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ASSOCIATION OF Child Life **Professionals**













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Life Lessons

sually, at this point in the development of an issue of *ACLP Bulletin*, I am reading through the upcoming content, looking for ideas or inspiration for my next Executive Editor column. This issue is different. The articles are the same excellent quality and offer many discussable ideas. The ACLP announcements are, as usual, exciting and hopeful. The work with the editorial team, the committee, and the authors continues to be extremely fulfilling. What is different, at this point in time, is me!

A few weeks ago, my sister, Marjorie, died suddenly and unexpectedly. I found her in her shower in the afternoon, after calling and texting her several times during the day. She was healthy and we still do not know the cause of death. Marjorie was my best friend and soul mate, ever since we were children. We lived in separate houses on the same property, traveled and vacationed with one another, shared goals and dreams, and made plans for growing older together. It is a devastating loss for me.

So, what does this have to do with being a child life professional or the editor of *ACLP Bulletin*? It has become very clear to me, in an incredibly visceral manner, that our personal lives are intertwined with our professional selves in a way that is deep and beyond our simple conscious control. Here I am, a well-trained and knowledgeable child life specialist. I have provided grief support to families experiencing loss for over 50 years and have been doing acute trauma work for at least 30 of those years. And yet, all my knowledge and expertise are not modifying the pain and vulnerability that I am experiencing now and expect to experience for a significant time to come.

As clinical professionals, we are all aware of the importance of knowing oneself. In her article, "Sentence in a Patient's Book," Sydney Ehinger stresses how important it is to understand who we each are as individuals. But it goes beyond understanding oneself at any particular moment in time. True self-awareness is a composite of all our thoughts, all our feelings, and all our experiences over a lifetime. Even with all my training,

I have never understood loss like I understand it now. As I read the wonderful tribute, by Colleen Lacey and Sheila Palm, to Diane Dingley, the winner of the Mary Barkey Clinical Excellence Award, I focused in on Diane's work creating sibling programs. All I could think about was how important sibling relationships can be, how sad it is when they must end prematurely, and how lucky I am to have had a special one with my sister Marjorie. The unique article "Empowering Connections," by Anish Raj and Meagan Fitzgerald, reminds us all about the universal need to he heard. One of their final statements, "...togetherness is central to the universal human experience..." touched me deeply. On a painful note, it makes me think about the connection I shared with my sister, but on a hopeful note, I feel truly fortunate to be part of the child life community, from which so many of you have reached out to me with comfort and support.

Is there an ending, or a summary, to this column? There really cannot be, because this is about a process, not about a conclusion. All of us bring into each personal, professional, or clinical encounter the total sum of what and who we are. This process is complex and changes constantly. For me, everything I have done, said, felt or thought over the past several weeks is colored by the loss of my sister. For you, perhaps it is a marriage, or a financial crisis, or the birth of a baby, or the loss of a parent that profoundly impacts your life. I do know that along with the sadness, I feel a powerful sense of gratitude. I am incredibly grateful to the editorial team for their patience and understanding of my distraction and forgetfulness as I move along this journey of loss. I am grateful to the leadership staff at Wonders and Worries in Austin, Texas, for their sensitivity and caring. I am grateful to my friends and family for allowing me to cry whenever I needed and to talk about my sister and my memories. Finally, I am grateful to you, the readers of ACLP Bulletin, for allowing me to use this platform not only to express my grief, but also to examine it within the context of the work that we all love and chose to do. Our profession does not give us immunity from the pain and struggles that are faced by all, but it does give us a framework and an identity within which to understand, cope, and move forward past life's most difficult experiences. *



The Future is Bright!

t is hard to believe that at this time last year, the association and its members were embarking on a journey into the unknown reality of COVID-19 and grappling with the state of social unrest across our country. The past year was full of challenges and hardships but there were also moments of growth. Child life professionals throughout our community led with compassion, strength, and perseverance.

This shift, whether it was felt by a child and family in your clinical work or through effective leadership with the implementation of programmatic and strategic initiatives, it has all contributed and led us to where we are today.

A few highlights of the past year are included below.

- Annual Conference: The event's attendance reached record breaking milestones - especially the number of student participants. An impressive array of child life professionals were able to participate through the virtual platform with so many opportunities for learning and connecting.
- Racially Conscious Collaboration: Over 50 ACLP members are six months in to participating in work facilitated by Tony Hudson. The collaboration will develop shared language and a common toolkit with the aim of advancing diversity, equity, and inclusion through the collective power of our community and through personal work, reflection, and commitment.
- Emotional Safety Framework: The Emotional Safety in Pediatrics paper was published, the Emotional Safety <u>website</u> went live, and the Emotional Safety Leaders educational package was launched.

ACLP and its Board of Directors have heard its members, have strived to listen effectively, and are working diligently to implement change accordingly. We are committed to continuing to do this with measures to ensure we are hearing from all of our members representing marginalized communities and to establish accountability metrics that all members can count on.

In June, ACLP hosted its Diversity, Equity, and Inclusion (DEI) Summit. The summit was an element of

the DEI needs assessment and DEI strategic planning work. Through Tony Hudson's facilitation and the intentional elevation of the voices of our members of color, specific DEI strategic priorities were examined and refined and will be a core element of this fall's strategic planning. As a first step, we will be diving into understanding the DEI needs assessment findings.

I want to recognize Bailey Kasten, who has championed this work. Bailey, thank you for your leadership as both our Chief Operating Officer and Interim Chief Executive Officer (CEO).

Looking ahead to next year, the future is indeed bright! Some of this year's exciting initiatives are:

- CEO: Alison Heron we will be joining us as our new CEO on July 12th, 2021.
- DEI Needs Assessment: The full report will be shared with the DEI Summit participants, DEI Committee, Board of Directors, and ultimately all the membership.
- Racially Conscious Collaboration: ACLP has retained Tony Hudson and his team for a second year to continue with the work to instill racial consciousness in all of ACLP's efforts.
- Strategic Planning: Board of Directors, staff, and members will engage in the strategic planning process which will serve as a catalyst for exploring our past, our present, and determining goals for the future. We remain committed to DEI, listening to the voices of all our members, and supporting the children and families we serve.
- Emotional Safety Summit: A multi-disciplinary group will come together to continue to advance emotional safety initiatives.

Please join me in this excitement about our future. Thank you for all that you do! It is my honor and privilege to serve you all as the President of the Board of Directors. Please know that you are welcome to reach out to me anytime at president@childlife.org.



CEO Shares

Bailey Kasten, CAE, Chief Operating Officer & Interim CEO

Moving Forward

he pandemic isn't over, and the threat of its resurgence still lingers for your patients and families across North America and the world. And yet, for many, life is beginning to return to some familiar patterns of normalcy: internships are largely back on track, family visitors are welcomed back to some degree, and the fog of uncertainty is lifting. As a method of coping with the trauma of the pandemic, many of us are seeking lessons to be learned and searching for whatever meaning we can from these harrowing past 18 months. As a leader of our association, I am reflecting too on the impact of the pandemic on our organization and what it may tell us about our future.

First, relationship matters. Listening to and connecting members are critical to ACLP's continued success and relevance. During the pandemic, we created our Member Meet Up events and established important connection points for our community that are focused on the affinity and common experiences we have within our larger group. ACLP will be looking to expand the opportunities to find these options for coming together — online and at our annual conference — to provide the support to our members to get through whatever gets thrown at child life.

Secondly, when we tap into our *inner and organizational resilience*, we survive and even thrive through major changes. With ACLP's efforts to examine the internship process through the Think Tank and in our upcoming strategic planning session, it seems inevitable that changes will be on the horizon for ACLP and our members. Perhaps we can lean on the resiliency and openness to change that we have honed over the past year to help us embrace new strategies for providing emotionally safe care for families and inclusive professional advancement for all members.

Finally, knowing that COVID-19 is not the only pandemic facing our society, but that we also need to work to *understand and eliminate the systemic racism* that faces us all. For its part, ACLP has embraced the framework of Racially Conscious Collaboration to help us effectively have the conversations that will become the work of creating a truly anti-racist organization. I invite you to join us in this learning through the many learning opportunities available to members this year and to be part of our ongoing work.

Now is the time to reflect on the losses we have endured and think about what is next. I wish for myself what I wish for all of us: resiliency and growth, together.

Warmly,
Bailey Kasten *

2021 CHILD LIFE VIRTUAL CONFERENCE RECAP

1,700+

RECORDING BREAKING ATTENDANCE

More than 1,700 child life professionals registered for this year's conference. We were so excited to welcome over 400 child life students!

KEYNOTE SPEAKER: TONY HUDSON

With more than 650 attendees, Tony Hudson delivered a dynamic keynote session on Racially Conscious Collaboration, challenging attendees to think critically about why DEI efforts fail.



KEYNOTE SPEAKER: RABBI G

Rabbi G delivered a heartwarming keynote session on how ill children can regain a sense of power by learning martial arts breathing techniques. "Breathe in the light. Push out the darkness."





AWARDS CEREMONY

The awards ceremony was an opportunity to celebrate and honor the achievements of the 2021 award winners. It was a pleasure to hear from the 2021 Mary Barkey Clinical Excellence Award, Distinguished Service Award, International Award Recipients, and the Professional and Student Research Recognition Awards.

Left: DSA Recipient Carla Barrentine, MSW, CCLS. Right: Mary Barkey Clinical Excellence Award Recipient Diane Dingley, MS, CCLS

NETWORKING

From discussions on how to conduct research and exploring emotional safety to a yoga session and happy hour, attendees had the chance to meet and network with peers from around the world.





THANK YOU!

Congratulations and thank you to the dedicated conference planning committee, speakers, exhibitors, and sponsors that made this year's virtual conference a success!



EMPOWERING CONNECTIONS:

Meeting Youth Where They Are

Anish Raj, MD

THE CHILDREN'S HOSPITAL OF PHILADELPHIA, PHILADELPHIA, PENNSYLVANIA

Meagan Fitzgerald, MS, CCLS

HASBRO CHILDREN'S HOSPITAL, PROVIDENCE, RHODE ISLAND

our weeks in, the dam broke, and the questions arrived rapid-fire.

"Wait, you don't *have* to come to this?"

"You *want* to be here?"

"Y'all are just here cause you care?"

As we sat around the group home dining table, the teenagers looked at each other incredulously. In their questions, we started to see answers. They were surprised that adults would simply make the *choice* to spend evenings with them when not required by their employer, child protective services, or other agencies.

According to national data estimates, more than 420,000 youth are in foster care at any given time with approximately 18,000 residing in a group home (United States Children's Bureau, 2020). It is widely known that foster care youth are at greater risk for a variety of negative psychosocial outcomes compared to peers who have never been in placement (Lanctôt, 2020). Key distinctions between the challenges experienced by youth transitioning to adulthood from care have been documented across gender (Lanctôt, 2020). Existing literature has demonstrated that domains particularly affected for women leaving care involve well-being, relationships, and socialization, and that interpersonal relations are central to the resilience process (Lanctôt, 2020).

Emerging research suggests that the notion of perceived social supports can be crucial in promoting resilience and preventing negative psychosocial outcomes (Lanctôt, 2020). However, given the complexities related to histories of maltreatment, disrupted attachments, and resultant mistrust experienced by many youths in care, establishing supportive

social networks can be challenging (Lanctôt, 2020). None-theless, a positive relationship with a supportive adult may be the strongest predictor of adaptation and resilience for these youth (Rabley et al., 2014). Non-parental caregivers, such as group home staff and mentors, are in a unique position to offer a surrogate family environment. Interviews aimed at gathering the perspectives of youth in group homes have revealed that the most positive of these relationships are often secondary to consistent interactions, open communication, trust, humor, and shared interests (Rabley et al., 2014). Recognizing that lack of engagement can be a barrier, studies have determined that youth-driven interventions, consistency, and incentive-based strategies can be beneficial in improving "buy-in" (Rabley et al., 2014; Boel-Studt et al., 2018).

Based on our clinical experience, the authors, a Triple Board resident physician and a child life specialist, observed that youth from local group homes seemed to present on a recurrent basis to the children's hospital. Youth often voiced dissatisfaction with their living arrangements, any prospect of their circumstances improving, the health care providers they encountered, and the cycle of returning to their assigned placements if medically and psychiatrically cleared. It became evident to us that there was a disconnect between what the youth were seeking in the hospital and the care that was being provided.

In the fall of 2019, we collaborated to think outside the box of traditional clinical roles to engage local youth and meet them "where they are" — literally and figuratively. Past efforts by the hospital to provide outreach to youth residing in group homes largely took place at the juvenile justice facility, local sexual violence agency, or child protection center. It was hypothesized that youth may benefit from the experience of "health care outsiders" coming to them and cultivating positive relationships in a non-clinical setting.

After initial conceptualization was complete, a focus group was convened with administrative stakeholders from a local, non-profit social service organization that manages multiple residential programs for adolescent females who are in the custody of the state. Based on geographical location, the number of residential youths, average length of stay, level of acuity, and opportunity for continuity, a particular group home was selected as the site of the pilot project. The identified group home was estimated to serve six to eight adolescent females at any given time with ages ranging from 14 to 17. Categorized as a step-down program, youth generally remained in the group home for multiple months. Supervision was provided around-the-clock by a minimum of two staff members.

We formulated a model of unstructured and non-curriculum-based evening sessions held once weekly on-site in the group home, facilitated by an inter-disciplinary team comprised of two to four physicians and child life specialists. The hope was that experiences within the group could build resilience factors and translate to favorable outcomes across such domains as interpersonal relationships, engagement with health care, and school functioning. The group was therefore titled Empowering Youth Connections (EYC).

Sessions typically comprised of dinner, discussion, and a group activity over the course of approximately two hours. One evening, a broad conversation about family was initiated while engaging in a freeform art project. As residential youth reflected on their respective childhoods, how those experiences shaped their present, and what their future aspirations looked like, the discussion branched out into dialogue about identity, personal values, and self-esteem. As the youth continued to provide their perspectives, individuals tied in their experiences related to sexual orientation and violence within relationships. The open forum also allowed for the sharing of adolescent outlooks on social media and societal influence on gender roles and inequalities. Rather than evoking a specific goal-directed approach, our objective was to listen to the substance underpinning the views, process in real time, and assist with interpretation. It would not be an exaggeration to acknowledge that we organically learned more about the backgrounds and perspectives of those six adolescents in two hours than perhaps we could have in weeks of clinical service.

Despite being a non-clinical setting, EYC offered a myriad of opportunities for the arts of medicine and child life practice to be exemplified (Ring & Clairborne Johnston, 2018). Unlike a packed outpatient schedule, there was time and space for every youth to be heard. Interactive discussion was predicated on a foundational understanding that resilience can be cultivated through emotional support, nurturance, and education. Even at points of disagreement or gentle anticipatory guidance, the emphasis was to "soothe, not solve" (Ring & Clairborne Johnston, 2018). Residential youth voiced appreciation for having a safe space to express their thoughts openly and be able to utilize caring adults in brainstorming exercises. Silly jokes at our expense were welcome; friendly banter was encouraged. The notion of youth controlling the narrative and being able to access these conversations without involvement of "the system" or having it affect their "file" or "case" was viewed as crucial. We posit that de-emphasizing our clinical responsibilities and securing a more spontaneous, natural interface was invaluable. It became clear that connections were not made based on knowledge of our day jobs or professional degrees. Rather, it was the implicit reality that adults with those day jobs and professional degrees would *choose* to show up consistently that seemed to matter.

Empowering Connections: Meeting Youth Where They Are

Ultimately, fostering connections with youth in a non-clinical setting may also benefit participating health care professionals in addition to the youth involved. Opportunities like EYC can serve as conduits for lifelong learning. Anthropologic studies have promoted home visit models to build providers' understanding of how people from diverse backgrounds experience life (Blaylock, 2000). It has been suggested that this awareness enhances the ability to meet needs more effectively, while also confronting personal biases and misconceptions (Blaylock, 2000). Similarly, evolving literature suggests that social empathy, which has been defined as the "ability to understand people by perceiving or experiencing their life situations, and as a result, gain insight into structural inequalities and disparities," can be honed by exposure and experience (Segal, 2011). Arguably no exposure or experience is more valuable in appreciating the psychosocial nuances of an individual's identity than spending time with them in their home.

As times change and generations evolve, it is imperative that health care professionals adapt to the needs of our communities and ensure that all youth, especially those at-risk for limited social supports, have access to positive relationships with responsible adults. However, as the Wednesday evenings in the group home reminded us, effective interventions do not necessarily have to be inherently sophisticated. Once we were able to demonstrate that we did not *have* to be there, but genuinely *wanted* to just because we *cared*, the guards came down, and a sense of cohesion emerged. EYC ultimately reaffirmed that a sense of togetherness is central to the universal human experience — regardless of age, background, or profession. For we were there to learn, to listen, to advocate, to validate, and to our pleasant surprise, we ourselves became empowered.

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REFERENCES:

United States Children's Bureau. (2020). The AFCARS report – preliminary FY 2019 estimates. https://www.acf.hhs.gov/sites/default/files/documents/cb/afcarsreport27.pdf

Lanctôt, N. (2020). Child maltreatment, maladaptive cognitive schemas, and perceptions of social support among young women care leavers. Child & Family Social Work, 25(3),619-627. https://doi.org/10.1111/cfs.12736

Rabley, S., Preyde, M., & Gharabaghi, K. (2014). A survey of adolescents' perceptions of their relationships with nonparental caregivers in group home settings: An attachment perspective. *Children and Youth Services Review*, 40, 61-70. https://doi.org/10.1016/j.childyouth.2014.02.012

Boel-Studt, S., Schelbe, L., Deichen Hansen, M., & Tobia, L. (2018). Increasing youth engagement in residential group care: A mixed methods pilot study of a youth-guided incentive program. *Child & Youth Care Forum*, 47(6), 863-880. https://doi.org/10.1007/s10566-018-9465-y

Ring, D., & Clairborne Johnston, S. (2018). Your best life: Resiliency and the art of medicine. *Clin Orthop Relat Res*, 476(5), 937-939. https://doi.org/10.1007/s11999.000000000000000268

Blaylock, B. (2000). Patients and families as teachers: inspiring an empathic connection. Fam Syst & Health, 18, 161-176. https://doi.org/10.1037/h0091844

Segal, E. (2011). Social empathy: A model built on empathy, contextual understanding, and social responsibility that promotes social justice. Journal of Social Service Research, 37, 266-277. https://doi.org/10.1080/01488376.2011.564040 THE JOURNAL OF CHILD LIFE IS NOW...

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2021 MARY BARKEY CLINICAL EXCELLENCE AWARD WINNER:

Diane Dingley

Colleen Lacey, MA, CCLS, LMFT

CHILDREN'S MINNESOTA, MINNEAPOLIS, MN

Sheila Palm, MA, CCLS

ACLP PAST-PRESIDENT, RETIRED CHILD LIFE MANAGER CHILDREN'S MINNESOTA, MINNEAPOLIS, MN

iane Dingley is the 2021 recipient of the Mary Barkey Clinical Excellence Award. Diane's dedication to and love of working with patients, their families, and her colleagues seems to have started at an early age. Diane always imagined she would work with children someday and jokes that her interests in helping those in the medical field may have been inspired by a Christmas gift, "Hurt Paw Puppy" she received at a young age. She began her career in the early 80's, completing three internships and her Masters of Science in Early Childhood Education and Child Life at Wheelock College. This was followed by her joining a department of two child life specialists at what is now called Children's Minnesota in Minneapolis.

Diane was initially hired to work in the medical-surgical and pediatric intensive care units. In these early years, Diane was aware of the significance of patient- and family-centered care, long before it was a coined phrase and regular health care practice. One former child life specialist recalled when the department was still under the umbrella of the Human Ecology department. The hospital's philosophy of family-centered care was an anthem on how care would be delivered. Diane worked to develop this philosophy as a standard of care. She was a groundbreaker in the development of patient care conferences as a means to gather the health care team involved with each patient's care. In many multifaceted methods, Diane has maintained this message for families on how to approach and communicate with their child's primary physician and other specialists involved.

While Diane prefers providing hands-on psychosocial and developmental care with children, she has also implemented best-practices and processes to ensure that all staff are providing this optimum care with families. She developed the child life role with the hematology/oncology patient population and expanded interventions with these patients beyond the hospital walls, creating and providing school visits, educating school personnel on the benefits of peer education, and writing a chapter in an American Cancer Society



2021 Mary Barkey Clinical Excellence Award Recipient Diane Dingley

publication on the process and benefits of school visits. She has also taken the lead in creating many diagnosis- or unit-specific child life positions in her 40 years at Children's Minnesota. Diane pioneered the path of child life services in uncharted areas, such as high-risk pregnancy, cardiology, radiology, and children of adult patients. It seems Diane has had a hand in creating much of what newer child life specialists may take for granted as standard services (long before they were standard).

For the last 20 years, Diane has provided services to the neonatal intensive care (NICU) patients and their families. However, when Diane first began providing child life programming in the NICU, it was novel territory. With this new endeavor, she immersed herself in literature to learn about this specific population. Diane collaborated with the health care team to gain insight for programming. She researched other programs that offered services in the NICU. Her efforts led to establishing the provision of a well-integrated and respected child life program in the neonatal care units of Children's Minnesota.

Many current and former NICU families will describe the simple things Diane has done to make them feel involved as a family even when they were separated by hospitalization. She excels at making families feel their care is individualized. She recognizes that, for most children, the hospital setting, or the absence of a parent or sibling is unsettling. She works with parents and their children to best match their needs, finding the balance that families can manage during their medical admissions or appointments. This might be by promoting activities based on quality time versus quantity of time for family. Diane often suggests parents send mail to their other children at home because "every kid loves getting mail." These small touches make a world of difference to families.

One example of this was when a grandparent of a premature infant patient asked for more medical play materials and toys because the patient's big sister regularly played "Diane" with her grandma. Most would assume kids might play "doctor." Not Diane's patients or siblings — they play "child life specialist."

As a proponent for patient- and family-centered care, Diane has been instrumental in the inclusion of siblings as part of a patient's hospital experience, addressing their needs within the medical environment and sharing this information when needed to the medical team. Diane routinely carves out time in her day to engage in play time with siblings of her patients, creating memorable experiences. One example of this was when a grandparent of a premature infant patient asked for more medical play materials and toys because the patient's big sister regularly played "Diane" with her grandma. Most would assume kids might play "doctor." Not Diane's patients or siblings — they play "child life specialist."

In addition to supporting siblings of her tiny patients, in 2007 Diane developed a reading program for these patients. Collaborating with Children's Minnesota neonatal developmental care committee and the hospital's Children's Library, Diane founded "Wee Read," an evidence-based program

designed to encourage parent-infant bonding and stimulate brain growth through reading. Under Diane's leadership, Wee Read has grown from circulating 119 books to NICU patients and families in 2007 to 1,630 book checkouts in 2020. The success of this program is a testament to Diane's ability to build relationships with nurses, physicians, and other members of the health care team who promote and champion the short-term and long-term benefits of the program with patient families. Along with Wee Read, she promoted a music listening program for parents and their infants, eventually launching music therapy services along with staff education on these topics.

Diane is often the department "go-to" member when creating medical play materials and equipment to increase patient and/or sibling comprehension, coping, and mastery of their experiences. Diane is adept at using a variety of educational materials, such as patient puppets, teaching photos, and bibliotherapy, as well as having patients share their own stories. Although she primarily works in the NICU, she can step in wherever patients need her, whether that is procedural support for a laceration or teaching a patient newly diagnosed with diabetes. She is always willing and proficient at jumping in with her child life skills, which makes for a wonderful team member.

As the patient population services and programming has expanded at Children's Minnesota, Diane has kept pace with evidence-based practices, often sharing literature she has read with department staff. She is quick to write up a tip sheet for the health care team and parents addressing world or current events that may directly or indirectly impact the emotional well-being of children. She has written countless articles regarding how to support children experiencing stress and manage feelings during difficult events.

As the department has grown from three child life specialists to a team of 35 child life specialists, six child life activities associates, six music therapists, and a healing arts coordinator, so has the need for Diane's expertise for professional development opportunities. An early leader of staff development efforts, Diane transformed the child life specialist's annual case review and topic presentation to incorporate relevant research into their discussions and consider ways to enhance assessments, interventions, and program development.

Diane leads the coordination of student programs with more than 80 students to date under her guidance and spearheaded efforts for Children's Minnesota to earn the

2021 Mary Barkey Clinical Excellence Award Winner: Diane Dingley

ACLP's internship accreditation. She partnered with a local community college in designing their child life assistant program and field experience at Children's Minnesota. Long before there was a standard of practice for internships, Diane remained up to date on research and resources that benefit students. Throughout the years, Diane has provided continuous evaluation for growth, relevance, and opportunities for improvement as health care and student coursework has evolved.

Diane is an outstanding example of what mentorship looks like. She works tirelessly to encourage and provide students with structure and expectations as they transition from student to professional. One of Diane's former students shared this lasting impression regarding relationship building:

Diane was my internship preceptor and one of the many things she modeled for me, was the importance to reflect on our words and actions and to search for clarity with others as a means of building authentic relationships. On the prescribed day, I handed in my journal and Diane reminded me that she was catching a plane and would not be able to discuss my journal with me until the next week. However, when I arrived to work the next morning, I found my journal on my desk, reviewed with comments in the margin. There was one firmly worded, cautionary note in the margin that gave me pause as this was not her norm. As a student I assumed the worst and began to stew about it. And then the phone rang. Diane was calling me from the airport because she had been reflecting on her comments and recognized that she may have come across differently than intended. We talked briefly and agreed to review the situation further when she returned. That moment has stuck with me and now that I am a supervisor of staff and students, I am reminded of the impact that reflection, correcting missteps and the pursuit of clarity can have on our professional relationships.

Diane has contributed to the growth of our profession from its early stages as the Association for the Care of Children's Health and now as an active ACLP member. She contributed to the values statement at the Child Life Council's (CLC) Mission, Vision, and Values conference, has presented at multiple CLC/ACLP conferences, continues to review abstracts, and actively engages in the internship coordinator's forum. Beyond the medical setting, she is a founding and current member of the Bereavement Services Program. She provided training to hospice volunteers and was instrumental in developing and facilitating end-of-life care, grief groups, memorial services, and (long before they were common) a weekend camp for children and teens. Her

positive character helped get that first camping trip through a weekend of tornado threats and a camper's minor injury requiring stitches.

Diane's commitment has been to providing exceptional care, not just as any child life specialist does, but in a well-rounded approach, laying a foundation and staying the course over the years. It is difficult to uncover something that Diane hasn't done in her child life career. Unless you ask Diane — she is not likely to volunteer her accomplishments. Yet, she's not one to shy away from an opportunity to learn something new or offer an improvement when it comes to children and families.

Diane excels in her work as a child life specialist. She's hard to keep up with both figuratively and literally — with a speedy gait to serve her families. When asked where she might keep her Mary Barkey Clinical Excellence Award, she hesitates about the permanence of putting a nail in the wall for a shelf (as if 40 years hasn't been somewhat permanent). We think she's worth the patchwork - but we'll worry about that in the years to come! Congratulations Diane!



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 Association of Child Life Professionals 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.

Organ Donation and Transplantation in Pediatric Care

By Jennifer Fieten, MA, CCLS

ORGAN DONATION SPECIALIST, GIFT OF HOPE, ITASCA, ILLINOIS ADJUNCT INSTRUCTOR, MARYVILLE UNIVERSITY, ST. LOUIS, MISSOURI

As child life specialists, the support that we provide children and families at diagnosis, throughout the treatment journey, and at times of decline and active dying is irreplaceable. Conversations regarding the need for transplantation are often integrated into discussions on plan of care. Alternatively, conversations regarding death and dying tend to be understandably sensitive in nature and emotionally laden. An additional layer to these conversations is the topic of organ donation and procurement. Child life specialists support the pediatric patient and family awaiting transplant, as well as the declining pediatric patient and family choosing organ and tissue donation. This support includes new diagnosis teaching and assessment of understanding and coping, procedural preparation and procedural support, provision of information regarding disease progression and active decline, ongoing emotional support, bereavement support, and thorough provision of information regarding the process and procedures associated with organ donation. According to the Health Resources & Services Administration (2020), there are currently nearly 2,000 children on the national transplant waiting list and, in 2019, there were over 900 pediatric donors.

Child life specialists provide support for the pediatric patient and family throughout the journey to transplantation and following its completion. The need for follow-up after organ transplantation is often an integral part of the care plan, and requires active involvement of child life in support, preparation, and coping strategies for both the child and the family. Child life alternately may also provide support for the child who is actively dying, and their family, as the donor conversation and process is initiated. This support may consist of the development of legacy and bereavement materials, bereavement support, provision of information regarding the donation process, proposing and facilitating ceremonies and rituals to honor the donor, and accompaniment of the patient to the operating room for procurement. Having resources to inform, support, and to address questions asked by our pediatric patients and their families is incredibly important. And we, as child life specialists, must also educate ourselves to be equipped to engage in these dialogues. The resources shared are intended to inform the pediatric patient awaiting transplant, the pediatric family, the donor family, and the child life professional.

REFERENCE:

Health Resources & Services Administration. (2020, March). Organ donation and children. *U.S. Government Information on Organ Donation and Transplantation*. https://www.organdonor.gov/about/donors/child-infant.html

PARENT/CAREGIVER BOOK RESOURCES (RECIPIENT)

- Baldauf, G. (2020). My new kidney & me: A PKD patient's transplant story.
 Beaver's Pond Press, Inc.
 - A story about the author's experience with kidney transplantation.
- Botwinick-Londoner, R. (2016). Unstoppable heart. Sonnenschein Books.
 A story about a family's experience having a child with complex medical needs.
- Morgan, K. (2019). Without skipping a beat: A child's heart transplant journey. Kirsten Morgan Publisher.
 - This is a story about an infant in heart failure and the experience of the child's family.
- Roby, J. (2016). A walk along path. West Bow Press.
 This is a story about a widowed mother's experience caring for her child with a congenital heart defect that needs a transplant.
- Storch, T. (2013). Taylor's gift. Baker Publishing Group.
 After a skiing accident, Taylor Storch's parents made the decision to donate her organs; this is the Storch family's experience.

PARENT/CAREGIVER/FAMILY BOOK RESOURCES (DONOR)

- Green, R. (2007). The gift that heals: Stories of hope, renewal, and transformation through organ and tissue donation. Author House.
 This resource contains a collection of stories about experiences of life coming out of death.
- Grunska, S. (2019). A kidney for a cowgirl: The true story of my kidney donation to a friend and how it forever changed my life. Independent Publisher.
 - This is the story of one woman's decision to donate a kidney to her friend.
- Judelson, M. (2020). Michael's legacy: Transcending life and death. Mascot Books
 - This resource explores the nature of organ donation from the perspectives of a donor's loved ones, members of the medical team, and from the perspectives of the recipients of his gifts.

PARENT/CAREGIVER WEBSITE RESOURCES (RECIPIENT)

- American Organ Transplant Association (AOTA): http://www.aotaonline.org
 This organization helps transplant patients by helping them obtain and sustain transplantation through resources and free transportation to the transplant center.
- Children's Organ Transplant Association: http://www.cota.org/
 The Children's Organ Transplant Association helps pediatric and adolescent patients who need a life-saving transplant by providing fundraising assistance and family support.

Specialized Resources: Organ Donation and Transplantation in Pediatric Care

- Gift of Life Family House Caregiver Lifeline Program: https://www.giftoflifefamilyhouse.org/bridge-caregiver-support/
 - Gift of Life Family House Caregiver Lifeline Program provides services specifically tailored to the needs of organ transplant patients, family members, and caregivers.
- National Foundation for Transplants (NFT): http://www.transplants.org/
 This organization assists families in acquiring the educational, financial, and long-term support needed for transplant.
- Transplant Recipients International Organization (TRIO): http://www.trioweb.org/about.html
 - TRIO is an organization committed to improving the quality of life of transplant candidates, recipients, their families, and the families of organ and tissue donors.

PATIENT RESOURCES (RECIPIENT)

- Morsi, N. (2017). Kinsey's kidney adventure. Mascot Books.
 This resource is based on the real-life journey of a little girl faced with organ donation after being diagnosed with a medical condition.
- Parker-Roberts, L. (2018). Lucy's liver transplant: A story about organ donation. (Kindle edition)
 - A story written to help initiate conversation about organ donation and organ transplants.
- Peters, S., & Read, K. (2018). How Billy (the kidney) earned his name:
 A kidney transplant book for kids. Create Space Independent Publishing Platform
 - This resource is intended for children who are experiencing kidney failure and that are coping with the challenge of kidney transplant.
- Scott, K., & Brown, S. (2016). The most special gift: Explaining organ donation to children. Lost and Found Grief Center.
 - A story of a young boy whose father died and became an organ donor.
- Storch, T. (2013). Taylor's gift. Baker Publishing Group. (Can be used for both parents and adolescent patients.)
 - After a skiing accident, Taylor Storch's parents made the decision to donate her organs; this is the Storch family's experience.
- Williams-McGowan, F. (2015). Hattie's journey: A child's second chance at life after a kidney transplant. Opportune Independent Publishing Company. This story provides a child's view of kidney failure.

CHILD LIFE PROFESSIONAL BOOK RESOURCES

- Graf, T. (2014). The gift of life: The reality behind donor organ retrieval.
 Firefly Books, Ltd.
 - This book is about the world of organ transplant coordinators that arrange for the donation of organs.
- Mezrich, J.D. (2019). When death becomes life: Notes from a transplant surgeon. Harper Collins Publishers.
 - When Death Becomes Life addresses advances in science intended to improve human lives and the stories of the author's transplant patients.
- Shaw, B. (2013). Last night in the OR: A transplant surgeon's odyssey.
 Penguin Random House, LLC.
 - This resource follows a surgeon's evolution from a surgical resident through his years of training in what was the relatively new field of liver transplantation.

- Yomtoob, P., & Schwartz, T. (1986). The gift of life: One family's story. St. Martin's Press.
 - This is the story of a young boy's struggle to survive a genetic disorder that can only be cured by a liver transplant.

CHILD LIFE PROFESSIONAL JOURNAL ARTICLE RESOURCES

- American Academy of Pediatrics Committee on Hospital Care, Section on Surgery, and Section on Critical Care. (2002). Policy statement: Pediatric organ donation and transplantation. Pediatrics, 125, 822-828.Pediatricians, pediatric medical specialists, and pediatric transplant surgeons need to be better acquainted with evolving national strategies that involve organ procurement and organ transplantation to help acquaint families with the benefits and risks of organ donation and transplantation.
- Ashkenazi, T., & Cohen J. (2015). Interactions between health care personnel and parents approached for organ and/or tissue donation: Influences on parents' adjustment to loss. *Progress in Transplantation*, 25(2), 124-30.
 - An article addressing the adjustment of a parent to loss of a child and the ways in which it is influenced by interactions with health care personnel; A positive experience in the hospital was significantly associated with the meaning of donation.
- Barr, J.L., Conners, A., & Cowart, C. (2017). Exploring organ donation with families of pediatric patients. American Nurse Today, 12(10), 6-9.
 An end-of-life discussion can be challenging, but this tragic situation can lead to positive outcomes if the family chooses to donate their child's organs and tissue after death.
- Harrison, C.H., & Laussen, P.C. (2008). Controversy and consensus on pediatric donation after cardiac death: Ethical issues and institutional process. *Transplantation Proceedings*, 40(4), 1044-1047.
 Donation after cardiac death (DCD) remains controversial in some pediatric institutions. An evidence-based, consensus-building approach to setting institutional policy about DCD can address the controversy openly and identify common ground.
- Rodrigue, J.R., Cornell, D.L., & Howard, R.J. (2008). Pediatric organ donation: What factors most influence parents' donation decisions? Pediatric Critical Care Medicine: A Journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care Societies, 9(2), 180-185.
- The goal of this study is to identify factors that influence parents' decisions when asked to donate a deceased child's organs.
- Sarnaik, A.A. (2015). Neonatal and pediatric organ donation: Ethical
 perspectives and implications for policy. Frontiers in Pediatrics, 3(100), 1-7.
 The lifesaving processes of organ donation and transplantation in
 neonatology and pediatrics carry important ethical considerations.
- Shemie, S.D., Robertson, A., Beitel, J., Chandler, J., Ferre, E., Evans, J., Haun, M., & Torrance, S. (2017). End of life conversations with families of potential donors: Leading practices in offering the opportunity for organ donation. *Transplantation*, 101(5S-1), s7-s26.
 - Presenting the opportunity for donation to families who are in a stressful, traumatic situation is difficult, but can be done in a way that leads to improved and well-informed decision making and support and can have a positive impact on donation rates.
- Siebelink, M.J., Geerts, E.A., Albers, M.J., Roodbol, P.F., van de Wiel, H.B. (2012). Children's opinions about organ donation: A first step to assent? European Journal of Public Health, 22(4), 529-533.
 The results of this study indicate that children at 12 through 15 years of



age are capable and willing to think about organ donation. Thought should be given about how to raise awareness and how to enable parents and children to develop some sort of health literacy concerning the concept of organ donation.

CHILD LIFE PROFESSIONAL WEBSITE RESOURCES

American Nurse: https://www.myamericannurse.com/organ-donation-pediatric-patients/

An evidence-based approach to help grief-stricken families make decisions regarding organ donation.

- American Society of Transplantation: https://www.myast.org/patient-information/resources-transplant-patients
 - This website provides online resources for transplant patients.
- Donate Life America: <u>http://www.shareyourlife.org/</u>
 - Donate Life America is a 501(c)3 nonprofit organization leading its national partners and Donate Life State Teams to increase the number of donated organs, eyes, and tissues available to save and heal lives through transplantation.
- Dose of Play: https://doseofplay.com/blog/explaining-brain-death-organ-donation
 - This webpage provides a developmentally friendly way to explain brain death and organ donation that has been written by a Certified Child Life Specialist.
- Gift of Life: http://www.donors1.org/
 Gift of Life is part of the nationwide organ and tissue sharing network run by
- the United Network for Organ Sharing (UNOS).

 Health Resources and Services Administration (HRSA): https://www.organdonor.gov/about/donors/child-infant.html
 - This website contains information and statistics about organ donation and children.

- International Pediatric Transplant Association: https://tts.org/ipta-pediatric-transplantation
 - The International Pediatric Transplant Association promotes the advancement of the science and practice of transplantation in children worldwide.
- Scientific Registry of Transplant Recipients: http://www.srtr.org/default.aspx
 This intention of this registry is to provide advanced statistical and epidemiological analyses related to solid organ allocation and transplantation in support of the Department of Health and Human Services and its agents in their oversight of the national organ transplantation system.
- U.S. Department of Health and Human Services: https://optn.transplant.hrsa.gov/
- This website provides information and resources regarding organ donation and organ allocation.
- United Network for Organ Sharing (UNOS): https://unos.org/
 The United Network for Organ Sharing website provides Information regarding the organ donation and transplant system.

Jennifer Fieten, MA, CCLS, has been a child life specialist for over 20 years, providing child life support for children and families both in hospitals and as a part of a pediatric palliative care and hospice program. Currently, Jennifer serves as an Organ Donation Specialist, working with children and families, through Gift of Hope, an organ procurement organization. For additional information, Jennifer can be reached at jfieten@giftofhope.org



A Sentence in a Patient's Book

Sydney Ehinger, BS

THE UNIVERSITY OF GEORGIA, MS IN CHILD LIFE CANDIDATE, ATHENS, GA

At the 2020 virtual ACLP conference, an anonymous attendee asked in the chat, "How do you balance equity with not compromising your own culture and beliefs?" The following is one student's response to this comment.

Dear conference attendee,

This letter is for you and any other child life professional who has had questions similar to what you asked here. As a student in the field, your question struck me. I can only assume you are a child life professional, someone who practices clinically, who daily works to support patients. In my studies, we emphasize that our primary job as a child life specialist is to serve a family, not impose our personal beliefs upon them in these relationships. I acknowledge it is impossible to remain completely neutral during patient interactions. If you find your biases showing up in your work, it merely means you are human. As I continue through my own graduate education, I am beginning to learn how and where my own biases show up. When someone brings up a concept I am uncomfortable with, for example hearing about one's fervent religious beliefs, I tend to use humor to deflect the heaviness I feel. However, this

goes against the child life tenant of simply "being with" and does not serve the other person, but instead serves me. By better understanding myself and my responses, I can understand how I am able to best support patients and families.

In one of my child life classes, we were tasked with writing a personal identity essay. This assignment had us look inward and apply Bronfenbrenner's Ecological Systems Theory (1979) to ourselves. Every child life specialist walks into a room carrying their own perspective, culture, beliefs, and biases. This is inevitable and an intrinsic component of being human. What we do with our personal story is what matters, especially when working with vulnerable populations in need of psychosocial support. In this assignment, we began this work to understand who we are and how our own story could show up in our future child life practice. I encourage you to write your own identity essay, especially if you are concerned about compromising your own culture.

What would that look like in a patient setting? How would it impact the way you hold a child in unconditional positive regard? Where exactly does this discomfort show up and why does it do so? Look inward and see how different components of yourself could impact your practice.

In your own practice, I implore you to reconsider how you personally make space for a family and their values when you step into a hospital room. You may be stepping into their lives at one of their lowest moments. You are a sentence in that patient's book. Your culture and beliefs should not be the shining component of that sentence, no matter how long it may be. Their story is for them. It is a privilege to become a facet of that journey, but our professional work impacts

more than just ourselves as individuals. In the hospital setting, we serve families; outside of it, we serve ourselves. I implore you to consider how you bear witness rather than leaning into your own views. This is, of course, easier said than done. This work is uncomfortable. It is messy and draining. Lean into that discomfort you feel. It is necessary for the future of our field. If we want to provide comprehensive family-centered care, we must first look within ourselves and understand who we are as individuals. Only then can we work to become better professionals and therefore better advocates for those we serve.

All the best, Sydney Ehinger *

REFERENCES

Bronfenbrenner, U. (1979). The ecology of human development: Experiments by nature and design. Harvard University Press.

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One Sound Can Make All the Difference: MRI & CT Prep

Martha Baranauskas, BS, CTRS, CCLS

MEMORIAL CARE MILLER CHILDREN'S & WOMEN'S HOSPITAL, LONG BEACH, CA

s child life specialists, one of the main foundations of our profession is to utilize play to prepare and educate our patients for upcoming medical procedures, thus supporting optimal coping and success. It is easy to become complacent when utilizing the most employed interventions; however, when you allow yourself to explore, challenge, and create, something wonderful and more engaging may be developed. The purpose of this article is to encourage readers to think outside the box when it comes to interventions with patients. Even though I had no prior exposure to 3D printing, this technology is an example I will be referring to throughout this article to emphasize that creative interventions take all shapes and sizes.

Some of the most common procedures performed in a hospital setting are Magnetic Resonance Imaging (MRI) and Computed Tomography (CT) scans. Unfortunately, these scans require that patients remain still and endure the unpleasant loud sounds that these machines produce, which can lead to patients needing sedation if they are unable to remain motionless. Sedation requires additional cost and time under observation, increased stress on the caregiver/patient, and can be unnecessary if the patient is provided preparation and exposure beforehand. One study random-

ized children who needed an MRI scan to a control group or an intervention group (Bharti et al., 2015). The intervention involved familiarizing the child with the MRI model machine, listing the steps involved in the scan to the child in detail, training the child to stand still for five minutes, and conducting several simulated runs using the model with a doll or a favorite toy. Within the control group, 40% of participants required sedation compared to the intervention group where only 20.5% required sedation (Bharti et al., 2015).

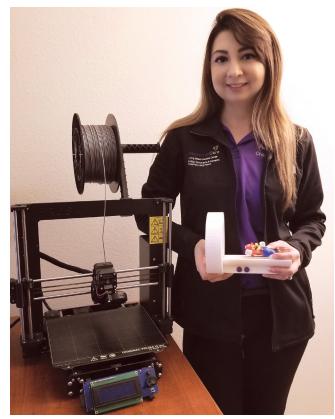
Child life specialists have a plethora of preparation materials to help a patient have a successful scan. These materials may include an iPad for playing back recorded sounds of an MRI/CT machine's operation, an MRI/CT simulation toy for the patient to manipulate for hands-on medical play, or an action figure or doll that will help the patient visualize the process.

During my child life internship at Miller Children's and Women's Hospital Long Beach, I was ready to prepare a patient for an MRI, and, since it was an autistic patient, hearing the sound prior to the scan was essential to achieve success without sedation. I was able to help the patient understand the purpose of the MRI scan, and the patient was fully engaged in medical play; however, I found myself in a situation where my iPad was not working, and I was unable to play the sounds of these machines for the patient. Due to the narrow timeframe which child life specialists

often encounter, there was insufficient time to fix the internet issue, grab a replacement iPad, or to use a personal cellphone to replicate the sounds before the technicians were ready to perform the scan on the patient. After walking into the MRI scan room, the patient heard the noise and became fearful. It was exceedingly difficult for the patient to remain still while exclaiming, "done now, done now!" The MRI technician was able to get a few images, but not as many as they had planned.

After encountering this technical difficulty during patient preparation, I began thinking that there needs to be a more reliable solution. While preparing a patient, child life specialists need dependable tools with minimal interruptions as time is rarely on our side. I began researching whether an MRI simulation toy, which runs on batteries and makes the sounds, existed. This type of solution would have avoided the problem I had experienced, as a single-function device tends to be more reliable. Preparation using a mock scanner has been shown to increase the success rate for children to complete both structural and functional MRIs without sedation (de Bie et al., 2010). Unfortunately, I was not able to find any commercially available MRI/CT machine simulation toys which were able to produce any sounds.

This fueled my passion even further to pursue my idea into a tangible intervention. I began to describe my idea of a simulation toy to my husband who is an electrical engineer. He suggested that I learn to use 3D design computer software to graphically present my ideas. After some time, I made my first design, and after showing it to my husband, he agreed that we could potentially implement a prototype. Thus, to fulfill my requirement of an internship project, I decided



Martha Baranauskas with her prototype MRI/CT machine simulation toy next to a 3D printer.

to design and 3D print the prototype MRI/CT simulation model. We were able to make the simulation model play back recorded sounds of both MRI & CT machines.



There are two buttons on this side; one to turn the model on and off and the other button to choose between three volume settings.



These two buttons function to play sounds to replicate a CT machine, and the other plays sounds to replicate an MRI machine.



An inside view of the cavity where the speakers are placed. A small lid is typically glued over the cavity, so the patient is unable to access any of the electronics.

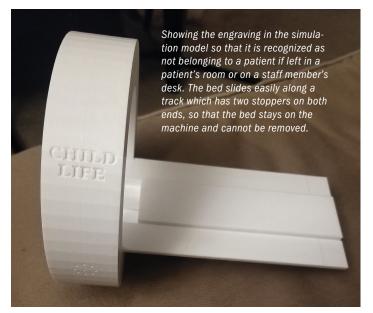
One Sound Can Make All the Difference: MRI & CT Prep



All of the electronics are securely hidden in a separate compartment with a lid held by a screw to make it more difficult to access by typical users.



3D-printed shell which looks like the castle cover. This shell can be easily placed over the machine for patients who will be scanned by the pediatric MRI machine.





To make medical play with the MRI as inviting as possible, different characters were included in our prep box.

Even though this MRI/CT 3D model was not in my field of expertise, I knew it would be an intervention that could be the deciding factor for a patient to have a successful scan. Now that I am working as a child life professional at Miller Children's and Women's Hospital Long Beach, it has been rewarding seeing the impact this project has continued to have on our patients.

Since each child is unique and requires an individualized approach, child life specialists must also tap into their inner child and view interventions through a child's eyes to think outside the box. It is important to constantly evaluate our interventions, question our levels of complacency, and think creatively about what might work best for each individual child. **

REFERENCES

Bharti, B., Malhi, P., & Khandelwal, N. (2015). MRI customized play therapy in children reduces the need for sedation: A randomized controlled trial. *The Indian Journal of Pediatrics*, 83(3), 209-213. https://doi.org/10.1007/s12098-015-1917-x.

de Bie, H. M., Boersma, M., Wattjes, M. P., Adriaanse, S., Vermeulen, R. J., Oostrom, K. J., & Waal, H. A. (2010). Preparing children with a mock scanner training protocol results in high quality structural and functional MRI scans. *European Journal of Pediatrics*, 169(9), 1079-1085. https://doi.org/10.1007/s00431-010-1181-z.



Utilizing CCTV and YouTube in Pediatric Health Care

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spent by children watching television or utilizing screens, such as phones, computers, and tablets for digital media. The American Academy of Child and Adolescent Psychiatry (2020) has determined that children between the ages of 8-12 years watch screens between four and six hours per day, and teens interact with screens for up to nine hours per day. Because of the influence television may have on the life of a child, it is incumbent upon child life professionals and others in health care to consider the utilization of television and other screen experiences in hospital settings.

e are all aware of the significant time

Hospitalized children watch more TV than non-hospitalized children and are exposed to more adult content (DiMaggio et al., 2003; Guttentag et al., 1981, 1983). Researchers have consistently recommended commercial-free, alternative programming to support developmental and coping needs of pediatric patients. Across North America, child life professionals have been utilizing closed-circuit television (CCTV) for decades (Guttentag, 1986; Guttentag et al., 1981). In 1983, Guttentag et al. reported alternative children's programming and live broadcasts by child life were preferred by patients (compared to commercial broadcasting) and had positive effects for patients and staff. Importantly, viewing CCTV had not replaced children's time in the play spaces but rather filled a void. In 1986, Guttentag summarized the "state of the art" in pediatric television after sending 178 surveys to child life directors at pediatric hospitals and general hospitals with more than 65 pediatric beds using the 1984 Directory of Child Life Programs in North America. Responses from 128 hospitals (85 pediatric hospitals and 43 general hospitals) provided insight into the tremendous vari-

Utilizing CCTV and YouTube in Pediatric Health Care

ability across CCTV stations in terms of funding, staffing, content, source of content (video) and/or live programming, and broadcast duration and capabilities. This range demonstrated that CCTV stations operated at various levels and could be instituted with very limited resources.

IWK Health in Nova Scotia, Canada, began the use of CCTV for patients and families in 1981 (learn more about the program in the sidebar on page 23). Since there has been no new research in the last 30 years regarding the use of CCTV programming for pediatric patients, child life staff at IWK Health made the decision to investigate if and how other child life programs across North America were utilizing CCTV. In 2018, a survey was launched to gather foundational information from 25 Canadian hospitals and 12 US hospitals with Seacrest Studios and/or known CCTV programs. We recognize this was a small sample of the number of programs that may exist. However, it was felt to be sufficient for our purpose: to inform our CL-TV programming and provide foundational information for research grant submissions. The purpose of this paper is to share the findings of this survey and explore implications for child life programs and practice.

Findings

Participants and Demographics

Nineteen of 37 participants completed the survey, an overall response rate of 51%. See Figure 1 for the breakdown of surveys distributed and the number of respondents with CCTV, hospital YouTube, and child life YouTube channels by country. Most respondents were from independent children's hospitals while the remainder were from various types of facilities (see Figure 2).

Figure 1
Survey Demographics

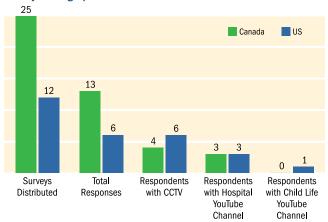
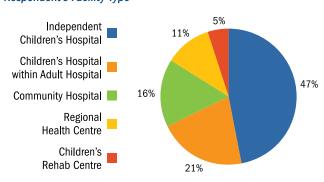


Figure 2

Respondent's Facility Type



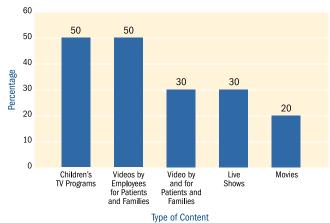
Child Life oversaw the CCTV Channel for 70% of the organizations while Public Relations (PR) managed most of the organizations' YouTube Channels. Child Life oversaw the one child life YouTube channel reported. Half of the organizations did not capture numbers of patients watching CCTV while the other half mentioned having done audits, surveys, or real-time counts.

CCTV Content

CCTV content varied and included: hospital information, TV programming, movies, videos by and for patients/ families, celebrity visits, live shows with special guests, patient education, and videos by staff or outside groups. More specifically, CCTV contained primarily children's TV programs (cable/TV shows) and videos created by employees for patients and families (hospital information, educational materials, etc.). Figure 3 illustrates the type of content primarily shown on these CCTV channels.

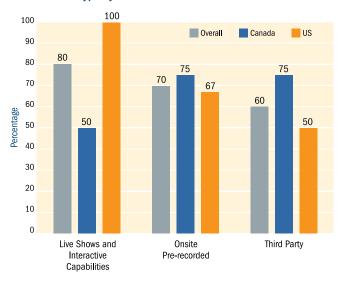
Figure 3

Type of Content Primarily Shown on CCTV



Child Life and Seacrest/ Studio staff were most often responsible for determining content to be used, while PR was also noted. Eighty percent of respondents indicated they provided live shows for their patients, 70% indicated they provided on-site pre-recorded videos (primarily in the activity area or patient rooms), and 60% indicated they provided third-party videos (see Figure 4a).

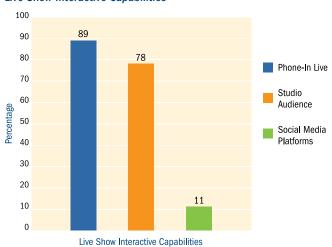
Figure 4a **CCTV Content Type by Location**



Those with live shows indicated they can have interactive capabilities via telephone, live studio audience, and social media platforms (see Figure 4b).

Figure 4b

Live Show Interactive Capabilities



CCTV at IWK Health in Nova Scotia, Canada

The use of CCTV for patients and families at IWK Health in Nova Scotia, Canada, began in 1981 as TV-4U (Television For You) with VHS video looping technology, broadcasting in-hospital-created videos as well as VHS shows/movies, 7 days a week during the day. Our CCTV program, now called Child Life Television (CL-TV), was relaunched in 2011 after a five-year hiatus. Two years later, CL-TV extended programming from inside the hospital walls to our IWK Child Life YouTube Channel with over 450 followers and nearly 200,000 views to date.

Patients and families can create patient*-led videos nearly anywhere in the hospital or in the theatre/studio. The recordings are edited and broadcast through our CCTV channel, and with consent, uploaded onto our Child Life YouTube channel. We believe co-creating a patient-led video with members of the child life team provides a form of play/expression, allows patients to take control of and be distracted from their environment and hospital experiences, explore their personal narrative, and move beyond the sick role.

Patient and Family Involvement in CCTV. Ten of 19 organizations have CCTV in their pediatric areas. The level of patient and family involvement in video creation varied: some patients and families assisted with writing, directing, and producing; some created content or participated in videos; and some assisted with technical support and video editing of CCTV programs. See Figure 5 for further details.

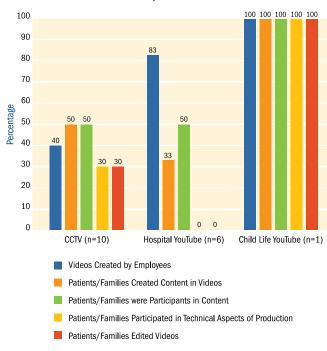
When asked about patient and family programming, respondents listed live broadcasts (game shows, Seacrest Studio live stream, celebrity visits), hospital and foundation education, information, and virtual tours. This also included live or pre-recorded shows with music, storytelling, science, Lego©, art, interviews, Clown TV, mindfulness, and trivia.

Location of CCTV Video Creation. Shows and videos were created in various locations. Six of the ten respondents with CCTV reported videos were made within the hospital and/ or in a studio space (2 Canadian respondents; 4 U.S. respondents), as well as patient rooms (50%) and activity areas

For brevity, "patient" in the context of this article represents child and youth patients as well as siblings

Utilizing CCTV and YouTube in Pediatric Health Care

Figure 5
Involvement in Content Development



(50%). Interestingly, 40% of these respondents indicated recordings also took place on location, outside the hospital.

Dedicated Resources for CCTV. Sixty percent of respondents indicated there was a dedicated budget for their CCTV program, and half had dedicated human resources assigned. Staffing included various roles: child life specialists, media program technicians, videographers, studio managers, child life specialist technician, volunteers, interns, and/or patient technology coordinators, with a range of parttime to full-time staff.

YouTube Channels

Six of 19 respondents had hospital YouTube channels, and only one had a child life YouTube channel. In the United States, all hospital YouTube channels were overseen by PR whereas in Canada, child life and PR were mentioned. The hospital YouTube channels contained videos created by employees for patients and families (83%), such as practical hospital information (67%) and advertising of products and services (33%), as well as cable/purchased programming (17%) and videos created by patients and families (17%).

Child life YouTube channel content was either created by patients and families or by employees for the benefit of patients and their families. The videos were recorded in studios/dedicated spaces, activity areas, and/or patient rooms. Child life services determined and managed the content, while patients and families participated in video development, created content, wrote, directed, produced, edited, and assisted in the technical production (see Figure 5). Some patients and families also received assistance from a videographer/technical support person.

Discussion and Implications for Practice

The purpose of the survey was to gain a better understanding of the hospitals who have CCTV in their pediatric units and how CCTV is used with/for pediatric patients and families, as well as human and financial resource information related to this programming. We also asked about the use of You-Tube channels for patients and families. Although the survey was not as widely distributed as Guttentag's survey in 1984, the variation in programs, types of CCTV content, pre-recorded and live programming, who manages the CCTV content, and human resource issues remain similar nearly thirty years later. In Canada, funding to provide regular, creative, and/or live programming remains a challenge for many hospitals.

Diverse programs, large and small, with varied resources are using CCTV for pediatric patients, and some are providing video creation or live programming with patients. We believe video creation and live programming with patients improve outcomes for hospitalized children and their families, however, more research is needed. Child life professionals can utilize these survey results in their own settings, collaborate with one another, share ideas and program content across settings, develop best practices, and advocate for quality viewing for hospitalized children.

Since this survey and the onset of the worldwide COVID-19 pandemic, more child life specialists are exploring CCTV and virtual technologies as tools to provide therapeutic interventions, social engagement, play programming, and virtual guest visitors. Child life specialists have been brainstorming and sharing innovative uses of CCTV and various technologies to support and mitigate the sense of isolation because of COVID-19 restrictions impacting playrooms, group programming, and decreased social interactions. Technology is quickly evolving, and we have confidence that video creation

and sharing will continue to offer alternative therapeutic programming to hospitalized children. New technologies are making video creation easier, and it is common for children and youth to upload their own videos and/or watch videos created by others.

Our survey findings provide insight to what currently exists and help us appreciate the similarities and differences among CCTV programs in North America. Of special interest to us was that about half of hospitals surveyed provide opportunities for patient and family participation in the development and creation of videos to be shown on their CCTV channels for pediatric areas. Our child life team believes the creation of videos with and for patients and families has enhanced television viewing for young patients at our centre and provides a valuable therapeutic tool to promote coping and resiliency. We believe it can positively influence their

personal narrative, while making the hospital a place of discovery, expression, and accomplishment. These survey results provide foundational information about CCTV in pediatrics and can inform grant/research funding applications. The findings can also act as a steppingstone for child life professionals to utilize this creative therapeutic medium, whether their budget and resources are large or small. Research is needed to explore the benefit of this therapeutic tool, and we are committed to contributing to this body of knowledge and evidence to support our clinical observations.

Acknowledgements: A special thank you to Kate Morrison, former CCLS and current IWK Child Life Television volunteer whose support and contribution to this work was so valued; to our colleagues at the Hospital for Sick Children in Toronto who took the time to provide feedback about the survey questions; and to all the individuals who completed the survey, glitches, and all!

REFERENCES

American Academy of Child & Adolescent Psychiatry. (2020). Screen Time and Children. https://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/FFF-Guide/Children-And-Watching-TV-054.aspx

DiMaggio, D.M., Sharif, I., & Hoffman-Rosenfeld, J. (2003). TV guides: Exposure of hospitalized children to inappropriate programming. Ambulatory Pediatrics, 3(2), 98-101. https://doi.org/10.1367/1539-4409(2003)003<0098:TGE0HC>2.0.C0;2.

Guttentag, D. (1986). Pediatric television: The state of the art. *Child Health Care*, 15(2), 82-90.

Guttentag, D., Albritton, W., & Kettner, R. (1981). Daytime viewing by hospitalized children. *Pediatrics*, 68(5), 672-676.

Guttentag, D., Albritton, W., & Kettner, R. (1983). Daytime television viewing by hospitalized children: The effect of alternative programming. *Pediatrics*, 71(4), 620-625.

for over 20 years! Waking hospital visits in the for over 20 years! William over 20 years!

2021 PROFESSIONAL RESEARCH AWARD WINNER

Exploration of the Relationship Between a Group Medical Play Intervention and

Children's Preoperative Fear and **Anxiety**

Authors: Maile Jones, MEd, CIMI

Marissa Kirkendall, MS, CCLS

Leslie Grissim, MA, CCLS Sarah Daniels, MS, CCLS Jessika Boles, PhD, CCLS Exploration of the Relationship Between a Group Medical Play Intervention and Children's Preoperation and Children's Preoperation Seems of Children's Preoperation Se

This article was published in the Journal of Pediatric Health Care Volume 35, Issue 1. To read the full article, click here.

Tell us about yourself.



Jessika Boles: I am a child life team lead at Monroe Carell Jr. Children's Hospital at Vanderbilt, where I serve the Pediatric Intensive Care Unit. I have been a child life specialist for 12 years, a team lead for almost two years, and a researcher pretty much my whole life (though with varying levels of knowledge and skill).



Sarah Daniels: I have been working at St. Jude Children's Research Hospital in Memphis, TN, as a CCLS for the past 5 years. I enjoy splitting my time between clinical work supporting our adolescent and young adult patients and performing research and quality improvement (QI) projects for our child life program.



Marissa Kirkendall: I've been certified and practicing in the field of child life since mid-2013 in a variety of in and outpatient settings. Currently, my role at Monroe Carell Jr. Children's Hospital at Vanderbilt is within the perioperative services unit.



Leslie Contreras Grissim: I am a Certified Child Life Specialist in the current role of Facility Dog Coordinator at Monroe Carell Jr. Children's Hospital at Vanderbilt in Nashville, Tennessee, with 30 years of experience as a child life specialist.



Maile Jones: I am currently a full-time research lab coordinator for the Stress and Coping Lab at Vanderbilt University where our research focuses on understanding the psychological, biological, and interpersonal processes in stress and coping among children and families facing health care adversities. During my

time in graduate school, I completed a child life practicum at Huntsville Hospital for Women & Children as well as an internship at Children's Mercy Hospital. I am excited to start my professional career as a Certified Child Life Specialist at Monroe Carell Jr. Children's Hospital at Vanderbilt.

Why did you decide to undergo this research project and what was your experience with research before you took on this project?

Leslie Contreras Grissim: This is my first project! I knew that I wanted to pursue some type of research project during my career as a CCLS and when I began work in the perioperative area, I saw a need to increase processing opportunities for patients. I initiated the idea of using medical play as the therapeutic activity to help lower anxieties, increase coping, and process information for children undergoing surgery or a procedure in a fast-paced area. Quick assessment and communication are so important in our role as a child life specialist and if we could design a plan to implement this therapeutic play opportunity in the waiting room and make it work into our schedule, I wanted to make that happen.

Marissa Kirkendall: Research has always been an interest of mine, as I feel it is one of the most beneficial ways to continue growing and expanding upon the Child Life profession. I was excited to embark upon the research process and learn, as this was one of my first opportunities to engage in research specifically designed and implemented solely by child life professionals.

Jessika Boles: Leslie and Marissa came to me with the idea for this research study. Their passion for the patient population and expertise in medical play paired well with my experiences designing a research study, applying for IRB approval, and managing data collection and analysis. Although I had done several research studies in my own area of interest, I was drawn to the opportunity to provide mentorship.

Sarah Daniels: As a doctoral candidate and child life researcher, I'm fortunate to have experience designing and conducting research and QI projects alongside other psychosocial and medical disciplines. It was a wonderful opportunity to be included in this research project so that I could collaborate with other child life researchers from a different institution.

Maile Jones: Participating in this research project provided me with the opportunity to see child life in action. In addition, I knew this research project would contribute to my professional growth by enhancing my ability in gathering and analyzing evidence through quantitative assessment. Prior to this research project, I had the opportunity to work on other projects at Vanderbilt.

What was your role in the research study?

Jessika Boles: I was the principal investigator for the study, so I assisted with study design, administration (proposal development, IRB approval, record-keeping), analysis, and writing/reviewing the manuscript drafts.

Marissa Kirkendall: Upon being introduced to the idea of the project, my primary roles were project design, implementation of the research intervention, and collaboration for publications following research analysis. I was also able to partake in the implementation of the research intervention as a CCLS that provided the medical play opportunity to research participants.

Maile Jones: My primary role as a graduate research assistant was to identify and recruit eligible patients in the preoperative waiting area. I was tasked with building rapport, providing developmentally appropriate information regarding the purpose of the study, and obtaining informed consent/assent and demographic information. I then conducted post-intervention interviews regarding pediatric patients' self-reported fear. Upon completion of data collection, I ran statistical analyses and contributed to the writing process

Leslie Contreras Grissim: I was one of two clinicians who planned, prepared, and implemented the intervention and collected information/data from participants.

Sarah Daniels: I performed the statistical analysis for this study.

What were the biggest things you learned during the process?

Marissa Kirkendall: Throughout this research project, I learned a great deal about the formal research process and how to navigate everything from a proposal for the IRB to analyzing and reporting our findings through publications. Our team was comprised of various child life professionals that each brought a unique perspective and strength to the process. The biggest thing I learned was how valuable each researcher and their unique skill set was. Without a diverse group, it would've been challenging to develop and implement a meaningful project.

Leslie Contreras Grissim: Jessika Boles taught me that there are manageable parts or phases to research that make it possible to get outcomes in a short amount of time, thus, feeling more empowered, confident, and successful when navigating the data. Choosing to do a smaller scale pilot study to test the design allowed me to see the results in a short amount of time.

Maile Jones: I learned so much during this whole process including how CCLS' provide medical play in health care settings, how to quantitatively assess pre-operative anxiety among pediatric patients, and how medical play interventions can effectively mitigate health care-related distress. Through recruitment of participants, I also learned the importance of building rapport and trust with pediatric

2021 Professional Research Award Winner

patients by meeting them where they were in their health-care journey.

What were the biggest challenges during the process?

Jessika Boles: We navigated a pilot project prior to the full study, which took extra time and resources but really helped us determine how to best conduct the study. We learned that we really needed two child life specialists present during data collection, and a stellar graduate student (Maile Jones) to help us recruit families and collect demographic information from parents. Additionally, we needed to re-do some of our statistical procedures during the peer-review process due to a conflict one of the reviewers noted; however, that gave us the opportunity to invite Sarah to join us and to learn more about another type of analysis.

Sarah Daniels: Performing nonparametric analyses in SPSS was a meticulous process. Because nonparametric analyses are not used as often as parametric statistics, I needed to devote extra time to ensure that the process was performed correctly. I have a passion for making sense of numbers through statistics, but this was a new challenge for me that I really enjoyed.

Marissa Kirkendall: One of the challenges I encountered was the standardization of the medical play intervention for this project. It felt challenging to create a protocol that met our research requirements, but also gave the freedom of spontaneity essential for this child-directed intervention. Nonetheless, we were able to create a safe environment where participants had the opportunity to explore and engage in a meaningful medical play intervention that did not feel limited.

Leslie Contreras Grissim: The biggest challenge would be the availability of time in the day to work on putting it all together. Working in a fast-paced area does not leave much time in the day to focus on details. Much of the time, energy, and investment came in the afterhours of a workday.

Maile Jones: The biggest challenge for me was learning how to effectively disseminate our data. It was hard to know where and how to begin crafting a narrative based on our findings. After many months of data analysis, reviewing the literature, and writing draft after draft, our team was able to publish a research article that helps convey the benefits of child life.

What tips would you give to someone just starting out in the research process?

Jessika Boles: It just takes one idea — an idea that you are passionate about, feel connected to, and really want to pursue. Next, think about who and what you will need to turn your idea into a reality. There are lots of folks out there that are ready and willing to collaborate, if you can help them understand what your interests and goals are. Your project may not always end up exactly how you envisioned it in the beginning, but you, yourself, will always find growth and transformation in seeing a research project through — which makes it worth your time and energy.

Sarah Daniels: Find a supportive research team, and don't be afraid to try something new. Whether you use a new methodological approach or attempt a new way to analyze your data, avoiding your comfort zone is a great way to learn during a research project. Research is a long process, but working alongside other passionate and driven researchers will help guarantee that you will meet your project goals.

Marissa Kirkendall: Patience throughout the research process is essential. From start to finish, the project required several revisions and adjustments, but ultimately lent to an incredible experience and data relevant to our scope of practice as child life professionals. Additionally, collaborating and establishing a work group with diverse experience allowed for our project to flourish.

Leslie Contreras Grissim:

- Choose a manageable design-start with a project that collects data suggesting the feasibility and effectiveness of an intervention.
- Identify a timeline of a start and end date for accountability.
- collaborate with colleagues who have experience with research projects.
- Prepare and educate your medical team as to your plan to execute during work time so that the flow of meeting patient needs is not disrupted.

Maile Jones: Do not be intimidated! Research is vital to raise the growth of the child life specialist as well as contribute to the validity of the profession. You can start by simply asking questions, reflecting on your own practice, or by reading more literature. Regardless of where you start, increasing your involvement in research helps improve interventions provided to patients and strengthens the child life profession.



Child life fellow and child interacting at Ann Arbor Hands-On Museum teddy bear clinic event. Photo: Ari Morris

Innovative Collaboration Comes Alive with Shared Vision

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ospitals and children's museums/science centers are both life-giving entities. At their best, hospitals address illness and injury to enhance physical life, and museums/ science centers provide educational experiences that enhance intellectual and emotional life. Here is the story of *Healing Through Hands-On Science* (HTHOS), a unique collaboration which began as a child life initiative in a midwestern community and has resulted in new mutual appreciation and surprisingly similar professional goals:

child life and museum educators collaborate to help improve patient experience and public health initiatives with families.

Goals of the Partnership:

The goal of the HTHOS partnership is three-fold: alleviate the impact of hospitalization by providing a distraction for patients and their caregivers, improve the quality of life through positive experiences, and help minimize fears of hospitals while building increased trust with health care providers. Partnering with cultural centers and science museums can accomplish these goals by providing patients with access to local community resources without needing to leave the hospital, helping patients to remain connected during a time when they may otherwise feel isolated.

Museums and cultural centers may also have access to special exhibits and activities or to expert staff who offer a different way of interacting with patients. Museum educators can provide science, technology, engineering, and mathematics (STEM) content that is unrelated to the health-specific education surrounding their condition that they may receive

Innovative Collaboration Comes Alive with Shared Vision

from child life staff. This triad of goals is accomplished by offering programs in both hospital and museum settings. For programs offered in the museum setting, the whole community can benefit from the opportunity to learn from health care providers in a non-emergent environment. Additionally, children's exposure to positive early health care experiences, even if they are only modeled, can also help to prepare them for later experiences or express their feelings around health or sickness.

Development of the Program

The initial inspiration for this program occurred through many years of community-based "one-off" medical play programs facilitated during Child Life Month as recognition of the role of child life specialists as part of ACLP's founding organization Association for the Care of Children's Health (ACCH) and Child Life Council (CLC). Pediatric nurses also facilitated hands-on activities during Nurses' Week in many local communities. The chief executive officer of C.S. Mott Children's Hospital recalled some of these programs at the Ann Arbor Hands-On Museum (AAHOM) and suggested to the child life director and patient experience project manager that, since the new hospital was now complete, it would be a wonderful time with more space to explore expanding community outreach and partnerships.

The initial meeting in December 2012 included the AAHOM director, museum outreach manager, child life director, and patient experience project manager (also a seasoned child life specialist). There was a rapid-fire brainstorming exchange of exciting ideas to try implementing, as well as suggestions of potential grants from community foundations and donors who supported both institutions. The collaborative communication has continued over the years with initial seed grants from the hospital followed by local, regional, and national grant applications, initiated by the museum with hospital partners named in each and every grant. The child life specialist/project manager has remained an integral part of the oversight of the program and has continued to explore ways to further public health and community engagement with outreach, distance learning, and avenues to involve multidisciplinary health care professionals highlighting information sharing, collaboration, and education as pivotal patient- and family-centered care pillars.

Word spread, and the program has expanded to additional museum and hospital partners and increased grant opportunities. Interest on the museum/science center side was generated after presentations at national museum conferences and the development of a Community of Practice as part of the Association for Science & Technology (ASTC).



Patients at Dell Children's Medical Center experiment with an engineering activity led by Thinkery museum educator. Photo: Michael Malloy

This work was also presented at the 2018 ACLP conference in Washington, DC, and received wide-spread interest as a community-building opportunity.

Several of our museum/hospital partners have also worked with child life specialists in their respective institutions to leverage health science discovery as education and distraction opportunities in permanent or rotating museum exhibits in hospital or clinic waiting spaces. In addition to C.S. Mott and AAHOM, other lead hospital/museum partners named in the national grant are: Erlanger Children's Hospital and Creative Discovery Museum in Chattanooga, TN, and Dell Children's Hospital and Thinkery in Austin, TX.

The Program in Action

Programs in the hospital setting take many forms, using various tools and resources. Many programs call for museum staff to bring science-focused, tabletop activities

into a designated space within the hospital. Possible locations include a family waiting room, an outpatient clinic, a communal setting for in-hospital patients, or even infusion centers and bedsides, when requested. Successful hospital activities are open-ended and appropriate for a variety of ages, allowing children to actively participate at any level of involvement. Activities will often include easy to find materials to encourage further exploration later. Though some are health-focused, many are not, since distraction from health issues is a primary goal. For example, tabletop catapults can be engaging and exciting for kids as they add a payload (puffballs, ping pong balls, etc.) and try to hit a target. Children can engage in the engineering process and experiment with altering different variables. Children of all ages can be successful, the catapult demonstrates scientific principles, and the activity is portable, even to a bedside. Museum educators can also connect the principles learned from this activity back to an exhibit at their location or to a patient's memory of a past museum visit, if applicable. Most importantly, this activity provides distraction, play experiences, and normalcy for the population being served.

When patients are unable to visit programming spaces during planned museum visits, pre-made museum activity backpacks can be distributed. Backpacks can include games and activities that would occupy children for a longer period of time than educator-led activities and contain facilitation instructions for caregivers. Advisors from the hospitals' Patient Family Advisory Councils provided many ideas and helpful feedback on the kinds of activities needed and the benefits of the backpack being deliverable to patients and families, especially during hospitalizations and/or lengthy outpatient clinic appointments. The backpacks continued to be helpful resources during pandemic restrictions and have been used as part of the C.S. Mott Children's Hospital virtual summer camp.



HTHOS Community Outreach School Event Partners

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Digital programs are another way HTHOS has reached children in the hospital. Closed-circuit TV broadcasts can be presented in different formats, but the science demo has been most effective. Typically, two to three different science demonstrations are presented, and sometimes an activity can have a "do-along" component using items that are available in the hospital room, like straws from a meal tray or wash-cloths and water. With help from the hospital's child life department staff, small activity kits can also be distributed to interested patients who want to join in with the video presentation. Many science museums are already equipped to deliver virtual programming in this fashion and can easily adapt to delivering for a hospital audience. This type of programming also works to reinforce connections to the community outside of the hospital walls.

Even for those who are not currently experiencing a health care crisis, it is likely that at some point they will become a patient or know someone who has a serious medical event. Partnerships like HTHOS can provide preparation and positive coping skills to those who are not yet patients, with a goal of providing positive experiences early in life that influence health outcomes later. Gathering community resources in one setting, such as a museum, can build trust in health care providers and demonstrate the benefits of patient-centered care. These museum events included many different areas of health care, such as nursing, nutrition, orthopedics, perioperative services, phlebotomy, physical therapy, mental health services, and pharmacy, to emphasize the multiple dimensions and necessary collaboration that make up quality medical care.

At one HTHOS community-based event, a second-grade girl in a leg cast and crutches hovered over the Teddy Bear Clinic surgical table. With her play scalpel and forceps, she



Children and Dell Children's Hospital medical professionals model an MRI procedure. Photo: Michael Malloy



C.S. Mott Children's Hospital OR Nurse interacting with the Children at HTHOS Community Event. Photo: Ari Morris

intensely focused on her play operation. The father stated he had never seen anything like this event before and wished he had experienced something similar in his youth, as he feared the hospital. Once the facilitator learned his daughter wanted to become a "brain doctor," she introduced her to a volunteer medical student. Her eyes stayed transfixed on "a real medical student" as she asked question after question. This event took place in a high-poverty, minority, and immigrant community. The event was a unique experience for all youth, especially marginalized youth. Children learned about medical procedures and coping strategies and were able to envision themselves in roles of medicine, science, and child life.

The Value of Partnership Collaborations

Shared goals are important for healthy thriving partnerships. Research shows that hospitalized children report increased levels of anxiety (Potaz et al., 2012), as do the caregivers of these patients (Ellerton, 1994). Children communicate and process emotions through play. This provides an outlet for anxiety and fear, which ultimately gives children a sense of control (Koukourikos et al., 2015). Children's museums and science centers have developed play-based, exploratory activities that engage children and provide distraction. Staff in these organizations are typically very adept at engaging a variety of children in a variety of settings. In the health care setting, child life specialists and other providers are constantly pivoting to build rapport with children and families quickly to support medical experiences, and have greatly appreciated the opportunity to be in the community sharing those important public health messages. One health care partner has framed this as "an opportunity to improve patient experiences before they occur."



C.S. Mott Children's Hospital OR Nurse interacting with the Children at HTHOS Community Event. Photo: Ari Morris

Teddy bear clinics at museums present an educational opportunity for multiple participants. The experience places children in the role of the medical professional, and they are afforded the opportunity to learn about medical equipment as well as process their own medical experiences. The teddy bear clinics have also provided a learning experience for child life interns at C.S Mott. During their internships and fellowships, students are immersed in learning opportunities related to diagnosis education, procedure support, and developmental play with patients within the hospital setting. This outreach opportunity offers opportunities to practice their medical play facilitation skills in a non-traditional setting to expand their child life reach into the community.

Conclusion

Successful partnerships between museums and hospitals result when one partner becomes the missing piece of the other partner's puzzle. Children's museums are no longer confined within the walls of a building, but look to reach outside of themselves to make connections in their community. This task requires community partners to bring expertise and authenticity into the museum setting. Hospitals provide real staff, objects, and experiences found in the medical profession. These museum puzzle pieces are filled by hospitals. Hospital and child life staff look to provide normalcy and connection to patients during their stay. Local museums can provide opportunities for science discovery and community connection.

The children referenced in this article had excellent medical interventions and care, and museum educators, in collaboration with child life, were able to offer discovery, distraction, and normalcy as a part of their hospital experience. Additionally, public health opportunities have been expanded to

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The Child Life Perspective

A seasoned child life specialist from C.S. Mott Children's Hospital (Mott) recalls an impactful experience from a family encounter during a museum-based HTHOS event. "An eight-year-old child was participating in our teddy bear clinic at the Hands-On Museum. During play, he shared that his sibling was a current patient at Mott. As the child placed an IV and bandages on his teddy bear, his grandma shared how timely this intervention was for their family. Grandma relayed that her grandson's older sibling had just been diagnosed with cancer that weekend. Using the natural language of play, this child was able to work through this new medical development in his family and claim control and mastery over this event personally."

The Museum Educator Perspective

From the museum educator perspective: "A six-year-old child had been critically injured in a school bus accident. His right side was paralyzed and he had not spoken or shown emotion since the accident three weeks before. His dad learned from a child life specialist that children's museum staff were onsite facilitating bedside activities with other hospitalized children and requested that museum educators come to his child's room to try to engage his son, who had not been out of his bed since the accident. The museum educator held an undecorated gingerbread house out to the child demonstrating how candy could be dipped into icing and placed on the house. Then she offered the child an opportunity to respond. Gently, lifting his hand from under the sheets, he began putting candies onto the house. Hospital staff who were in the room were amazed at the child's response and asked other staff to, "Come see." Then, the engagement expanded even more. The child took a candy, dipped it into the icing as if he was going to place it onto the house, but instead, he put it on his head and gave a half smile to the museum educator. The implications of the child's response showed the child's spirit emerging underneath his traumatized and paralyzed exterior.

Though the activity brought to the side of this child's hospital bed was not a miracle cure, it offered a new distraction and discovery opportunity for that child to play, explore, and engage in normalcy for a brief time. In that moment of normalcy, hospital staff, the father of this child, and museum partners were able to witness hope in action. The museum educators learned the impact of collaboration with nearby community resources. The family was able to share in future community connections when they visited the museum after being discharged from the hospital.

Innovative Collaboration Comes Alive with Shared Vision

support coping and offer natural teachable moments in community settings. In these moments of normalcy, the child's potential for physical, intellectual, and emotional healing has been revealed. HTHOS provides a nexus where the life-giving properties of medicine and education meet to positively affect the trajectory of children and their caregivers.

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views, findings, conclusions, or recommendations expressed in this article do not necessarily represent those of the Institute of Museum and Library Services. **

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Table 1.

Research Evidence/Effort Categorized by Component of Child Life

PARTNERSHIPS	ANN ARBOR HANDS-ON MUSEUM AND C.S. MOTT CHILDREN'S HOSPITAL	THINKERY AND DELL CHILDREN'S MEDICAL CENTER OF CENTRAL TEXAS	CREATIVE DISCOVERY MUSEUM AND CHILDREN'S HOSPITAL AT ERLANGER
Location	Ann Arbor, MI	Austin, TX	Chattanooga, TN
Staff/Volunteers	 Museum education/programs staff, child life department, creative arts, patient experience leaders, interdisciplinary staff Professional Organization Providers: phlebotomy, nursing, PT/OT/speech, perioperative services, acute pain service, emergency techs Volunteers: Patient-family advisors, teen advisors, university students including: child life, medical, dental, and nursing, and public health students 		
Funding	Internal Grants through Michigan Medicine FRIENDS GIFT Shop provided seed funding to begin the original program. Institute of Museums and Library Services (IMLS) Donors interested in both institutions have supported museum exhibit installations at children's hospitals, health-focused exhibits at museums, and programming and supplies	Institute of Museums and Library Services (IMLS)	Institute of Museums and Library Services (IMLS)
Resources:	Toolkit: https://www.aahom.org/educate/healing-through-hands-science Link to video What's in Your Blood? MottTube: https://youtu.be/nHc_d2fr5ml		

REFERENCES

Ellerton, ML., & Merriam, C. (1994). Preparing children and families psychologically for day surgery: An evaluation. *Journal of Advanced Nursing*, 19(6), 1057-62.

Koukourikos, K., Tzeha, L., Pantelidou, P., & Tsaloglidou, A. (2015). The importance of play during hospitalization. *Mater Sociomed*, 27(6), 438-441.

Li, H.C.W., and Lopez, V. (2008). Effectiveness and appropriateness of therapeutic play intervention in preparing children for surgery: A randomized controlled trial study. *Journal for Specialists in Pediatric Nursing*, 13, 63-73.

Michigan Medicine. (2020). Office of Patient Experience. https://medicine.umich.edu/dept/office-patient-experience-child-k-Family-Life-https://www.mottchildren.org/mott-support-services/cfl

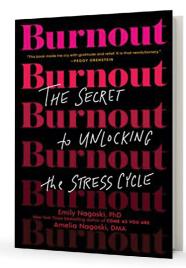
Potaz, C., Vilela De Varela, M.J., Coin De Carvalho, L., Fernandes Do Prado, L., & Fernandes Do Prado, G. (2012). Effect of play activities on hospitalized children's stress: A randomized clinical trial. Scandinavian Journal of Occupational Therapy. Early Online, 1–9.

Rollins, J., Bolig, R., & Mahan, C. (2005). Meeting children's psychosocial needs across the health care continuum. *Preparing Children, and Play in Healthcare Settings*, pp. 43-117.



Burnout: The Secret to Unlocking the Stress Cycle

by Emily Nagoski and Amelia Nagoski



e can do hard things" is a mantra made popular by author Glennon Doyle, and if any group of professionals is proof of this, it's child life specialists. But how do we keep doing hard things, over time, without burning out? Authors, educators, and twin sisters Emily Nagoski, PhD, and Amelia Nagoski, DMA, discuss this in depth in Burnout: The Secret to Unlocking the Stress Cycle. They offer a fresh perspective to a topic that generally manifests eye-rolls or wry smiles with accompanying statements like "I know the importance of self-care, but who has time/money for that?" Self-care, compassion fatigue, and burnout are real concerns in the child life field. Add in a global pandemic mixed with social and political unrest, and perhaps the topic of burnout has never been quite this relevant. Consistent with child life standards of evidence-based practice, the authors use empirical evidence to explain the science behind burnout and their recommendations for addressing it. The book offers a unique lens about how Western culture and socialization impacts our responses to stress and our ability to effectively process it. Written with an accessible mix of science, heart, and humor, readers will likely experience feelings of validation, self-compassion, and empowerment — as well as gain some new ideas (really!) to implement that could reduce stress and burnout.

Nagoski and Nagoski include scientific explanations of the stress response cycle along with the concept of *emotional tunnels*, an analogy that describes the feeling of being "stuck" when unable to effectively process difficult emotions related to stressful experiences. Our stress response systems are meant to be activated temporarily so we can face specific stressors, and once we have addressed the stressor, our nervous system should begin to go back to baseline. However, as the authors point out, "one thing we know for sure doesn't

work: just telling yourself that everything is okay now. Completing the cycle isn't an intellectual decision; it's a physiological shift" (p. 21). When faced with ongoing or daily stressors, our stress response system will stay activated over days, months, or even years, leading to all sorts of negative physical and emotional effects, including burnout. Child life specialists tend to be driven, passionate, empathic, and feel great pride and reward in the support we provide for patients and families. We provide this support within the most stressful of circumstances, and compassion fatigue and burnout are valid responses to this difficult work. This book helps us understand why the high value we place on our work or traditional suggestions for self-care practices are not necessarily enough to protect us from burnout. The authors discuss how readers can learn to better connect with their body to assess whether they are stuck in an emotional tunnel and offer specific ways to make physiological shifts to complete the stress cycle.

Although this book was published before the pandemic, it feels particularly relevant now, when many of us feel the exhaustion of role strain by having to "do it all" in the face of unprecedented stress. Women, and particularly mothers, have been identified as being extraordinarily impacted by the cumulative strain of the past year and a half. Experts predict the social and economic impact for women will last for decades and potentially set the trajectory for gender parity back by a full generation (World Economic Forum, 2021). The Nagoski sisters acknowledge that their discussion of the impact of patriarchy on our society may make some readers uncomfortable. It may be well worth pushing through any resistance to this term to reflect on how social conditioning, particularly of women, has made it more difficult to process stress effectively. While also celebrating the strength, determination, and caretaking qualities that contribute to success in fields such as ours, readers are offered a perspective about how gen-

Book Review: Burnout: The Secret to Unlocking the Stress Cycle

dered social conditioning, striving for perfection, and being "human givers" can lead to increased emotional burnout and may inhibit our ability to fully benefit from meaning-making opportunities. Of course, males have their own significant and valid cultural conditioning that impacts their stress responses and emotional expression, but that is not the focus of this book. In this regard, male child life specialists may not find all the chapters of this book directly relevant to their own experiences.

Practically speaking, the authors offer many opportunities for learning and self-reflection, including sporadic writing prompts that encourage readers to process their own experiences and set attainable goals. They share relatable stories of women from various backgrounds, connecting and applying concepts presented throughout the book. Readers are encouraged to begin to shift mindsets, patterns, and behavior to thrive both personally and professionally. The authors introduce specific

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practices that promote coping with stressors: both those over which we have control, and those we don't. This topic may be particularly relevant for child life specialists, who tend to be excellent planners and problem solvers, but who also face many situations within which we inherently have little or no control. Unique strategies are useful for different types of stressors, and acknowledging this may be a key part of improving our ability to effectively process the emotions and stress that result from each.

Author Peggy Orenstein is quoted on the cover of this book, stating "this book made me cry with gratitude and relief. It is that revolutionary." It may not be hyperbole to make this bold claim — readers may find themselves tearing up with the relief of validation, exclaiming "yes!" out loud to the pages of this book or pausing in the middle of a chapter to share quotes with colleagues or friends. Burnout offers a new conversation and direction for a topic that, despite its importance, had grown somewhat stagnant. The conclusion of the book states: "Your joy matters. Please tell everyone you know." For all of you amazing child life specialists who are doing it all and bringing joy to so many in the face of heartache and pain: your joy matters, too. Prioritizing your well-being will bring you more of it and may prolong your ability to continue to do this work with greater satisfaction, more energy, and, of course, less burnout. 🔭

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UPCOMING WEBINARS

Emotional Safety: Staff Communication, Education, and Training Pillar July 15, 1pm EST

Supporting LGBTQ+ Youth and Families: The Role of Child Life
July 30, 1pm EST

Engaging Community Partners in Virtual VisitsAugust 10, 1pm EST

Leveraging Extended Reality to Shape the Future of Patient Experience
August 16, 1pm EST

Applying Ethical Principles to Everyday Situations

August 30, 1pm EST

Foundational Interventions of Child Life Practice

September 15, 1pm EST

Child Life & Digital Art Therapy Collaboration September 30, 1pm EST

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JULY

- 1 Submission deadline for ACLP Bulletin articles for consideration for the Fall 2021 issue
- 1-31 Call for 2022 Child Life Annual Conference Abstract Submissions
 - 14 Call for nominations for the 2022 Distinguished Service Award open
 - 14 Call for nominations for the 2022 Mary Barkey Clinical Excellence Award open
 - 21 Layered Book Club Meeting: Living on the Borderlines

AUGUST

- 9 Initial application with names only due for 2022 Distinguished Service Award
- 9 Initial application with names only due for 2022 Mary Barkey Clinical Excellence Award
- 10 Deadline to apply for the August administration of the Child Life Professional Certification Exam
- 15-30 Child Life Professional Certification Exam administration testing window
 - 22 Deadline to submit transcripts and other documentation in time to apply for the 2022 Winter/Spring Internship
 - 30 2022 International Scholarship applications open

SEPTEMBER

- 5 Application deadline for the 2022 Winter/Spring Internship
- **TBD** Application deadline for Mentor Program
 - 9 Supporting documentation due for 2022 Distinguished Service Award
 - 9 Supporting documentation due for 2022 Mary Barkey Clinical Excellence Award

OCTOBER

- 1 Submission deadline for ACLP Bulletin articles for consideration in the Winter 2022 issue
- 1 Application open for 2022 Research Recognition Awards (Professional and Student)
- 18 Deadline to submit your coursework documents for review in time to register for the November Child Life Professional Certification Exam
- 27 Deadline to apply for the November administration of the Child Life Professional Certification Exam
- 31 Deadline to apply to recertify through PDUs

NOVEMBER

- 1 Applications due for 2022 Research Recognition Awards (Professional and Student)
- 18 Applications due for 2022 Winter/Spring Diversity Scholarships

DECEMBER

- 20 Your documents must arrive at the ACLP office by this date to ensure sufficient time for processing and approval before the January 5, 2022 deadline to apply for a summer 2022 internship.
- 31 Last day to reinstate lapsed CCLS credential