even a way to do that in this situation? Jake, who has autism, had never experienced anything that difficult before. How would he handle it, and how would we handle him? When it came down to it, we sat them down in the living room and just told them.

“Mom’s really sick. Her lungs aren’t holding oxygen very well and it’s getting worse. She has to have a tube in her throat to breathe right now, and she may have to stay in the hospital for a while” my dad said. The child life specialist in me was impressed by his choice of words.

The next few weeks were a blur. Things seemed slightly better, and then drastically worse. My grandfather and his wife drove through the night from California because things reached such a critical point. My brothers and I sobbed in hallways, thinking of the things our mother would never see us do. We took pictures holding her hand and my dad started to plan for her funeral, asking me if she would have wanted to be buried or cremated. We contacted our priest, who came to perform the Anointing of the Sick. And then, one day, she just got better, again with no explanation, and we were makings plans for transitioning to a rehab hospital.

I wish I could say the stress of those few weeks, just over six years ago, have dissipated, but this was a life-changing experience for our family. Just as children in the hospital and their family members may experience, watching a loved one endure illness or injury challenges one’s coping mechanisms to the max. We all coped with the situation differently, yet the same. We each kept to ourselves, tried to distract our minds from the constant worries, and occasionally overcame our fear...continued on page 27
CEO Shares...

Experience all that the CLC Annual Conference has to Offer

James Gandorf, CAE

Child Life Council’s most exciting weekend—our annual conference—is fast approaching! Join your colleagues from around the globe as we celebrate the innovation, imagination, and inspiration of child life work in Orlando, FL, May 19-22, 2016. The Annual Conference on Professional Issues includes opportunities to learn more about the latest program developments, research findings, and other topics of interest in child life, as well as the chance to network with other child life professionals. And because it’s child life, you can expect opportunities for play, fun, and camaraderie!

At this year’s annual conference, you can earn more PDUs than ever before: up to 17 PDUs, plus an additional 9 PDUs by attending Intensives on Thursday and Saturday. In addition, CLC will be recording workshops at the Annual Conference and making them available after the event to full conference attendees for only $25. You can continue your education and earn PDUs after the conference with this invaluable new resource. Purchase the All Access Pass for $25 when you register for the CLC 34th Annual Conference on Professional Issues.

There are many choices to make about events to attend throughout the conference, so I’d like to take a moment to highlight some special happenings:

• During the Opening Session, Colleen Sweeney, RN, BS, Founder and Owner of Sweeney Healthcare Enterprises, will deliver the Emma Plank Keynote Address. On a mission to transform healthcare, she will share her experiences and results of a three-year research study she conducted called The Patient Empathy Project™. We will also celebrate the accomplishments of Diane Hart, MA, CCLS, EDAC, as she receives the Distinguished Service Award, the highest award presented by the Child Life Council Board of Directors, which recognizes exceptional members for outstanding contributions to the field of child life. Both of these presentations will inspire and encourage child life professionals, regardless of experience level or service area.

• Three concurrent plenary sessions will be offered on Saturday, on topics ranging from communication with children, to meaning-making in grief, to ethics.

• Recognizing the need to accommodate different adult learning styles, the Conference Planning Committee is excited to introduce the Innovation, Imagination, Inspiration Talks – a new format this year, consisting of three 30-minute presentations on widely varying topics, with a Q&A session to follow.

• Connect with colleagues, see old friends, and make new ones at one of the many networking events, including a Welcome to Orlando reception on Thursday evening and lunch and Opening Night reception in the exhibit hall on Friday.

All Access Pass FAQ:

Q: How many PDUs will I earn for watching the recorded conference sessions?
A: The PDUs will be comparable to those of live attendance - 1.5 hours will equal 1.5 PDUs.

Q: How many recordings can I view to earn PDUs?
A: There is no limit on how many recordings you can view. And, as long as you successfully complete the quiz after reviewing the recorded workshop, those PDUs count towards your recertification.

Q: Can I purchase this if I’m not going to attend this year’s conference?
A: This exclusive opportunity is ONLY available to full conference attendees.

Q: Can I purchase the All Access Pass after conference?
A: No, the All Access Pass is available only for a limited time, until May 22, 2016.

Q: How long do I have to watch the recordings and earn PDUs?
A: The All Access Pass is good for a year, until next year’s conference.

Purchase the All Access Pass for $25 when you register for the CLC 34th Annual Conference on Professional Issues.

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Pathways to EBP

Over the last year, the child life team at Children’s Medical Center Dallas has been working to incorporate evidence-based practices into their daily clinical work in a way that is gradual and organic. Their EBP initiative and outcomes are outlined below. We hope this inspires some ideas for incorporating EBP into the daily practices of your department!

Putting Evidence-Based Practice into Practice

Christine Knefley, MS, CCLS
Children's Medical Center Dallas, Dallas, TX
Lizzy Peterson, MA, CCLS
Children's Medical Center Dallas, Dallas, TX

In early 2015, the Clinical Practice Committee at Children’s Medical Center Dallas set a goal to make evidenced-based practice (EBP) a part of the everyday culture. The primary aim was to increase awareness of the need for EBP as an essential part of remaining current in best practice. When provided with the most up-to-date research, child life specialists are equipped to effectively communicate using the same type of language as medical care providers. This in turn leads to more opportunities for collaboration and advocacy, which ultimately opens doors to better patient care.

In order to raise understanding, increase comfort, and promote staff buy-in, the decision was made to focus on EBP topics that apply to existing practice and to utilize existing weekly staff meetings for EBP-specific education. Due to feedback received from the department, an identified concern was that EBP initiatives would be time consuming. Therefore, the committee felt that the department would most benefit from articulating the theory behind their everyday work as opposed to attempting to create new policy statements. Based upon hospital-wide and departmental initiatives, three main programming domains were identified: continuing education, performance evaluations, and student programming.

Continuing Education

Implemented: Given the importance of continued learning, the Clinical Practice Committee identified department-wide education as the highest priority. The committee planned to facilitate a series of short presentations at department meetings. Initially, a Clinical Practice Committee member took responsibility for the presentations. Once the larger department was familiarized with the format and expectations, non-committee members were approached about participating. Presenters were asked to create a 10-minute presentation and to facilitate a brief Q & A session after the presentation. Each presentation included a review of the available literature, implications for child life practice, and related hospital policies. The first four topics covered were identified by the committee: pet therapy, pill swallowing protocol, oral sucrose, and topical anesthesia. The department was responsive to the presentations, stating that the presentations helped demystify EBP and made it more approachable. Feedback from staff indicated that the information was especially helpful to child life specialists who work in areas with fewer opportunities or exposure on the topic. EBP presentations are slated to continue on a bimonthly basis through 2016.

Next Step: Beginning in January 2016, EBP presentations are now partnered with small group discussions to allow all staff greater opportunity to apply the information directly to their work area. On alternating months, Clinical Practice Committee members facilitate small group discussions related to the previous month’s EBP topic. All staff are asked to come to the staff meeting prepared to discuss a case example or with questions on how to implement the information into their work areas. A list of prompting questions are provided to the small group facilitators to assist in the discussion.

Performance Evaluations

Implemented: All staff at Children’s Health are required to identify at least one individual performance objective each year. The child life leadership team works with individuals to identify a goal that will encourage personal learning, enhance clinical practice, and/or enrich departmental goals. In 2015, the leadership team requested that staff consider incorporating an EBP component into goals. For example, a goal that addressed enhancing medical record documentation included the requirement to review the literature regarding initial patient assessment. This translated into systematic changes in the flow and content of documentation in our department. Additionally, departmental goals contained EBP components. For example, one goal included building new program interventions with sensory integration tactics to reduce anxiety and stress and improve coping of hospitalized children. EBP was used to support this goal during skill building sessions, departmental education, and in identifying appropriate resources.

Next Step: Our department revised child life competencies in 2015 to be more hands-on, more applicable, and more representative of individual skill sets. In 2016, the department is further incorporating EBP into the annual competency evaluation. Child life specialists are now required to utilize EBP in supporting best practice in certain competencies.

When provided with the most up-to-date research, child life specialists are equipped to effectively communicate using the same type of language as medical care providers. This in turn leads to more opportunities for collaboration and advocacy, which ultimately opens doors to better patient care.

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When asked about the role of a child life specialist, people in our field generally think of helping children cope with hospitalization, invasive or painful procedures, and new diagnoses. When I began working in a hospice setting, I had to rethink my role and how I could use my skills as a child life specialist to support patients who are dying at home. The children I work with are not occasional visitors to the hospital, terrified of medical staff and anxious about getting pokes; they are the experts when it comes to healthcare. Most of them have seen it all, developed close friendships with their medical staff, and can tell you more about their diagnosis than most medical students, and are most often exhausted by it all. The patients I work with are now at the place where there is no more treatment available, so they are no longer going to the hospital for chemotherapy and scans, but instead have been given the opportunity to die at home surrounded by their family and friends.

Just like any other child life position, I am frequently educating staff about my role on the interdisciplinary team, including when to make a referral for child life services, and how to introduce my role to the family. Once I am in the home, I find I have to re-introduce child life services as many of the patients know child life as the person who taught them how to cope with getting their port accessed, or the person who organized bingo on the floor each week. I typically tell families that the major differences between hospital child life specialists and hospice child life specialists are that I am able to work with children in their space at a time during the day that is convenient for them, and I am able to work with children on their individual needs, rather than base services around the medical needs (i.e., procedures, exams, physical therapy, etc.). However, before I was able to explain my role to families and staff, I first had to really understand how I could utilize my child life skills when there are no hospitals, painful procedures, or new diagnoses. I quickly realized that the normalization and preparation skills I had learned throughout my education and prior child life experience were the same skills I needed now. I just had to look at them through a different lens.

**Normalization**

Normalization is a core child life concept. In the typical hospital setting, normalization means creating a structure and familiarity in an unfamiliar and often scary place. However, when children are at home, as they often are in hospice, they are in their natural and normal setting, so what do we need to normalize? Working in hospice, I normalize their feelings. I let the patient, siblings, and families know that they are not alone, and that what they are experiencing and feeling is normal and okay. The fear of dying is normal, the loss of control is normal, and the hope for a miracle even when they know it’s not possible is normal. A large part of my role is normalizing the abnormal, which in this case is the death of a child.

When a child is dying, they may not know how to live their last few months. However, most children I work with at this phase really desire to be “normal.” This usually means going to school, being around their friends, going to the movies, planning for the future, and other typical activities that they may have been able to do before they were sick. As a child life specialist, I have the opportunity to use my creative skills to figure out how this can be done; whether it is Skyping with the school, bringing the movies to the child, allowing the child to dream about who they will be when they grow up, or encouraging the family that it is okay and safe for the child to still do “normal” things. Modeling that dying children can still participate in normal activities is a great way to encourage caregivers to allow them to do this, even when it may feel scary. One way I model for parents is through play.

**Play**

As every child life specialist knows, play is a universal language. Play is the core of what we do, whether it is in the hospital, school, shelter, or in the home. Play is the most important aspect of our jobs, and play is just as important at the end of life, even when play continued on page 26
Balancing work with personal life has always been fairly easy for me. I know that in order for me to work with patients who are experiencing challenging healthcare experiences, including new diagnoses or death, for many years, I need to maintain a balance. I focus on filling my cup outside of work so that I can provide cup-filling work to others while in the hospital. Last year, a week before Thanksgiving, the balance I have been able to maintain was disrupted. My brother contacted me from 350 miles away to tell me that his wife had died suddenly and he was unsure how to tell his 5-year-old son.

As a child life specialist working with patients in the hematology/oncology division of Monroe Carell Jr. Children’s Hospital at Vanderbilt, I have lots of experience participating in difficult conversations. Many times the conversations started with adults tearfully asking how to share bad news with the children in their lives. The conversation with my brother was different emotionally, but the same contextually. I shared developmentally appropriate understanding of death and suggestions for sharing this news with my nephew with an emotional lump in my throat. I stated, “You have to tell him the truth. Her body isn’t working anymore. Her body is too hurt. She died.” Hearing my older brother barely managing to confirm the truth. Her body isn’t working anymore. Her body is too hurt. She died.” Hearing my older brother barely managing to confirm his understanding made my world stop. I paced back and forth, cancelled plans for the day, and began packing for the 7-hour trip home.

For the next week, I gathered resources I often use at work, spoke with my nephew’s teacher, explained cremation to him, and helped him write a letter and buy flowers on the day of his mother’s memorial service.

About an hour into the memorial service he tugged on my shirt and said “When is it my turn to talk?”

I knelt down beside him and explained that each person was sharing stories about his mom because they missed her adding, “If you’d like to talk, I’ll come down with you.” He barely had time to say “okay” before he galloped down the stairs and walked up the middle aisle. He stated his full name then how he loved spending time with his mom. I helped him read the letter he had written, and he ran back to his dad with pride even as the tears in the room flowed. As a child life specialist and his aunt for the same amount of time, I was proud to see him empowered in a time when most feel powerless.

“I don’t know how you do it.” I hear this a lot when I tell others about my work with kids in the hospital. I provide support as they navigate the many emotions associated with new diagnoses, scary procedures, and overwhelming events. This was one experience where I fully agreed. I held it together, provided education and support, and maintained composure during a tough week for my entire family. I remember finally crying when I returned home, wondering how the week would have gone without my expertise.

As a child life specialist there have been many times when I have provided resources, rehearsed how to share bad news, and empowered parents to support their children through tough experiences; most of the time I am unsure of the outcome. I can only hope that with the tools I give and the confidence I help instill, children gain the same opportunity my nephew had to say goodbye and begin healing.

**Milestones**

Shawna Grissom, Jessika Boles, Katherine Bailey, and Amy Kennedy of the child life program at St. Jude Children’s Research Hospital recently published their manuscript, “Play Based Procedural Preparation and Support Intervention for Cranial Radiation,” in the academic journal *Supportive Care in Cancer*. This retrospective study highlights the relationship between play-based procedural preparation and support provided by child life specialists and sedation use in children undergoing cranial radiation therapy, while also emphasizing the medical cost savings associated with child life support. The manuscript is currently available online, and is also slated to be featured in an upcoming printed issue of the journal. The authors are grateful for the funding and support received from the Child Life Council through the Advancing the Field of Play for Hospitalized Children Initiative, which helped to cover costs incurred by this research project.

Kris Murray, CCLS, passed away in February at the age of 48. Kris’s child life career included positions at the University of Minnesota Children’s Hospital, Rockford Memorial Medical Center, and most recently the American Family Children’s Hospital, in Madison, WI, where she worked in the pediatric specialty clinics, day treatment, and sedation, being the first full-time child life specialist in these settings. She was a member of the board of directors of the Society for Pediatric Sedation (SPS), section editor for the Child Life Corner of the SPS Newsletter, and co-author of the chapter “Non-Pharmacologic Interventions in Children During Medical and Surgical Procedures” in *Procedural Sedation for Infants, Children*, and Adolescents (American Academy of Pediatrics, 2015). Recently SPS recognized Kris for her exemplary care and clinical skill with children in a procedural environment. She will be remembered as a continuous advocate for patient- and family-centered care, for her smile, and for her ability to find a way to bring out a child’s giggle or laugh. Having learned so much from Kris, her colleagues feel blessed to have had her as an integral part of their team, and will honor her by continuing to bring moments of support and laughter into practice every day.

**Upcoming Events**

July 25-27, 2016
The 7th International Conference on Patient- and Family-Centered Care: Partnerships in Care, Interprofessional Education, and Research
New York Marriott Marquis
New York, NY
For information, visit the [IPFCC website](http://ipfcc.org) or contact Racquel Codling at rcodling@ipfcc.org or 301-652-0281

September 24, 2016
Mountain West 3rd Biennial Conference: “Child Life Amplified: Your Mountain is Waiting”
Denver, CO
For information, visit the [Mountain West Child Life Association Website](http://www.mwcl.org)
Child Life in the Philippines: From Service Provider to Capacity Builder

Angie Sievert-Fernandez, PhD, CCLS
Kythe Foundation Inc., Quezon City, Philippines

Pediatric health care in the Philippines can be accessed through the private or public sectors, with some barangay (the smallest, most basic political unit of administration in the country, generally consisting of at least 2000 people) health centers in rural areas. Being an archipelagic nation, the geography of the Philippines makes transportation difficult and access to health care unequally distributed. As of 2005, the Department of Health reports that 94% of the population has access to a rural health unit within a 15-minute walk, but these clinics are often underutilized due to their lack of supplies, poor staffing, and long wait times (Republic of the Philippines Department of Health, 2005). Other factors that affect access to adequate pediatric health care include poverty, inadequate health insurance coverage, and spiritual beliefs. In rural areas, there is still the tendency to first seek the help of faith healers (albularyos) before considering going to the doctor. Moreover, pediatric psychosocial programs are available only in a few hospitals, with Kythe Foundation Inc. as the only organization currently providing such services to chronically ill children and their families.

In February 2017, Kythe Foundation Inc. will celebrate its 25th year. An independent non-governmental organization, Kythe was started when two graduate students from one of the country’s premier universities interacted with children with cancer in a government hospital as part of their course requirement. The two students, Fatima Garcia-Lorenzo and Icar Castro, saw how playing with the children made them happier, eased their boredom, and allowed opportunities for emotional expression. Thus, they felt they couldn’t leave the children behind even after accomplishing their academic requirements. In 1994, Kythe was registered with the country’s Securities and Exchange Commission as a non-stock, non-profit corporation, and in 1998, it implemented the first child life program in the Philippines. Ms. Garcia-Lorenzo, Co-founder and Executive Director, became the first Certified Child Life Specialist in the country.

Kythe has worked at furthering its advocacy through partnerships with individual and corporate donors, sponsors, and a strong volunteer arm. By its 20th year in 2012, there were child life programs in 13 hospitals nationwide, including in the only two free-standing children’s hospitals in the country. The core services of the Kythe Child Life Program (CLP), as it came to be known, formed the acronym PETALS for Play, Educate and Prepare Children, Tend to the Emotional Needs of Child and Family, Assist During Medical Procedures, Lend Financial and Medical Assistance, and Support Parental Involvement. These services are provided by full-time child life coordinators, the majority of whom are employed by the organization. Currently, only two coordinators are organic in the hospitals where they work, but it is a goal that hospitals will have a position and provide the salary for a coordinator.

Though psychosocial care is the primary objective of the program, providing financial and medical assistance is an aspect that, in the Philippine context, goes hand in hand with it. Though there is a social work department in most hospitals, the number of people and the amount of help needed can be overwhelming, thus, assistance from non-governmental organizations (NGOs) like Kythe, individual donors, and other government agencies is always welcome. Working with mostly indigent patients, many factors get in the way of seeking treatment: among them the cost of treatment and diagnostics, inadequate healthcare insurance coverage, transportation expenses, and lack of temporary accommodations. The balance to ensure that psychosocial, as well as financial and medical needs are met is extremely challenging. Often, the help of volunteers is relied on to provide play opportunities to the children. Kythe has celebrated many successes over these past 25 years, yet challenges were never far behind.

Over the years, Kythe CLPs have been funded primarily by donations, and as anyone who has worked in such a setting may know, this is not always sustainable. In 2013, a series of natural calamities struck the country, including the most powerful typhoon to ever hit land, and devastated parts of the Philippines. Donors and sponsors redirected their assistance to the rehabilitation of the affected people and places. By the third quarter of 2014, despite efforts to keep things afloat, Kythe CLPs in five hospitals had to be put on hold, one program had to be permanently closed, and only seven programs were able to remain open to serve the children and their families.

A change in strategy had to ensue if the future of Kythe was to remain a reality. Sad, but not disheartened, remaining team members began training for a shift from service provision to capacity building
in late 2014. This strategy focused on enhancing and empowering the abilities of significant stakeholders so that the organization could move forward in a more sustainable manner. The shift in mindset did not come easily, but by early 2015, Kythe, through its Child Life Program, initiated three capacity-building strategies with its key stakeholders: parents, medical teams, and the children. These strategies were designed to facilitate better care of patients, and focused on the vision of having sustainable child life programs in the hospitals.

The first strategy, Empowering Parents, looks into equipping parents of chronically ill children with the skills and knowledge to manage their children’s treatment process. Kythe is understaffed and it needs all the hands it can have to ensure that the children are supported as much as possible. Thus, after numerous focus group discussions with parents and meetings with medical consultants, parent programs were formed and carried out. By the beginning of the second quarter of 2016, a published Parents’ Handbook with basic information about childhood cancer, its treatment process, and related information will be ready for distribution to parents in our partner hospitals. The parents’ involvement has not only empowered them to take a more active role in their children’s care, but has also enabled them to connect, educate, and support parents of newly diagnosed children as they, too, begin their journeys.

The second strategy, conducting Passion for Caring workshops with medical and allied medical teams in Kythe’s partner hospitals, has the goal of enhancing skills for more effective care of pediatric patients. Workshops present eight modules with topics such as psychosocial care in children, their development, understanding play and therapeutic play, communicating effectively with children and teens, breaking bad news, non-pharmacological pain management strategies, and talking to children about death and dying. By the end of the first quarter of 2016, Kythe had carried out all eight modules with groups of doctors, nurses, and social workers in the two children’s hospitals, and is halfway through the same modules with a group of medical students in one of the country’s most respected medical schools.

The third strategy, Creating an Enabling Environment for Holistic Child Care, has an admittedly lofty, but extremely important goal of working for a policy incorporating child life or psychosocial programs in hospitals with a pediatric ward. Kythe has joined forces with Hospice Philippines and the Philippine Alliance of Patients Organization (PAPO), to push this agenda. Kythe executive director Fatima Garcia-Lorenzo is currently the president of PAPO, of which Kythe is also a founding member. Among the strides that have been made over the last year are Kythe and PAPO becoming members of the National Cancer Prevention and Control Committee. Kythe is part of the Experts Group for Pediatric and Adolescent malignancies of the National Cancer Control Program. Additionally, patient engagement programs like the Kythe CLP are now included as indicators in the Department of Health’s Hospital Scorecard, which is used to evaluate hospital performance. Backed by evidence through research that Kythe has conducted over the past years, through the support of child life champions, and by Kythe’s significant involvement in the national level, steps in the right direction are being taken to ensure that despite some struggles, the advocacy for psychosocial care for children and their families will not be left behind.

Child life specialists around the world have the same passion for providing support to ensure that chronically ill children adjust to their healthcare experiences as best they can, thereby decreasing the possibility of long-term negative effects. Advocating for this goal in the Philippines has been most challenging, but we continue to push forward despite some setbacks along the way. Kythe is taking its own route, in its own time, within our context, always believing that we will get to our destination. As we say in Kythe, “Always in all ways, for the Filipino children.”

References
Atraumatic Care: A Device to Reduce Pain in the Pediatric Population During Painful Ambulatory Procedures

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Atraumatic care is defined by Wong as “the use of interventions that eliminate or minimize the psychological and physical distress experienced by children and their families in the health care system” (Hockenberry & Wilson, 2013, p.14). The philosophy of atraumatic care identifies methods by which professionals can provide pharmacological and non-pharmacological interventions to pediatric patients facing potentially painful and/or anxiety provoking procedures. It is important to provide these interventions to build trust with the patient and family and to minimize long-term fear associated with future medical experience. Even if children are too young to remember the actual painful experience, pain can impact the child’s body and sensitivity to other experiences. At MetroHealth Medical Center, the Atraumatic Care Committee designed a quality improvement initiative utilizing Buzzy™, a non-pharmacological pain management tool. The goal of this initiative was to educate staff about a way to reduce pain and anxiety in children and improve the overall medical experience throughout the healthcare system of all pediatric patients. This project outcome will aid in determining if Buzzy™ should continue to be used as non-pharmacological standard of care.

Buzzy™ is a bee-shaped, palm-sized pain relief device that uses cold ice “wings” and vibrations to help reduce pain for children by desensitizing nerves. This is done as the A-beta and C nerve fibers are stimulated by the vibration and cold sensations respectively. This interrupts the transmission of pain. Buzzy™ can be used for IV starts, injections, blood draws or any potentially painful or scary procedure. Buzzy™ also provides distraction before and during the procedure and helps a child see that he or she can cope with a procedure and make the experience more manageable in the future. Buzzy™ is FDA approved. The use of cold and vibrations to reduce pain is supported by the gate control theory of pain (Melzack & Wall, 1965). In this theory cold and vibration stimuli transmit along the same pathway as pain. Buzzy™ thus takes over some of the pathways leaving less room for the needle stick pain to be transmitted.

Multiple studies have been conducted looking at the benefit of Buzzy™. One recent study focused on pain relief during peripheral IVs in children age 7 to 12 years, and those who received Buzzy™ one minute before peripheral IV through the end of the procedure reported lower pain and anxiety levels than a control group (Cambalat, Ayhan, & Inal, 2015). In another trial, children age 6 to 12 years had a blood draw either with no intervention or with Buzzy™. The Buzzy™ group reported lower pain and anxiety (Inal, 2012). In 2014, a quality improvement project asked both patients and phlebotomists about Buzzy™. Patients with previous blood draw experiences appeared to benefit most, with a reported decrease in pain, and 81% of phlebotomist agreed (Whelan & Kuselman, 2014). Additional studies have been completed examining the benefits of Buzzy™ in specific areas such as allergy (Troger, Robinson, Mancia, Sharma, & Kelly, 2014), plastic surgery (Nahai, 2014), and dermatology (Bechara & Sand, 2007).

The question addressed by the current project was whether patients and/or their parents felt that utilization of the Buzzy™ device helped minimize pain and anxiety during a variety of potentially painful procedures such as blood draws, IV starts, injections, and finger sticks in an ambulatory pediatric setting.

**Method**

Education about Buzzy™ and its use was provided to nursing staff and child life specialists in the ambulatory pediatric setting by the child life manager. Implications for use and contraindications, according to information in the Buzzy™ package insert, were reviewed. Group sessions were held in the break room to allow time for a ten-minute orientation and hands-on practice with Buzzy™. Employees practiced on each other during the orientation to provide an opportunity for staff feedback prior to utilizing the tool.

Three Buzzys™ were purchased and made available for utilization by trained staff in the ambulatory pediatric setting. Buzzy™ was stored along with frozen wings in each medication room. This provided easy access for staff and enabled the utilization of Buzzy™ with all appropriate procedures. Buzzy™ with ice wings, was applied by either child life specialists or nursing staff during potentially painful procedures.

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Public Policy: Empowering Child Life Specialists with Information and Resources

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Caring for a sick child is something most of us would expect as part of the work of a child life specialist. Public policy, on the other hand, is not a typical expectation of child life practice. Public policy is simply a term to describe how the government addresses the needs of its people through regulations, laws, and mandates. Influencing public policy can take many forms - many of us participate simply by voting on Election Day. Others get more involved by working with their elected officials or employers to help advance specific causes. There are many ways that we can use our expertise to help influence public policy. While it may seem intimidating at first, we hope this information will help to simplify the process and give you some ideas on how you can become more involved.

Child life specialists are already champions for children’s health because we have a unique passion and love for working with children and their family members in a variety of settings. Oftentimes this passion manifests itself into a desire to extend our reach outside of our own hospital walls, and this is when public policy is often most useful. For child life specialists who have found themselves wondering “What more can I do?” the resources highlighted here will help you better understand how you can incorporate public policy into your work. Whether you are a public policy veteran or just wondering how it works, we hope you will find some valuable resources to help get you involved.

When advocating for specific policies that enable health care facilities to better serve children, one of the first things you can do is to identify the bills that your state or local government is taking into consideration that may have an impact on children’s health. If you are able to identify a cause that you support or oppose, one of the first steps you can take is to contact your elected officials and express your stance on the issue. There are several options for getting in touch with your elected officials: social media, writing directly to their offices, old-fashioned phone calls, or even trying to schedule a face-to-face meeting. The more personal the interaction, the more attention your request is likely to receive. If a direct meeting is not an option, then consider a video message to share with your official and others who will support the cause.

While there are many ways to communicate with your legislator, timing is important. An optimal time to reach out is after a bill is introduced and assigned a number, as lawmakers are looking for input from the public about how the proposed bill will affect the community. No matter how or when you decide to communicate, remember to keep it short, simple, direct, and to make sure to ask your official specifically about the bill for which you are seeking support. You will not know if your legislator will support or oppose legislation unless you ask directly. Also, try to convey a personal story about why you care so much about the issue. As child life specialists, we have countless examples to share as we see every day the struggles that our patients experience. For additional information on how to get started, the Children’s Hospital Association has an excellent online tool-kit for your reference.

Another great resource is the State Legislation Tracker available from Safe Kids Worldwide. Safe Kids is a global organization that is dedicated to education about and prevention of childhood injuries. Each year in the United States, over 9 million children are treated in emergency rooms for unintentional injuries, which are the leading cause of death of children in this country. One of the missions of Safe Kids is to advocate for laws that keep kids safer and prevent these tragedies from happening. Safe Kids Worldwide’s Legislation Tracker is intended to keep people informed of bills being proposed on a state level to protect children from injury.

If you have identified a cause that you feel is not currently being addressed by your legislature, Becoming an Effective Policy Advocate: From Policy Practice to Social Justice (Jansson, 2011) is a great resource. The book outlines and describes concrete tasks that policy advocates can embark on to change policies and promote social justice, which makes it a great road map that child life specialists can use to get involved. Furthermore, Jansson discusses important issues such as the role of evidence-based practice for public policy and advocacy and the leadership opportunities that policy work can provide as professionals seek change that impacts vulnerable publics.

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Specialized Resources

Specialized Resources is a column designed to share books, websites, apps, and other resources that may be helpful for child life specialists working with a specific population.

This column represents only the personal views of the author, and the Child Life Council does not endorse or sponsor the products or services mentioned. In addition, the authors of this column verify that they have no affiliation with the companies or organizations related to the products and services mentioned in this article, unless specifically disclosed.

Pediatric Palliative and Hospice Care

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When one hears the terms palliative and hospice care, the associated thought is often that the two are interchangeable. However, there is a slight difference. According to the National Hospice and Palliative Care Organization (2015), the focus of palliative care is maximizing quality of life and anticipating, preventing, and treating unnecessary suffering, and while death is a potential outcome, it is not necessarily imminent. In comparison, in hospice care death is imminent. Hospice care emphasizes care rather than curative measures (National Hospice and Palliative Care Organization, 2015). Pediatric patients receiving hospice services can benefit from child life support to assist in processing their prognosis and in creating memories and legacies. In this capacity, the following resources can be extremely helpful.

Reference


Recommended Resources

Caregiver Resources

Stillwell, E. (1998). Sweet memories: for children and adults... to create healing and loving memories for holidays and other special days. Omaha, NE: Centering Corporation.

Child and Adolescent Resources


Child Life Resources


Websites

Center for Loss and Life Transitions – The Center for Loss is dedicated to supporting grieving individuals as they mourn their losses. www.centerforloss.com
Hello Grief – Hello Grief is a website that offers resources and articles related to grief and that also provides a way for teens to share their personal experiences with grief and loss. http://www.hellogrief.org
PBS Kids Go! – It’s My Life deals with life and the concerns that children and teens deal with every day. In this specific section, developmentally-appropriate information is provided regarding death and questions that surround death. Children and teens also share their thoughts, experiences, and feelings about the death of their loved ones. Resources are provided to assist the child and teen who is grieving. www.PBSkids.org/itsmylife/emotions/death

Jennifer Fieten has been a child life specialist working with children impacted by death for 14 years. She has worked with JourneyCare, in Barrington, IL, for the past year, providing palliative care and hospice services for pediatric patients and their families in their homes. Jennifer can be contacted at jfieten@journeycare.org with questions or requests for further information regarding the resources listed. The author verifies that there are no financial affiliations with any of the above mentioned organizations or entities.
The Impact of a Child’s Illness on Family Coping: An Empirical Analysis

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Sally, a 3-year-old, is newly diagnosed with diabetes and is displaying high levels of acting-out behavior throughout her health care encounters. Alex, Sally’s 5-year-old brother, is in kindergarten and his teacher reports that he is displaying atypical behaviors in class, including not paying attention and refusing to nap at rest time. Sally’s father, David, continues to work each day, taking on additional hours to keep the family’s income sustained. He regrets not being present to support his wife, Karen, with the frequent and demanding health care visits. Karen believed the family already ate healthy meals, but is now confronted with the realization that everything they have been doing must change in order to nutritionally support Sally’s health. Karen feels overwhelmed with this new information and feels guilty, thinking that she should have known to do something sooner for Sally.

The previous scenario demonstrates that a child’s illness impacts all members of the family in unique ways. It may seem that the child with the illness is most affected by this life stressor due to the direct physiological experiences, yet parents and siblings may experience their own reality of stress. Child life specialists understand the impact of stress on the family system and the critical role of family-centered care. In this paper, McCubbin, Cauble, and Patterson’s (1982) double ABC-X model will be utilized to examine the ways in which a child’s illness impacts the stress of the whole family.

The double ABC-X model, new to some in the child life profession and well known to others, can be instrumental in understanding family stress. One goal for this article is to provide child life professionals with an easily understandable, theoretically-based model to enhance their own knowledge. Another purpose of this article is to equip child life specialists with a tool to bolster their professional credibility with interdisciplinary team members. The double ABC-X model can prove a useful educational framework when informing fellow health care professionals about families experiencing stress. This article will address the origins and history of the double ABC-X model, provide research support of the various model elements, and incorporate application to child life practice.

ABC-X Model Origins

Boss (2006) describes family stress as strain or friction on usual life, which disturbs the family’s balance. In 1949, Hill developed the first theory on family stress, and he is credited as being the founder of family stress research to this day. Hill’s (1949) ABC-X model of family stress and crisis was based on his studies of families experiencing stress and crisis due to “war separation and subsequent reunion” (Hill, 1949, p. 11). Even as research in this area has grown, Hill’s (1958) theory is still endorsed as currently relevant to family stress and coping (Boss, 2006).

Hill’s (1958) ABC-X framework begins with A, the stressor event that generates change within the family. This stressor creates an interaction with B, the family’s strengths and resources. This connection of A and B intermingles with C, the connotation and significance the family assigns the event. The sequence of interactions constructs X, which is the quantity of stress or crisis produced in reaction to a stressor. This sequence of encounters between elements is the basis of understanding Hill’s (1949) Family Stress Theory.

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DOUBLE ABC-X MODEL: AN EXPANDED PERSPECTIVE

McCubbin, Cauble, and Patterson's (1982) double ABC-X model originated from a quantitative prediction model and "an inductively derived model" (p. 47) from the research evidence. To differentiate between the models, the double ABC-X model begins with Hill's (1949) version, but adds lower case a, b, and c as pre-crisis elements with x as the crisis. McCubbin, Cauble, and Patterson's (1982) expanded version includes: (A) stress pileup; (B) existing and new resources; (C) the family's perception of the crisis (X), plus stressor event (a); pileup (A); and existing and new resources (b and B). This version's (X) relates to the continuum of adaptation. (See Figure 1.)

Stress pileup is identified in the McCubbin, Cauble, and Patterson (1982) model as double A, which includes stress and change. Price, Price, and McKenry (2010) define stress pileup as, "The clustering of stressor events (normative and/or nonnormative)” (p. 8). Three types of stressors included in the double A factor are the original stressor event, changes and happenings in the family unrelated to the original stressor, and effects of the family's attempts at coping with the stressor event.

The double B in this model consists of the family's resources, which include existing resources they already possess, such as "coping resources (personal, family, and social) strengthened or developed in response to the 'crisis' situation" (McCubbin, Cauble, & Patterson, 1982, p. 45).

Next in the model, family perception is the double C, and may take two forms; family members' perception of the stressor event, or their perception of the crisis. Their perception of the stressor event entails "the family's view of how stressful the event may be or is" (McCubbin, Cauble, & Patterson, 1982, p. 45). The perception of the crisis includes "not only the family's view of the stressor and related hardships, the pile-up of life events, but also the meaning the families attach to the total family situation" (McCubbin, Cauble, & Patterson, 1982, p. 45).

The double X factor represents family adaptation as an outcome after a crisis. McCubbin, Cauble, and Patterson (1982) state, “Adaptation involves the processes of stimulus regulation, environmental control, and balancing to achieve a level of functioning, which preserves family unity and enhances the family system and member growth and development” (p. 45). Adaptation not only allows the family to attain functional equilibrium in life, but goes beyond to enrich the family unit as a whole, as well as its individual members.

ADVANTAGES FOR CHILD LIFE PRACTICE

Hill's (1949) original version clearly set the foundation for understanding family stress while McCubbin, Cauble, and Patterson (1982) built upon that initial foundation to incorporate more depth in the model. This depth broadened the theoretical and practical applications for further holistic understanding of family stress. Child life specialists benefit from knowledge of both ABC-X models and are fortunate to have a reputable, critically evaluated theoretical framework guiding clinical practice.

Both versions of this model, Hill's (1949) and McCubbin, Cauble, and Patterson's (1982), are fundamental to understanding family stress theory; the ABC-X model is flexible enough to build upon as modern day phenomena are realized. Boss (2002) provided insight into the continued development of family stress theory, incorporating pertinent current discoveries such as: (a) "mind-body-family connection" (p. 2); (b) family resilience; (c) spirituality and faith; (d) post traumatic stress disorder; (e) role of disaster relief teams; (f) caregiver stress; (g) work life balance; (h) notions of stress inducing events; (i) social constructionism; and (j) using narrative analysis. The addition of emerging evidence-based developments contributes to the ABC-X model’s durability and trustworthiness for ongoing child life practice.

LITERATURE SUPPORT AND EXAMPLES

This section provides brief examples from the literature to illuminate the double ABC-X model. The goal is to demonstrate its applicability to the types of scenarios encountered daily in children's health care settings. While child life specialists may be well acquainted with the scenarios, this broad overview should provide insight into each specific element of the double ABC-X model.

STRESSOR EVENT (aA)

Childhood serious illness, whether acute or chronic, is a nonnormative stressor in a child and family's life due to its unexpected nature. Parents expect children to be healthy and grow up well due to highly developed preventative medical care and current technological advances in treatment of common childhood illnesses. This expectation compounds the nonnormative stressor event, as parents truly do not expect their children to become seriously ill.

Of the 72 million American children currently under age 18, eight percent of those children between the ages of 5 and 17 years old are affected by a chronic illness...
leading to a rough estimate of the number of children affected at about 5 million. While this is a large number, it remains a small percentage of the total population, which supports the nonnormative classification for this stressor.

The double A (aA) component includes stress pileup from the family's inability to resolve all aspects of the child's illness and its effects on family life during the initial crisis. An example would be parents being so overwhelmed about the diagnosis that they are unable to focus on anything other than the odds of survival. Parents trying to cope with a child’s diagnosis may neglect daily family life responsibilities like finances, which can lead to other family stressors when bills are not paid. The child’s illness stressor combined with stress in everyday life demonstrates that stress pileup can present serious challenges for a family.

As a child life specialist, the author has observed this (aA) example firsthand many times in families served throughout the years. In the author’s experience, the family of a child newly-diagnosed with a life threatening illness often experience stress related to financial problems, job loss, or marital difficulties. Independently, each was a significant stressor event, but some were brought on or exacerbated by the fact that the family was experiencing a child's illness. Child life specialists assess all aspects of stress a family experiences to provide the appropriate coping resources.

**RESOURCES (bB)**

Resources are (bB) in the double ABC-X model and include resources the family possesses and accesses to diminish the effects of the stressor. In the (bB) component, coping resources refers to those that may exist, but need to be strengthened for family coping, or new coping resources the family could develop. Coping resources may exist at personal, family, or community levels.

A family's high socioeconomic status is an example of a resource (bB) the family might already have to assist in dealing with the stressor. O’Brien, Duffy, and Nicholl (2009), performed a review of the literature regarding the effects of childhood illness on siblings. The authors found that the family’s socioeconomic status and income were effective predictors for family functioning related to sibling experiences. Financial security may offer the family support to take time off work and stay with their child in the hospital. It would afford the family security in paying for their health care bills, as they would most likely have health insurance and the necessary income to pay deductibles and co-payments.

Social support is a resource (bB) that Tak and McCubbin (2002) define as “one of the primary moderators (buffers) or mediators between stress and psychological well-being” (p. 192). Social support can be applied at the personal, family, and community level.

On a personal level, a mother may seek out her best friend for support when focused on a child’s illness. Having close female friends to share struggles with meets her need for social support.

Social support as a resource (bB) can be demonstrated at the family level when parents are present caring for the child who is ill. Kars, Duijnste, Pool, van Delden, and Grypdonck (2008) found parents displaying family level social support through their parental need to be there for their child diagnosed with cancer. Two purposes noted for this were protection and preservation.

This study discussed various examples of both purposes including “a trusting relationship, presence, emotional support, advocacy, routines and rituals, and effecting oneself” (p. 1558). These elements were all social supports with a family level focus. Child life specialists work to promote and enable parental presence during health care admissions. In addition, child life professionals continually look for ways to support family-centered care through maintenance of families’ special rituals, routines, and interactions that reinforce their bond.

**PERCEPTIONS (cC)**

Perceptions (cC) in the model represent the meaning the family assigns the stressor event. While the family as a whole may perceive the stressor with a family perspective, the diagnosis of a child’s illness jeopardizes the child’s health to create various family members’ perceptions. For example, parents perceive themselves to be parents of a healthy child, but with the onset of a diagnosis parental perceptions typically change. Literature examples will focus on fathers, siblings, and quality of life.

Mothers are often thought of as the primary caregiver for children in families (Cabizuca, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009); however, fathers are becoming more involved in the daily caretaking needs of children. Goble (2004) states that fathers’ lives are “profoundly affected” (p. 161) by a child’s illness, so it is important to look at their

perceptions (cC) as well. Goble found that fathers can find it challenging to talk about the family’s situation and may feel that others do not understand them. This reinforces the fathers’ silent coping, which limits social support. In this study, fathers often shared that they felt that interviewers should speak with their wives instead. This statement could be due to the fathers’ perception that their wives would have more to offer regarding the family’s stress. Child life specialists should be conscious to thoroughly involve fathers in their children’s health care experience. This can help fathers foster their self-confidence and competence in their role as caregiver.

In addition, father’s perceptions (cC) of their role in the child’s illness stressor may be changing. Wolff, Pak, Meeske, Worden, & Katz (2011) researched fathers who took on the primary medical care for their children with life-threatening illnesses. Their reasons for taking this primary care role varied from marital status, employment, finances, age, culture, and socioeconomic status. The authors found the fathers’ “stories challenge commonly held assumptions that mothers are always better equipped to be primary caregivers” (p. 153), because they demonstrated such “intuitive and responsive” (p. 153) care for their children’s daily and emotional needs. The researchers noted a rise in fathers across the United States who are taking on the role of primary caregiver for their children. Encouragement was provided for all health care professionals not to assume that mothers will be the primary caregivers, to think of the unique needs of fathers, to provide support to single fathers and those with cultural and ethnic needs, and to examine possible biases regarding fathers as primary caregivers. Child life specialists are in prime position to assess specific needs and to implement services to support each father’s role as a caregiver.

Siblings’ daily life quickly changes when a brother or sister becomes ill. They are often cared for by extended relatives or close adult friends . . . thus, siblings may feel forgotten and unloved when parents’ time and attention are focused on the child who is ill.

Siblings bring their own perceptions (cC) of the family stress event. In a systematic review of the literature, Limbers and Skipper (2014) found that siblings of children with a physical chronic illness reported higher health-related quality of life (HRQOL) than their sibling with the illness. Parents’ ratings of the HRQOL of siblings without the illness were higher than the siblings’ own reports of their HRQOL. The researchers believed this oversight in the siblings’ adjustment to be a result of parents’ preoccupation with the child who has the illness. Sibling programs and camps were noted as beneficial for meeting siblings’ needs, and child life specialists can provide similar psychosocial services for siblings in their care.

Janse, Sinnema, Uiterwaal, Kimpen, and Gemke (2008) studied the health-related quality of life perceptions (cC) of parents of children with chronic illness. Their findings indicate that parents and their children gave similar ratings in the physical domain, but found disagreement in the social and emotional domains. This demonstrates that parental perceptions of the child’s quality of life due to illness can differ from the child’s perceptions within the same family stressor, and may indicate a misinterpretation of the child’s perceptions of the illness crisis by the parents. It is important for child life specialists to work with both the child and parent to fully understand each perspective and work to help parents understand their child’s psychosocial experiences.

**Crisis (x)**

In this model, (x) represents the family crisis. All family members are affected by the crisis (x) of a child’s illness. Norberg and Bowman (2008) found that parents of children diagnosed with cancer experienced posttraumatic stress, anxiety, and depression due to the crisis. Cabizuca, Marques-Portella, Mendolowicz, Coutinho, and Figueira (2009) found through meta-analysis that approximately one in four parents of children with a chronic disease meet the posttraumatic stress disorder (PTSD) diagnostic conditions, with the incidence of mothers’ PTSD higher than that of the overall population. The children’s mothers displayed more PTSD symptoms than fathers, which the authors contributed to the mothers’ major role in most families as primary caregiver for the children. Child life specialists should be aware that mothers of children with chronic illness may experience crisis more frequently than fathers, and assess their psychosocial state, provide support, and encourage referrals.

Parents of children who are ill experience stress in many areas and may feel an array of difficult emotions. Blame and bitterness were associated with various physical symptoms, which Hopia, Paavilainen, and Astedt-Kurki (2005) report as common among parents of children who are ill or in hospitals. This study also noted that the parents’ relationship is usually affected by the stress associated with a child’s illness. Thus, parents are relationally affected by the crisis. While child life specialists are not marriage or relationship therapists, they can provide a reassuring voice to advocate for necessary resources, such as Licensed Clinical Social Workers within the hospital.

Stress from the crisis (x) can make daily parenting more challenging. Hilliard, Monaghan, Cogen, and Streisand (2010) found parents’ anxiety was related to pediatric stress and frequency of behavior problems in children with type 1 diabetes.
The authors made the connection that parents are stressed due to the chronic illness, which may decrease their ability to cope with typical behavior problems when compared to parents of healthy children. Child life specialists are advocates for parents’ maintenance of their role and can help them navigate the challenges of parenting in a health care environment.

**Coping, Adjustment, and Adaptation (X)**

The model’s (X) component includes the family’s stress response and adaptation. Adaptation entails the family’s recovery from the stressor, and incorporates family competence and resiliency to foster more successful functioning than even prior to the child’s diagnosis. In order to change their perception of the stressor, families may utilize many cognitive coping strategies to directly decrease the stress, reframe the event, or control their emotions. The family’s use of existing or new resources for positive coping allows for adjustment to the stressor. The ultimate goal for coping is reaching adaptation. Child life specialists can work to help families with the stress by working to help them adapt (X) to life with the stressor.

One example of an adaptation (X) is benefit finding, which incorporates optimism. Individuals using benefit finding search for benefits resulting from the stressor or for positive experiences associated with the stressor event. Michiel, Taylor, Absalom, and Eiser (2009) discovered that children with cancer found positive ways of looking at their illness experience and life beyond the diagnosis. Hopeful thinking was related to self-efficacy for children dealing with a chronic illness (Venning, Elliott, Withford, & Honnor, 2007). Hopeful thinking is a coping mechanism that assists children in setting goals and meeting medical requirements to reach their goals. The child’s belief in God was connected to their hopeful thinking, suggesting that spirituality may play a part in adjustment and adaptation. Child life specialists’ reinforcement of benefit finding may support the family in their adaptation.

Fathers of survivors of childhood cancer who engaged in a research study of benefit finding retrospectively reported they were positively impacted by their child’s illness...

They perceived that the experience equipped them to cope with the challenges life brings, heightened their spiritual lives, and strengthened their relationships with nuclear and extended family members, as well as friends.
important role as a social support resource within pediatric health care for the whole family.

A VALUABLE TOOL FOR EDUCATING INTERDISCIPLINARY TEAM MEMBERS

An important implication regarding application of the double ABC-X model to childhood illness as a family stressor is for health care professionals. There is a need for professional development focused on families and stress in health care practice. Health care team members often need further education on family-centered care, family systems, stress, coping, adjustment, or adaptation. Health care team members may not understand a family that displays a coping style different from their own, or may have difficulty working with a family that is not adapting in a timeframe they deem to be appropriate. Psychosocial team members are relied upon for support and intervention when a family stressor arises in the medical setting. This is a vital opportunity for child life specialists to build professional credibility by sharing theoretical knowledge of family stress.

Child life specialists provide ongoing and supportive education regarding family-centered care, family stress, and coping. These efforts help normalize family stressor experiences for medical team members and provide guidance in ways they can assist children and families experiencing stress. The double ABC-X model is a valuable tool for explaining family stressors observed in pediatric health care. The model provides theoretically sound substantiation, via an understandable framework, to assist child life specialists in educating interdisciplinary team members while advocating for patients and families.

CONCLUSION

Families of children with an illness make the daunting journey to adaptation. This journey begins the day a child is diagnosed and profoundly affects the whole family. Families learn new ways to support their family during the stressor (aA) and identify invaluable resources (bB) that they possess. They experience individual perceptions (cC) about the illness, what it means to them as a family, and how they will forever be changed due to this experience. As coping efforts lead to adjustment together, they reach their new reality of adaptation (X). This final destination allows families to reflect on their journey, seeing their competence and resiliency. Child life specialists are professional, psychosocial companions with families on their journeys, well prepared to support families in reaching this goal.

REFERENCES


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Child life work naturally includes frequent exposure to the pain and anxiety of vulnerable populations, and child life specialists may experience emotional strain, compassion fatigue, or even professional burnout. One resource that may benefit child life professionals is Trauma Stewardship: An Everyday Guide to Caring for Self While Caring for Others. “Trauma stewardship” is an innovative framework for understanding and addressing the self-care needs of those in helping professions (van Dernoot Lipsky & Burk, 2009). The authors illustrate this concept with real-life examples from a wide variety of fields and identify warning signs of “trauma exposure response,” the authors’ term for how helping professionals may be negatively impacted by their work. The book concludes with directions for creating an individualized path to trauma stewardship. This resource is appropriate for child life specialists seeking a personal guide that encourages self-reflection rather than an academic text or a structured workbook focused on professional development.

The book is organized into four parts. The introduction and part one lay the groundwork for understanding the concept of trauma stewardship. The primary author, Laura van Dernoot Lipsky, developed the concept of trauma stewardship following years of work as an emergency room social worker, community organizer, and advocate for victims of abuse. Van Dernoot Lipsky frequently shares examples from her work and private life to demonstrate specific points. Most chapters also include one or two profiles of professionals from diverse fields, such as law enforcement, health care, ecology, and education, who describe how exposure to trauma has impacted their lives and their work. Unlike other resources that may be aimed at a specific professional audience, the authors state that trauma stewardship is for “anyone who interacts with the suffering, pain, and crisis of others” (p. 11), which aptly characterizes the child life profession.

Part two in the book details sixteen warning signs of “trauma exposure response.” In the child life field, this phenomenon may be more commonly known as compassion fatigue or burnout (Gottlieb, Hennessy, & Squires, 2004). A section is devoted to each sign of trauma exposure response, some of which include feeling helpless and hopeless, hypervigilance, diminished creativity, deliberate avoidance, and chronic exhaustion. Each section begins with a quote from a professional that illustrates the behavior or belief. The authors then provide a description that normalizes each of the 16 responses to trauma and highlights potential negative consequences for the individual or the population they serve. Child life specialists seeking to address or prevent professional burnout will likely find validation in the examples provided.

The authors acknowledge that any trauma exposure response begins as a strategy for coping. For instance, minimizing often occurs after witnessing significant trauma or repeated exposure to the suffering of others. Less extreme experiences begin to feel less real or important in comparison, and professionals feel frustration or struggle to show empathy for these seemingly “minimal” concerns. A child life specialist who has supported multiple patients and families through bereavement may notice feeling impatient with the child struggling with an IV start or annoyed at a friend complaining about a difficult day in the office.

The second half of the book is focused on providing a guide for professionals. Part three revisits trauma stewardship as a daily practice that requires mindfulness, self-compassion, and open inquiry into one’s intentions and decisions. Part four introduces the “Five Directions” as a tool for developing trauma stewardship in one’s life. The Five Directions concept is based on the image of a compass where each point is associated with a different focus, such as “North: Creating Space for Inquiry” and “West: Finding Balance.” The fifth direction is in the center of the compass and is appropriately associated with “A Daily Practice of Centering Myself.” An illustration of the navigational tool is provided on the inside back cover of the book as a quick reference. Chapters are devoted to each of the Five Directions and include “Try This” sections that provide specific suggestions for the reader to engage in self-reflection or practice a self-care skill.

It is important to note that this resource may not fit the needs of every reader. The framework of trauma stewardship is seated within a broad spiritual context that draws on Native American traditions, Buddhism, and ancient Chinese teachings, among others. Some readers may find this unfamiliar or uncomfortable, although the Five Directions tool could potentially be adapted to better align with an individual’s religious or cultural background. Additionally, the book is not explicitly evidence-based, and the use of different/new terminology for concepts that have previously been defined and researched seems destined to create confusion. Nonetheless, the seamless integration of personal narrative, psychological research, and spiritual wisdom makes this book engaging and accessible to many levels of readers.

As child life specialists, we recognize that building effective coping skills takes time and practice. In the same way, this resource does not provide quick or easy prescriptions for how to address specific concerns as result of trauma exposure. Instead, it encourages self-reflection, being present in the moment, and making incremental changes to create a sustainable practice of self-care. For both emerging and seasoned child life practitioners, this guidebook may be a valuable resource for relieving compassion fatigue and preventing burnout.

References

Opinions about the books reviewed in Bulletin are those of the individual reviewer, and do not reflect endorsement by the Child Life Council.
Introducing Child Life Services to a Radiation Oncology Department

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Radiation therapy can be a strange and scary experience for pediatric patients and their families. Commonly, a radiation clinic is heavily populated by adult patients and is located offsite from the children’s hospital that may be more familiar to most patients. These adult-driven clinics often lack the child life services imperative to children’s mastery of their own treatment, resulting in frequent use of sedation. Through child life preparation and treatment support, patients can be empowered to complete their treatment without sedation, resulting in safer treatments, less cost, and more satisfied families and staff. Similar clinics to radiation have implemented child life services and reduced their need for sedation by 44.9% (Khan et al., 2007). To address the specific needs of children and their families in the radiation oncology clinic, child life was introduced to the University of Michigan Radiation Oncology Department in 2011 with the goals of providing treatment preparation, reducing sedation, increasing patient safety, accelerating clinic flow, and reducing costs.

Prior to child life’s introduction to the University of Michigan Radiation Oncology Clinic, almost 40% of pediatric patients were sedated each day of treatment, for up to 30 sessions over six weeks. These patients were at risk of general anesthesia side effects and complications such as nausea, vomiting, dry mouth, sore throat, heart attack, and stroke (Mayo Clinic Health Letter, 2005). Along with health risks, pediatric patients using anesthesia each day for treatment required more time in the treatment room and more medical staff time during treatment than a patient not being sedated, and incurred an average additional cost of $45,000 for six weeks of anesthesia medications. In addition, a child receiving anesthesia each day required either a port access, a broviac catheter, or an IV, resulting in at least 30 additional venipunctures to administer the anesthesia medication for a child receiving daily treatment.

Initially, child life specialists from various units of C.S. Mott Children’s Hospital attempted to cover pediatric patients scheduled for radiation treatment. However, due to a lack of child life specialists’ availability, child life support was sporadic and depended on back fill coverage of specialists’ home units. With inconsistent child life support, 36.67% of pediatric patients were still being sedated daily.

A pilot child life specialist position was created in February 2011 when a multidisciplinary team combined of radiation oncology administrators, child life specialists, nurses, anesthesiologists, and radiation therapists acknowledged the need for child life support. The multidisciplinary team’s goals were to increase patient preparation and coping, resulting in less anesthesia use, safer treatments, and higher satisfaction rates from families and staff.

Prior to the start of the pilot, this team met monthly to discuss the logistics of a child life specialist position, including funding options, and decided that the radiation oncology and child and family life departments would equally share the costs of the child life position during the pilot period. The pilot was funded for six months and included one full time child life specialist position. Further goals of the pilot included: 100% of pediatric patients being seen by child life throughout each step of radiation; improved patient, family, and staff satisfaction; process flow improvement; reduction of sedation; and an increase of patient and family preparation before treatment. To meet these goals, coverage was provided from available child life specialists at C.S. Mott Children’s Hospital if the radiation oncology child life specialist was absent.

During the pilot, child life recorded daily statistics including patient interactions, coping techniques, and time spent with patients. The child life specialist shared patient interaction statistics, anesthesia rate statistics, staff and patient feedback, and benchmarking results with radiation oncology and child life leadership at monthly meetings throughout the pilot.

Because children who are psychologically prepared for medical procedures will often recover faster with less emotional stress (McGee, 2003), a child life specialist initiated preparation for each pediatric patient at time of radiation consult, radiation simulation, and each day thereafter for radiation treatment. To decrease fear and promote normalcy, the radiation masks worn by patients with head, neck, or brain tumors to restrict movement during treatment were often referred to as “Spiderman” masks. A child life specialist would walk children through the mask-making process and allow them to make a miniature mask on their finger or a medical play doll.

Patients were also able to view other pediatric patients completing their radiation by viewing videos made by child life and patients. These videos included step-by-step examples of patients’ radiation experiences and descriptions of radiation provided by pediatric patients. Children were also able to decorate and paint their masks as they wished at the completion of their radiation treatments and ring the radiation oncology “Victor’s Bell” to honor the completion of their radiation journey.
Once treatment began, coping strategies and relaxation techniques such as music, books, and play were implemented. iPods were placed in each treatment room with various genres of music and audiobooks for patients to select, since music is a valued tool that calms and decreases muscle tension in the body (Sulan, 2011). Music therapy was also consulted for further support prior to treatment. In addition, a child life specialist was able to read to patients from the control room during radiation treatment, as reading has also been found to provide distraction during stressful times (Sulan, 2011).

Throughout the pilot, sedation rates decreased from 36.67% to 4.76% for patients under the age of 18 (see Figure 1). This resulted in families saving the cost of anesthesia medications and reducing their time at the hospital each day by hours. Anesthesia side effects and risks were also eliminated for these patients.

To further evaluate the success of the pilot, child life satisfaction surveys were distributed to radiation oncology families and staff. Families received their surveys as their child finished treatment, completed them anonymously, and turned them in to the clinic desk. Selected family survey results are presented in Table 1. One parent shared, “It was very helpful to have someone act as liaison in the radiation oncology department. Having the toys and activities to look forward to took some of the anxiety out of the experience for us and our daughter. Child life’s presence certainly helped us avoid the use of anesthesia.” Another parent shared, “Child life played a huge part in making my son comfortable. He would look for child life every day.”

Staff surveys were offered prior to the pilot, half way through the pilot, and during the last month of the pilot. These surveys were collected anonymously following radiation therapist’s staff meetings. Selected results of the final staff survey are presented in Table 2. One radiation therapist reported, “Child life helps me accomplish my job more efficiently, due to less anxious patients and parents.” Another radiation therapist stated, “Child life sets a calming atmosphere that has greatly reduced the amount of anxiety felt by the patient and their family.” Within five months of launching the pilot, child life was completely immersed in the clinic and had become an essential service within radiation oncology, and a permanent full time child life specialist position was established and fully funded by the department of radiation oncology. Sedation rates have continued to decrease since the child life specialist position was approved. In 2015, only three children required sedation for treatment. Dr. Theodore Lawrence, Director of the University of Michigan Comprehensive Cancer Center and Chair of the Department of Radiation Oncology stated, “The child life position has been a wonderful addition to our department. In addition to happier patients and families, our need for anesthesia for all but the youngest children has decreased dramatically.”

### References


### Table 1. Family Survey Results (N=40)

<table>
<thead>
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<th>Statement</th>
<th>Percentage of Caregivers Strongly Agreeing</th>
<th>Percentage of Caregivers Agreeing</th>
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<td>Child life helped reduce the length of time of the procedure or exam</td>
<td>100%</td>
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<td>Child life assisted in putting child at ease during radiation treatment</td>
<td>94%</td>
<td>6%</td>
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<tr>
<td>Child life helped increase patient and family understanding of treatment</td>
<td>93%</td>
<td>6%</td>
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### Table 2. Staff Survey Results (N=49)

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<th>Percentage of Caregivers Agreeing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child life helped reduce the length of time of procedure/exam/treatment/scan</td>
<td>78%</td>
<td>21%</td>
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<td>Child life increased patient compliance of procedure/exam/treatment/scan</td>
<td>93%</td>
<td>7%</td>
</tr>
<tr>
<td>Child life helped with the reduction of anxiety of pediatric patients</td>
<td>93%</td>
<td>7%</td>
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Distinguished Service Award

continued from page 1

at the time, an innovation in transition planning and support for young patients and families preparing for the move to adult care. Developed with nursing and physician colleagues, this program continues to grow and thrive today. A few years later, Diane had the chance to take a one-year leave of absence from the child life department to work in the BCCH Foundation as a fundraising manager, a position that gave Diane the opportunity to make valuable connections and strong relationships with the foundation and its donors. Upon her return to the child life department to resume her role as site supervisor, Diane expanded the music therapy program, developed a child life creative arts program, implemented a trial of child life services in the outpatient lab, and secured additional support for inpatient child life services.

Her path to her current position as director of patient- and family-centered care has made multiple impacts and positive change for the children, families, and staff at BCCH. She designed, implemented, and evaluated a child life fellowship in radiology and the surgical program at BCCH. When funding from the initial fellowship grant ended, Diane was able to secure additional funding to keep the program running. Letters of support for Diane have poured in to the CLC awards committee representing colleagues in nursing, medicine, child life, and executive administration. The letters all speak to Diane’s commitment, poise, warmth, professional attitude, integrity, leadership, and passion for family centered care.

Outside of the impressive array of projects she has led and leadership positions she has held at BCCH, Diane has and continues to play an active role in both the Canadian Association of Child Life Leaders (CACLL) and the Child Life Council. She has held the position of president in both associations—an accomplishment only a select few in the child life field have attained, and a career highlight for Diane. She has been involved as a member of several different committees and working groups for both organizations. Diane has served on the CLC Board of Directors for seven years in various positions, has chaired the Nominating Committee, Past Presidents Advisory Group, Leadership Development Committee, Conference Planning Committee, and currently chairs the Bylaws Subcommittee. The opportunity to be chair of the CLC Conference Planning Committee early in her career was particularly impactful as she credits the experience as a real cornerstone that led to the introduction of many influential, life-long colleagues and friends, and to a range of volunteer experiences relevant to the child life profession that followed.

In 2006, Diane completed her Master’s of Art in Leadership and Training to add to her impressive resume. Her role as a leader, mentor, and teacher involves strengthening ties between BCCH and the community at large. Diane has been instrumental in developing a child life internship program that links outlying general hospitals with paediatric units to BCCH and local universities offering child life internships, ensuring a well-rounded clinical training experience. Her role as a member of the Partners in Care Parent Advisory Committee over the years resulted in the Award of Distinction given to Diane in 2013—a high honour bestowed upon BCCH staff who go above and beyond in their advocacy and support of family centered care. Diane has particularly valued the ability to participate in the CLC program development and review service, utilizing her years of experience to offer suggestions and recommendations to help other programs succeed.

Diane’s advice for future leaders of the child life profession is to “take advantage of opportunities as they come up, appreciate them, and run with them!” Although the timing of opportunities has not always been ideal, she never turned away from them, no matter how scary or overwhelming they seemed, and found these experiences to be career-changing. In particular, Diane encourages child life specialists to get involved with CLC and their local organizations. She believes that, as a profession, we have one of the most engaged memberships of any professional association, and involvement of professionals at various levels really helps to keep our profession strong because “front line child life staff represent the job and our field on a daily basis to patients, families, and other health care professionals”.

Looking back on the last 28 years of her career, Diane’s most rewarding highlights include the creation of the child life fellowship program at BCCH, and most recently, the BCCH site re-development project, where the child life team has been fully involved, ensuring that patients and families are engaged and included in the

Letters of support for Diane have poured in to the CLC awards committee representing colleagues in nursing, medicine, child life, and executive administration. The letters all speak to Diane’s commitment, poise, warmth, professional attitude, integrity, leadership, and passion for family centered care.

Distinguished Service Award

Since 1988, the Child Life Council has honored the child life profession’s outstanding leaders and pioneers with the Distinguished Service Award. This award recognizes exceptional members, not only for their outstanding contributions to the field of child life, but also for their professional experience, leadership, integrity, and vision. Award recipients are nominated by members of the CLC Awards Committee in July, and nominations are typically reviewed and approved by the CLC Board of Directors in November. To suggest a child life leader who meets the aforementioned criteria for consideration, please contact an Awards Committee member at awards@childlife.org. To read about previous recipients of the Distinguished Service Award, please visit the CLC website.
Pathways to EBP
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**Student Programming**

*Implemented:* Student programming is a large component of the child life department. The Student Programming Committee wove EBP into multiple facets of the existing student program as well as identifying new opportunities for growth. Students already had several assignments which incorporated EBP, including an internship project, diagnosis presentation, and case studies. Students were asked to highlight and speak to EBP in these assignments and presentations. Additionally, a small group session on EBP was added to the daily student group schedule. In this session, a child life specialist discusses the importance of the research behind the interventions as well as ways to incorporate and articulate EBP into routine interactions with other clinicians. Students are also required to complete several reviews of journal articles. Student group teachers are routinely required to update literature used in each student group.

*Next Step:* In the coming year, student supervisors will be asked to incorporate EBP into their teaching of child life roles and responsibilities. For example, when modeling trauma debriefing with a patient, the child life specialist will be asked to provide or point a student to the literature in support of the intervention.

As we begin 2016, the impact of the initiatives is already becoming apparent. Staff report increased levels of comfort and a better understanding of how to use EBP in daily practice. With each exposure from various presentations and learning opportunities, staff have become accustomed to incorporating EBP into their own presentations and updating their own personal knowledge base. From the seasoned child life specialist to the new graduate, everyone has benefitted from this initiative. ☕

Interested in learning more about evidence-based practice (EBP)? Explore previous articles in the Pathways to EBP series on the Evidence-Based Practice Committee’s blog.

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decision making process. Diane’s qualification in Evidence-Based Design Accreditation and Certification (EDAC), in conjunction with her knowledge of family-centered care, give her involvement in the re-development project an added impact. In achieving the EDAC certification, Diane demonstrates her commitment to continue learning and growing as a leader, building on her knowledge base along the way, and staying informed about best practices in a variety of areas, both within and outside of the child life profession.

Diane’s colleagues and friends describe her as having a wry sense of humour, and note that she generously shares her joy of travel, is a fabulous and fun event planner, and wears a different seasonal outfit for every day of December! She is confident enough to allow herself to be herself, and people are drawn to her. She is a natural speaker and advocate, using these skills every day in support of child life and the CLC, and supporting those qualities in others around her. Diane’s drive and ambition extend to her personal life as well. Diane is currently training for her 10th half-marathon! Balancing her work with a fulfilling personal life also includes an interest in photography, a love of reading, and a passion for traveling. Diane is a shining star and being bestowed with the Distinguished Service Award will provide her with the recognition she deserves for all that she has done in contributing to the successes of the child life profession, BCCH, her community, and her colleagues.

Please join us in celebrating Diane’s achievements at the Distinguished Service Award Presentation, which will take place on Friday, May 20, during the Opening Session of the 34th Annual Conference on Professional Issues in Orlando, Florida. 🌟
"E" is for Essential Oils

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as sweet almond, jojoba, or olive oil, for promoting comfort, relaxation, relief from colic, and reduced distress. Using EOs may enhance the effect of infant massage and may also promote emotional bonding for infants and caregivers since the sense of smell is directly connected to the same area of the brain that processes emotions (Edge, 2003; O’Flaherty, Van Dijk, Albertyn, Millar, & Rode, 2012; Raybern, 2014; Stewart, 2013).

Aromatherapy and the practice of using EOs has recently expanded into a diverse array of professional fields concerned with health and well-being, including the field of child life. For example, in a previous issue of Child Life Focus, one study discussed the use of bubbles infused with lavender, Roman chamomile and Ylang Ylang oils in a pre-operative area for distraction and anxiety relief (Schuler & Hedayat, 2014). In this study, each participating patient was prepared for surgery by a child life specialist. After preparation, half of the participants were given oil-infused bubbles and the other half were given unscented bubbles. Although this study did not find that infusing bubbles with scented oil for pre-surgery preparation made a significant difference in anxiety levels compared to non-scented bubbles (Schuler & Hedayat, 2014), research from other medical disciplines has shown that while EOs may not always demonstrate significant difference in coping (Ndao et al., 2012), they can still have calming effects in medical contexts (Edge, 2003; O’Flaherty et al., 2012).

With the increasing interest in including EOs in child life practice, an important consideration is the quality of the selected EO. Using a therapeutic grade, or complete high quality oil, increases therapeutic benefits regarding the optimal well-being of the whole child and may hold promise for helping children and families cope in a variety of ways beyond pre-surgical preparation (Buckle, 2002; Bakkali, Averbeck, Averbeck, & Idaomar, 2008; Raybern, 2014; Stewart, 2014). Furthermore, pure therapeutic grade EOs are hypoallergenic, antiviral, antifungal, and antibacterial (Bakkali, et al., 2008; Buckle, 2002) and have never been documented as causing negative side effects. Caution should be taken in evaluating commercially available aromatherapy products, as the scents they contain may not be good quality EOs. While such tools may be effective for simple aromatherapy usage, unless you can fill the device with your own oils, there isn’t a way of controlling the quality of oil used.

In seeking therapeutic and healing results, the oil’s chemical make-up should be as pure as possible (Bakkali, et al., 2008; Stewart, 2013). Many oils distributed for use in food, cosmetics, soaps, and aromatherapy are not therapeutic grade and often contain synthetic compounds that can be harmful with extensive use or, simply not as effective. Multiple studies have demonstrated EOs are more effective as complete oils rather than as separated compounds or synthetically altered oils (Bakkali et al., 2008). However, the FDA only requires that 5% of the original plant compound exist in oil labeled as 100% pure, increasing the importance of knowing the difference in oil quality (Bakkali, et al., 2008; Buckle, 2002; Stewart, 2013).

In light of the wide array of impacts that EOs can have, there are several possible applications for child life. Because it is typical for children to experience emotional and behavioral reactions to hospitalization and medical procedures (Crowley et al., 2011; Thompson & Stanford, 1981), utilizing EOs as a part of coping and stress-relieving strategies may not only be effective, but may also contribute to greater healing and more positive mood in patients (Buckle, 2002; Edge, 2003; Itai et al., 2000). While topical application may also be a potential option for alleviating anxiety, increasing emotional well-being, and pain management, child life specialists should understand the uses and effects of EOs and consult with medical professionals, parents, and patients before using EOs topically. For families and patients interested and seeking options for pain management, coping, anxiety relief, stress relief, and working through potentially traumatic experiences, it may be of particular interest for child life specialists to be knowledgeable about and able to offer resources about EOs. Gentle Babies by Raybern (2014) is an easy read and would definitely be a good resource to educate families, while Essential Oils Desk Reference by Essential Science Publishing (2009) is large and more extensive, geared towards someone who is committed to a deeper knowledge and wider use of EOs. In addition, for child life specialists interested in furthering their education about EOs, training is available on the history, chemistry, application, and therapeutic uses of aromatherapy. Certification in the use of these techniques is possible with more extensive study.

Adding EOs into the child life tool kit offers broader creativity for addressing sensory information, an important aspect of child life practice. Fear associated with new surroundings, hospital settings, and even the unfamiliar or unpleasant smells of the hospital could potentially be alleviated by diffusing a calming or familiar scent of EO in a patient’s room. Exposure to familiar scents has been shown to alleviate symptoms of distress in infants and may also be effective for older children. (Kim et al, 2011; Sadathosseini et al., 2013). Diffusing EOs in a safe environment such as the playroom could be a helpful strategy for children to associate a pleasant scent with positive, safe feelings, thus increasing the benefits of using that scent with a child for calming and anxiety-relieving purposes outside of the playroom. Since the goal of child life practice is to promote optimal development and well-being of the whole child (Child Life Council, 2002), EOs can contribute to the emotional and pain management support that child life specialists often provide. There are great potential benefits when incorporating EOs into child life practice as safe, non-pharmalogical tools for sensory stimulation and...
coping, but there are many considerations to make before utilizing them with children and families.

**References**


Kim, S., Kim, H., Yeo, J., Hong, S., Lee, J., & Jeon, Y. (2011). The effect of lavender oil on stress, coping, but there are many considerations to make before utilizing them with children and families.


Upcoming CLC Webinars

CLC members have consistently requested frequent webinars on a wide variety of topics, and the Webinar Advisory Group is planning a full schedule of presentations throughout the year. For details of each session and to register for a webinar, see the webinar page on the CLC website. Check back often, as the schedule will be updated as new sessions are added!

Unless otherwise noted, CLC 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 On-Demand webinars are now available! See the CLC website for details.

**Tuesday, April 5** — Empowering the Voices of Siblings: Supporting Brothers and Sisters at End of Life

**April 6** — A Preparation Kit for Student Selection: Practices to Improve the Process

**April 13** — Understanding Self-Regulation in Children: Strategies to Support Children’s Return to Calm

**April 20** — Child Life in the Inner City: Empowering Children and Families in Social, Physical, and Economic Conflict

**Tuesday, April 26** — Public Policy 101: From Problem Identification to Policy Evaluation ***This is a Free Webinar Offered by the Public Policy Committee***

**April 27** — Putting the Why in What We Do: Making Evidence-Based Practice (EBP) More Accessible in Student Programming

**May 4** — When Medical Errors Happen in Pediatrics: Do Child Life Specialists Have a Role?
Home Hospice

Continued from page 6

may seem impossible. While some may view play as the physical act of playing a game, throwing a ball, running, jumping, and laughing, when a child is dying we have to think of play in broader terms, as activities that bring the child joy. With one patient, watching her favorite cooking show while getting her feet rubbed brought her joy. For other children, going outside to ride bikes might make them feel joyful; being read to, listening to music, or even watching others play can bring joy. Play in the home setting can take different forms based on who is home at the time or the child’s energy level. I meet children where they are, whether it is the act of simply being with a resting child, or the act of engaging in physical play.

Play in the home setting also allows the opportunity to engage siblings, family members, and friends. In some situations, I work with the siblings and provide them with a safe space to ask questions, discuss their feelings, process information, and interact with their sick brother or sister. Other times, I may focus my visit on the patient only, which can also allow the opportunity for the parents to engage, or can allow parents to have that time to themselves, which they rarely have at this stage of their child’s care.

When a child is dying in the home, the family can feel overwhelmed and they often view my role as helping children to delve deeper into their feelings about death and dying. However, as we know, a trusting relationship must be built before this is feasible, and often this rapport is built through play. When a child is in hospice care, I sometimes have months to develop a trusting relationship, and other times I have days or weeks. Sometimes, a child or adolescent may decline child life services, and validating their feelings about this decision can be the first step in rapport building. In other situations, I may be working months with a patient and we may not ever reach the point of talking about deep feelings before a child dies. Meeting the children where they are is a practice all child life specialists know, but at the end of life this can take many different forms. When I am providing services, I always strive to provide them with joy and happiness at the end of life, which I view as the best and most important service to provide.

Preparation

In a traditional child life setting, preparation generally means preparing a child for a medical event (IV start, surgery, hospitalization, discharge, etc.). We use child friendly terminology, medical play, and role reversal to teach the child about what is going to happen to them and offer them some control and mastery over their experiences. In the hospice setting, however, preparation looks a little different, as I am preparing patients and families for what to expect at the end of life and after the death.

Siblings

An important part of my role in hospice is working with the siblings of pediatric patients and preparing them for the next few months and years. Questions that generally come up include: Can my brother or sister still play with me? Will I still be a brother or sister after my sibling dies? What will our family do after he/she dies? How will I know when my sibling is actually dying, what will he/she look like? What if I am the one who is with him/her when he/she dies? What is a funeral? Where will his/her body go? The preparation skills I’ve learned as child life specialist help me work through these questions with the siblings. Educating the siblings about what death may look like, providing opportunities to be involved in the decision making for services, and possibly even touring the funeral home are all opportunities to prepare a sibling. When I am able to openly prepare siblings for a death, I am able to discuss their choices, such as whether they want to be in the home when their sibling dies or when their body is removed, or whether they want to attend the funeral or have a special role in the funeral. Often, I find that the children already have the answers; they just need someone they can trust to openly talk about what they think will happen, and that is where child life can help.

Legacy Projects

In some cases, when working with pediatric patients at the end of life, preparation can take the form of legacy projects. Creating photo slideshows, making blankets out of their favorite t-shirts, writing letters to their loved ones, and taking special trips can all be ways that we help children prepare to die. Some children may be able to discuss their own legacy and how they want to be remembered. For example, one teenager I worked with was able to tell her parents that after she dies, she needed to know that they would get out of bed. After this teenager died, her parents let me know that on the days when they thought it would be impossible to get out of bed, they heard their daughter’s voice telling them they had to face the day. This patient was preparing her own family for life after her death. Providing opportunities to speak openly and honestly about the choices patients and siblings have at the end of life helps to empower the children and provides them with choices at a time when there are not many choices left. However, the opportunity to utilize preparation skills does not always exist in the hospice setting. A family must be open and honest about the dying process before a child life specialist can speak openly with the patient or siblings. When the words “dying,” “hospice,” and “end of life” are not openly discussed in the home, it is important to respect the family’s wishes and utilize other important child life skills in order to have a positive impact at end of life.

People often ask me “How do you do your job?” or “Why would you want to do that?” While people always have questioned how I could work with sick kids, when I now tell them that I work with dying kids, their reaction is even stronger and most often a conversation stopper. However, if I can be that person who puts a smile on a child’s face, whether they are in the hospital undergoing a procedure or dying at home, that is all that matters. Being a child life specialist in the hospice setting allows me to help make this unimaginable time just a bit more joyful and make the end a little bit easier. That, I tell people, is why I chose child life and why I love this work.

When a child is dying in the home, the family can feel overwhelmed and they often view my role as helping children to delve deeper into their feelings about death and dying.
Public Policy

Continued from page 11

populations. As professionals, child life specialists are ethically bound to use beneficence to help the populations that they serve. We all have a vision of what a better society should look like as we aim to be more effective policy advocates.

Another useful resource is a journal article highlighting the importance of incorporating evidence-based practice into public policy (Crane & Winsler, 2008). Crane and Winsler explore the history of legislation related to mental and physical disabilities and how public policy has shaped the care these children receive. This article also delves into the steps that need to be taken in the future to ensure the appropriate diagnosis and treatment for the best possible outcomes. This is a great example of how, over the years, public policy advocacy has helped to shape and change the way we diagnose, treat, and care for children with autism.

An important point to consider when getting involved with public policy is your employer’s guidelines on speaking out on behalf of outside causes. In many cases you will be required to simply be a motivated “private citizen” and not declare your hospital affiliation. Depending on the issue, you may want to consider finding others within your facility who share your passion and who might help generate enough support for your hospital to get involved directly. For example, at Kosair Children’s Hospital in Louisville, KY, a group of medical staff were concerned because they saw an increase in the number of children being admitted to the hospital for child abuse, so they came together to form the Child Abuse Task Force. This multi-disciplinary team is made up of physicians, nurses, child life specialists, and social workers from Kosair Children’s Hospital as well as other hospital staff within the region; the group focuses on research and prevention of non-accidental trauma. A key result has been more public awareness throughout Kentucky of this horrific problem that is 100 percent preventable.

We hope that the resources presented will broaden your understanding of public policy as it relates to children and health care. It can seem overwhelming at times, but there are many ways to learn more, to do more, and to get involved. The Child Life Council’s Public Policy Work Group has a blog that provides examples of advocacy work that has been done by child life professionals across the country. Please feel free to contact the Public Policy Task Force (communityadmin@childlife.org) for more information or to get involved.

References

From the Executive Editor

Continued from page 3

of vulnerability to talk to each other about it. Familial roles and responsibilities were changed. My dad became father and mother at the same time, and I found myself subtly and overtly taking on mothering roles for my brothers. Routines were shifted as well. Christmas didn’t happen until January that year, in a rehabilitation hospital where we were tightly huddled inside of a blue hospital curtain with Mom, who was now awake, alert, and alive.

The one certainty in life is that change will happen, and with change often comes stress – whether productive and useful stress, or the kind that is challenging and uncomfortable. Sometimes those changes rock our personal and professional lives to the core, much like the tsunami that greatly impacted the Kythe Foundation’s child life programs in the Philippines featured in this issue’s Global Perspectives column. Sometimes the stress itself is generated by overlapping responsibilities at home and in the workplace, or as Katie Beard shows us in her piece, “Work/Life Unbalanced,” when our home life and work life converge through familial injury or illness. In those times the distinction between life and work becomes blurred and overlapping, challenging coping resources on both fronts. Another constant is that stressors will require coping efforts, but these too can be as diverse as the conditions that elicit stress in our lifetimes.

As child life specialists, we know both that change is stressful and stress is life-changing; as it alters our developmental course and coping security, we learn new things about ourselves, our families, and our abilities to interact with and manage the demands of our world. As Cara Sisk reminds us in this issue’s Focus article, familial stress is a multifaceted concept that has been heavily studied and clearly theorized in an operational and useful way – the Double ABCx model. In times when we are walking with families through some of the most devastating conditions that one can humanly imagine, we must remind ourselves to think with theory, to return to the foundations of our field, and to employ evidence-based models and interventions to ensure that we are providing the most comprehensive and beneficial child life services. To understand and promote coping, we must delve deeper into understanding stress and those who are most at risk for experiencing its detrimental or longstanding effects. This is not only our work as child life specialists, but as members of our families, workplaces, and communities.
such as immunizations, blood draws, IV starts, and finger sticks for children age two to twenty one.

A seven-question survey (See page 28) was developed for completion by patients and/or parents. IRB approval was obtained, and guidance provided by the nursing research department. Over the course of one year, 50 surveys were completed by patients and/or their parents. Surveys were distributed by child life students and research volunteers. Not all families agreed to use Buzzy™ or complete a survey.

**Results**

Fifty patients, and/or their parents, in the ambulatory pediatric setting agreed to use Buzzy™ for a potentially painful or anxiety provoking procedure. The patients and/or their parents then completed an anonymous survey. The patients’ mean age was 8.08 years (SD=5.788, range 0-20); gender distribution was 48% female and 52% male. Most participants used Buzzy™ for immunizations (see Table 5.788, range 0-20); gender distribution was 48% female and 52% male. Most participants used Buzzy™ at MetroHealth system, as well as provide data for the implementation of new standards of procedure for pediatric pain management. One limitation of this study is that the sample size was small. A larger trial across other ambulatory settings such as dermatology, dentistry, and surgery as well as inpatient pediatric units would provide both a larger and more diverse sample. In future studies, researchers could look into whether parent satisfaction improved and children’s anxiety decreased with use of Buzzy™.

This project outcome did aid in the continued use of Buzzy™ as one tool to help minimize psychological and physical distress experienced by children and their families. The Atraumatic Care Committee continues to educate and promote the use of Buzzy™ throughout the health care system.

**References**


The Abstract Selection Process – Not So Abstract After All

Catherine Leung, CCLS
BC Children’s Hospital, Vancouver, BC, Canada
Member, CLC Conference Program Committee

The Child Life Council’s Annual Conference on Professional Issues is, by all accounts, an event; the receptions, exhibits, and local hospitality create a hub of excitement and inspiration among the attendees. The cornerstone of the conference, however, is professional development. The conference is highly anticipated for its professional development capacity in its intensives, workshops, keynotes, plenaries, posters, and the new “Innovation, Imagination, and Inspiration” talks – this year, totalling 71 sessions.

The CLC Conference Program Committee is responsible for selecting the sessions for presentation and building a conference program that is diverse, innovative, and in line with current issues in child life practice. This year, the committee reviewed 152 abstracts. So, how are they selected? If you have ever wondered about the journey of an abstract from online submission to conference program, here is an explanation of the process. Spoiler alert: it’s not so abstract after all!

The abstract review process takes place in three rounds.

In round one, abstracts are divided amongst the reviewers, made up of committee members and adjunct reviewers. Each abstract is independently scored by five reviewers in a blind review – that is, the author’s name(s) and identifying information are concealed from the reviewer. The abstracts are scored on a 5-point scale. Reviewers score each subsection of the abstract according to the quality of the content and its alignment with the requirements of the official call for abstracts. The overall organization of the abstract and the quality of writing are also scored on the same scale. Scores are tallied and abstracts are divided into three groups. Abstracts that score in the top third are automatically accepted. Abstracts scoring in the bottom third are declined. Abstracts in the mid score range move on to round two.

In round two, each abstract in the mid score range is reviewed a second time, blindly and independently, by three committee members. Reviewers label these abstracts “accept” or “decline”. Unanimous reviews result in acceptance or decline. Abstracts that receive mixed reviews proceed to round three.

Round three abstracts are reviewed and rated as accepted or declined by each committee member. Ratings are shared and discussed; final decisions are made by committee consensus.

The committee places the accepted abstracts in a draft schedule, which is submitted to CLC headquarters. The CLC staff then notifies all authors about the success of their abstracts.

Year after year, the CLC Conference Program Committee has the privilege to read about many trail-blazing projects and thoughtful insights expressed in the conference abstracts. We invite you to share yours at the 2017 CLC Annual Conference on Professional Issues in Las Vegas. Please take a look at the 2017 Call for Abstracts on the CLC website for more information.

CEO Shares
continued from page 4

- Add an optional tour to your itinerary: Arnold Palmer Hospital for Children, Nemours Children's Hospital, and Florida Hospital for Children will all host tours for conference attendees. In addition, Give Kids The World Village will offer an inside look at the 79-acre nonprofit “storybook” resort for children with life-threatening illnesses and their families.
- The weekend will wrap up at the Closing General Session, where Amy Kennedy, CCLS will be presented with the Mary Barkey Clinical Excellence Award, recognizing her exemplary child life skills. Finally, Bob Kodzis, President and Chief Creative Catalyst at Flight of Ideas, Inc. will inspire and entertain us with Ready for Anything, an insightful and funny look at what it takes to be ready for whatever the world throws our way.
- Extend the fun by taking advantage of a special offer we have arranged on Disney park tickets for conference attendees, friends, and family travelling with you – including pre- or post-conference stays. These tickets are only available for purchase until Sunday, May 15 at 9 pm EST and will not be available on-site at conference. Click here to learn more or to purchase Disney park tickets.

Planning for conference takes nearly two years! We hope you’ll join us in Orlando for the CLC 34th Annual Conference on Professional Issues.

Fun Facts About CLC’s Annual Conference

- CLC’s Conference is the largest gathering of child life specialists in one place—more than 1000 people are expected to attend!
- More than 76% of attendees are child life specialists, about 14% are administrators, and nearly 7% are educators and students.
- Attendee satisfaction is exceptionally high – 98% of last year’s attendees would recommend the conference to other child life professionals.
- The conference is truly an international event—last year, 10 countries were represented among attendees.
- Twenty-five different cities have hosted the conference.
- The first independent CLC conference was held in Chicago in 1983 and 125 people attended.
- This year, CLC will host between 50 and 70 exhibitors in the exhibit hall.
- Attendee satisfaction is exceptionally high — 98% of last year’s attendees would recommend the conference to other child life professionals.
Does anyone recognize this photo? One of the benefits of the CLC Archives is that there are many interesting reminders of where we have been and what we were up to! Many of our members probably do not remember “the old days” when the Child Life Council was just another booth in the Association for the Care of Children’s Health (ACCH) interdisciplinary conference. Nowadays, in addition to learning from the conference sessions, we have some delicious hors d’oeuvres, a glass of wine, and meander through the exhibit hall greeting friends and collecting handouts. But then there was work to be done—we had to get the word out about what child life was and what we could accomplish if we all worked together! In the oral transcripts of interviews with many of our colleagues, Linda Skinner has a wonderful quote about the struggles we faced as a young organization: “I think that’s what’s made us really strong and really committed and really fiery old ladies—because we really have had to struggle a lot!”

In the early days of the Child Life Council, members staffed a booth at an ACCH Conference in the late 1970s in the hopes of spreading the word about child life.

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**CLC Calendar**

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<tr>
<th>May</th>
<th>19-22</th>
<th>34th Annual Conference on Professional Issues in Orlando, FL</th>
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<tr>
<td>July</td>
<td>1</td>
<td>Submission deadline for Bulletin and Focus articles for consideration for the Fall 2016 issue</td>
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<td>1-15</td>
<td>Abstract submission for 2017 35th Annual Conference on Professional Issues in Las Vegas, NV</td>
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<tr>
<td>August</td>
<td>8</td>
<td>Initial Mary Barkey Clinical Excellence Award nominations due</td>
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<td>10</td>
<td>Deadline to apply for the August administration of Child Life Professional Certification Exam</td>
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<td>15-30</td>
<td>Child Life Professional Certification Exam Administration Testing Window</td>
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<td>September</td>
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<td>Supporting documentation for Mary Barkey Clinical Excellence Award nominations due</td>
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<td>October</td>
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<td>Submission deadline for Bulletin and Focus articles for consideration for the Winter 2017 issue</td>
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<td>27</td>
<td>Deadline to apply for the November administration of Child Life Professional Certification Exam</td>
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<td>31</td>
<td>Deadline to apply to recertify through PDUs</td>
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