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ACLCP Bulletin

A PUBLICATION OF THE ASSOCIATION OF CHILD LIFE PROFESSIONALS

SUMMER 2019 | VOL. 37 NO. 3

In Focus:

**Voice and Choice:
Upholding Autonomy and
Other Critical Ethical
Constructs in Pediatrics**

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OF CHILD LIFE PROFESSIONALS

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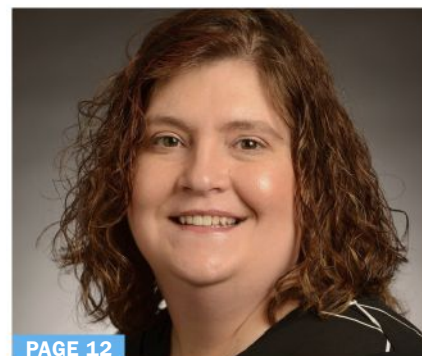
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CHILD LIFE FOCUS:

- 29 Voice and Choice: Upholding Autonomy and Other Critical Ethical Constructs in Pediatrics





from the **Executive Editor**
Kathryn Cantrell, PhD, CCLS

Introducing *The Journal of Child Life: Psychosocial Theory and Practice*

One of the ways child life professionals ensure that their practice is ethically sound is by remaining well informed on the latest research, theory, and practice innovations in the field. But finding research on child life can be a daunting task, as many studies are published in journals developed for other fields including nursing, psychology, and medicine. Having our own empirical journal specific to the field of child life guarantees that we have easy access to advancements in evidence-based practice. The editorial team is honored to take time in this special issue to announce the unveiling of a new space for disseminating your latest and greatest ideas. In March 2020, ACLP will launch *The Journal of Child Life: Psychosocial Theory and Practice* as a biannual publication aimed at housing your writings on original research, theory, program evaluation, and more. *ACLP Bulletin* will remain a quarterly newsletter but will no longer include *Focus* as an insert; instead, articles previously published in *Focus* will be moved to the new journal. The launch is a culmination of years of hard work by the current and past editorial teams, the Bulletin Committee and Focus Review Board's tremendous volunteers, ACLP staff, and the ACLP Board of Directors. We are thrilled to share the results of this work with you and watch the project come to life. Please see our one-page ad on page 5 to learn more about the publication and our call for papers. We encourage you to share your voice with your peers in this exciting new format.

As you begin to brainstorm what to write for

our new publication, look no further than this issue to remain up to date on advancements in the field. This special issue's theme is "Ethics as a Professional Mandate in Child Life." We chose the term *mandate* to emphasize the inevitability of encountering ethical dilemmas in our work. Each day, child life professionals are faced with decisions that require us to question how our work protects patients, promotes good, and delivers justice. As we choose which patients to prioritize, which programs to fund, which information to share, we are constantly making decisions that rely on our ethical knowledge and skills. As such, "it is imperative that all child life professionals understand the basic principles of ethics and how to apply them not only to significant decisions but also to daily healthcare scenarios" (Hannan, 2019, p.6). We anticipate each reader, whether a student, intern, practicing specialist, or veteran in the field, will find something in this issue to expand their ethical understanding. To set the stage, multiple articles cover foundational ethical principles while others provide valuable resources to assist with ethical decision making. In addition, the issue contains in-depth discussions of specific ethical dilemmas including separation at the border, working with families who refuse services, the cost of child life training, and working in patients' homes. The issue culminates with Emily Margolis, MS, CCLS's in-depth *Focus* article exploring variables that impact patient autonomy across healthcare settings. From practical updates to theoretical discussion, we expect you will find something new in our special issue to expand your view on ethics.

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Past President's Reflection

Stephanie Hopkinson, MA, CCLS

Appreciation, Reflections, and the Future

Child life community—what an honor and privilege it was to serve you as president of our association. As I reflect on this year of service, I am grateful to be a part of an association and professional community who work so hard to move us forward, and I am inspired every day by the work that is done. ACLP has accomplished so much over the past 12 months and work continues to lead the way in many aspects of child life and healthcare. ACLP's new strategic plan positions us for where we are going next, with exciting movement already taking place. Committees, task forces, the board of directors, ACLP executive leaders, and ACLP staff continue to work hard with thought, care, and focus. The work over the past several years to create a central system where we can collect data across child life programs is amazing and continues to be an area that we want to build upon. As we continue to enter data in the Child Life Professional Data Center and gather more information, we are well positioned to capture the capacity of impact of our work, tell the stories of services, and advocate for our work using data. The endorsement of academic programs has gotten off to a great start, and more programs continue to be acknowledged for their work. The Patient and Family Experience Committee is working with ACLP staff to design an emotional safety summit, where we will have the opportunity to bring together key stakeholders both inside and outside of ACLP. The opportunity to engage in critical dialogues on the current landscape of all that encompasses emotional safety in pediatric healthcare will help us set the stage for leading the

Our engagement with other associations and organizations has given us the opportunity to contribute to the momentum of change in healthcare, positioning us in a place where others come to us for our expertise, knowledge, and experience.

way in this critical area. Two new position statements have been released: Child Life Practice in Community Based Settings and Child Life Practice with Children of Adult Patients. These statements acknowledge the current work of child life practice in community-based settings. New task forces have been approved: a Clinical Ladder Task Force; a Diversity, Equity and Inclusion Task Force; and a Student Education Task Force. These task forces create opportunities for us to dig deeper into the current trends and needs in child life and support the trajectory of movement forward. Our engagement with other associations and organizations has given us the opportunity to contribute to the momentum of change in healthcare, positioning us in a place where others come to us for our expertise, knowledge, and experience.

At ACLP's annual conference in April, the synergy of our community was seen and felt as participants moved through the hallways, exhibit hall, and sessions. Attendees engaged in thought-provoking conversations and experienced opportunities for learning and growth throughout the conference. Jason Wolfe, CEO and President of the Beryl Institute, shared a motivating keynote address acknowledging our expertise in healthcare and inspiring us in our everyday work with children and families. The Child Life Archives came to life in the exhibit hall this year, and the highlights of our history being displayed allowed us a place to connect with the richness of our past.

Each of our stories connects us together as we strive in our vision of advancing psychosocial care and the emotional safety of children, youth, and families impacted by healthcare and significant life events. I am inspired by each of you and the work you do every day to move child life forward. As I end this year of serving as president, I am excited and profoundly honored to pass this leadership onto our next president, Jill Koss, MS, CCLS, and I want to express my deep appreciation to all of the volunteers, staff, and the board of directors for your unwavering commitment to ACLP!

We are ACLP!



CEO Shares

Jennifer Lipsey, MA

Ethics as a Professional Mandate in Child Life

This issue of *ACLP Bulletin* marks the middle of the year and provides the perfect opportunity to assess where we are in meeting our annual goals specific to our strategic plan. We are on a strong trajectory, having created three new task forces (Diversity, Equity, and Inclusion; Student Education; and Clinical Ladder); approved a new membership structure that will roll out in the fall; nearly doubled our traffic and sales of online content in our new learning management system; and exceeded our registration, exhibitor, and sponsorship goals for our 2019 Annual Child Life Conference. Progress builds excitement and motivates further momentum. The challenge is to temper enthusiasm with a cautionary approach, which oftentimes require patience and a watchful eye on trends to inform next steps forward.

The topic of ethics always produces lively and engaging discussions. Most recently, an ethical issue related to social media arose through a call to action from a few members requesting that ACLP intervene and/or take disciplinary action against some social media users who were posting satirical memes about child life. Specific posts were brought to our attention that were seen by some as characterizing child life specialists, the profession, and/or the association in a derogatory manner. While the content posted may be controversial, our fiduciary responsibility supersedes our initial reaction to respond. Protecting the public from entering into a therapeutic relationship with an unqualified practitioner is the main purpose of the CCLS credential. Although Certified Child Life Specialists are obliged to follow the Child Life Certification Commission (CLCC) Code of Ethics, ethical violations can be challenging to define. One consideration CLCC must make when imposing sanctions is whether a patient or family was put in harm's way because of a Certified Child Life Specialist's actions. Regardless of how we may personally feel about this

social media content, it is not injurious to patients and their families.

While some may find such content offensive, distasteful, or potentially harmful to the profession's or association's image, ACLP cannot interfere with individuals' freedom of speech. More so, we should expect and welcome public scrutiny as opposed to reprimanding individuals for their use of their personal social media accounts. This is not to say that we condone such content, but rather, we suggest that, if so inclined, individuals may comment directly to the creator of the content with which they disagree. This kind of rebuke could make the other party aware of the potential consequences of their social media presence. We also remind members that people (peers, future employers, etc.) may perceive social media content as a reflection on one's character. Many of us may use sarcasm and wit to commiserate and connect on occasion; however, creating an environment steeped in it could be toxic and counterproductive.

Another matter that may produce equally lively discussion is related to our heightened focus on diversity, equity, and inclusion. It is relevant in this discussion of ethics because it presents questions of right and wrong. Unfortunately, like many ethical dilemmas, these issues are not clear-cut. However, our ethical obligations compel us to examine the demographics of our membership and the conditions that have kept the profession homogenous. We have a moral imperative to investigate whether our infrastructure discriminates and what adjustments can be made to ensure that all have an equal opportunity to become engaged and successful in the child life community. We must identify factors that have led to our membership being comprised of so many of the same socioeconomic class, race, and gender. We want child life practitioners to be as culturally diverse as their patient populations. As

[*continued on page 4*](#)

Ethics as a Professional Mandate in Child Life

such, we should strive to build a membership more representative of patients' and families' cultural identities. We don't yet know what possible solutions may exist, but to do nothing except accept the status quo without reflection on its impact on patient engagement would most definitely be wrong.

While the CLCC is actively completing a feasibility study to assess whether to develop an advanced practice certificate/credential, ACLP is also considering other avenues to leadership development. As more leaders look to retire in the upcoming years, we want to ensure that their positions are backfilled by fellow child life professionals. We are considering whether a mechanism

such as a credential or certificate could help hospital administrators recognize that child life specialists have demonstrated mastery of content specific to child life and leadership, making them uniquely qualified for desirable manager/director roles.

Ethics, diversity, leadership development, advanced practice . . . these are only some of the stepping stones before us as we finish 2019. They are topics heavy in gravity that will stretch and challenge us. We will approach them with enthusiasm, diligence, and care, knowing that it is our time to demonstrate our thought leadership, strong community, and commitment to ethical behavior. ✨

Milestones

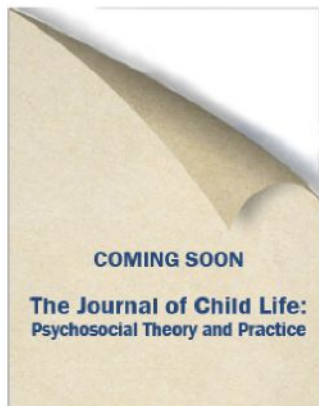
The global child life community lost a pioneer of child life in Kenya when child life specialist **Jayne Kamau** died in the Ethiopian Airlines crash on March 10, 2019. Jayne worked with the Sally Test child life team at the Shoe4Africa Children's Hospital at Moi Teaching and Referral Hospital in Eldoret, Kenya, and was a founding board member of the Kenya Association of Child Life. Jayne fell in love with child life and used her passion to introduce the profession into a medical culture unfamiliar with it. Jayne was devoted to building the profession within Kenya and across Africa in a locally sustainable way. She was a dynamic presenter at international pediatric oncology conferences about innovative child life supports for retinoblastoma patients in Kenya. Bank Street College of Education awarded Jayne an honorary master's degree posthumously. Jayne will be sorely missed by her colleagues and friends, who will remember her for her constant support, passionate advocacy, and quiet leadership for greater child life presence across Africa.

The child life world suffered another loss in April of this year, when **Charlotte "Charlie" Wallinga** passed away. Charlie was instrumental in building the foundation for child life education at the University of Georgia, where she developed the child life program and directed it for more than 25 years. Charlie retired in 2014 after more than 30 years as a faculty member. During her long career, she inspired students to pursue the field of child life and continued to be a supportive presence even during their professional careers in the field. Charlie was a sparkling presence in the department; her voice and laughter bright and loud, and her commitment to her students fierce. Charlie had a vision she fought for regardless of challenges. Her energy, kindness, and spirit were well known among her many colleagues, former students, and friends. Charlie was a true pioneer in child life education and an inspiration to so many. She will be missed.

Sheila Palm, MA, CCLS, recently retired as the child life manager at Children's Hospitals and Clinics of Minnesota after 43 years of service with this organization and with ACLP. Following her internship at Johns Hopkins Hospital, she began her career at Minneapolis Children's Medical Center, transforming a three-person program into a staff of 20 members. In 1993, the pediatric hospital merged with Children's-St. Paul creating Children's-Minnesota, with Sheila leading the integration of two separate child life programs into a system-wide department. Under her steady and innovative leadership, the staff has grown to a department of over 50 individuals, including music therapy and healing arts, at two pediatric hospitals, four off-site community locations, and pain/palliative programming.

Beyond her work within her own institution, Sheila continually shares her expertise as a consultant on the ACLP Program Review and Development Service. Sheila's ACLP commitments included time as president and treasurer, as well as significant work on the ACCH/CLC transition task force, certification, clinical supervision, strategic planning, and as a book author. She has been chair and a member of many committees that have moved the profession forward. In retirement, Sheila plans to engage her love of the outdoors and travel.

The Journal of Child Life: Psychosocial Theory and Practice



Call for Articles

For several years, the Association of Child Life Professionals has been exploring the possibility of having a professional journal. This goal will become a reality when we launch ***The Journal of Child Life: Psychosocial Theory and Practice*** in March 2020 during Child Life Month.

“This is an important step in moving the profession forward, and we need your help to make it a success.”

**Jill Koss, MS, CCLS
ACLP President**

This new journal, with more robust research content, will be an outgrowth of *Focus*, which will no longer be a part of *ACLP Bulletin* in 2020. The editors of *The Journal of Child Life: Psychosocial Theory and Practice* are seeking the following types of articles:

- Quantitative research
- Qualitative research
- Substantive, systemic literature reviews
- Program development, with pre- and post-implementation data
- Analysis of theory as applied to child life

See *Submission Guidelines & Instructions* on the ACLP website.

Look for more exciting updates as we roll out *The Journal of Child Life: Psychosocial Theory and Practice*!

www.childlife.org



Editors' Introduction to the Special Issue on Ethics

We are very excited to bring you this special issue of ACLP Bulletin, focusing on ethics in the profession of child life. This issue addresses an extensive variety of topics that impact child life professionals at all phases of their careers. Please note that the study and application of ethical principles may be defined in a number of different ways by various authors, and no one particular overview is universally accepted as the only correct or acceptable description of ethics. For example, some ethical theorists assign three major components to ethics, some list four, and some include even more. We hope you will appreciate the diversity of approaches to this topic as presented by our various authors.

HONORING CHILDREN IN HEALTHCARE: An Ethics-Based Approach to Acute Decision Making

Ann Hannan, MT-BC

RILEY HOSPITAL FOR CHILDREN, INDIANAPOLIS, IN

Ethical decision making is complex and multifaceted. Ethical principles can often come into direct conflict with each other, presenting unique challenges for healthcare clinicians. When supporting children, families, and colleagues during the hospital experience, it is imperative that all child life professionals understand the basic principles of ethics and how to apply them, not only to significant decisions, but also to daily healthcare scenarios.

An introduction to ethical principles includes identifying the four fundamental principles of autonomy, beneficence, non-maleficence, and justice. In addition to these principles, the concept of veracity and fidelity are integral components to providing balanced delivery of care. The following scenarios will demonstrate each of these principles, how they interact with each other, and how ethically-motivated clinicians can utilize these concepts to distribute clinical intervention, promote resilience in patients and families, and engage in practices to

develop healthy professional relationships and work balance.

The principle of autonomy focuses on the concept of respect for persons. With regards to children, this includes evaluating developmental capacity for assent, creating an environment that supports realistic and consistent choices, and facilitating a balance between the child's preferences and those of the parents, guardians, and caregivers. Regardless of age and developmental capacity, children should be active participants in their healthcare experience, and the child life

specialist can promote this participation through careful assessment and creative intervention.

When engaging in the delivery of healthcare interventions, each goal contains a component of beneficence: the promotion of good. While there are differing approaches to the philosophy of this concept, ultimately the intention of a child's plan of care is to maintain or improve the current state from a physical, physiological, psychosocial, emotional, and spiritual perspective.

The quintessential tenant of the Hippocratic Oath is "First, do no harm." Non-maleficence is the proactive identification of potential harm and active mitigation of this harm. Due to the invasive nature of healthcare intervention, elimination of all harm is impossible. For example, life-saving medications and fluids are delivered by a process of venous puncture, which inevitably causes physical pain and the potential for emotional distress related to the child's perception of the procedure. This process is considered a "harm." To proactively decrease the negative impact of such an intervention, a child life specialist can prepare a child for the impact of an IV placement through developmentally-sensitive preparation and active engagement during and after the procedure to assess physical pain and emotional distress.

The concept of justice in healthcare includes not only the provision of services but also the manner in which each service is provided, including the frequency and intensity of each intervention. Child life support is a valuable resource

which is limited by external factors, including the balance between the availability of clinicians and the volume of patients in need. This ethical principle is demonstrated during each healthcare decision and creates the greatest opportunity for dissatisfaction for patients, their families, and providers. Each decision in the clinical treatment process leads to a situation of "have" and "have not." When a child life specialist intervenes with one patient, another child may not receive service at that time. A clinical decision to triage one procedure over another creates a hardship for the physician or nurse left to conduct a treatment intervention without child life support.

These dichotomous situations lead to conflict between healthcare professionals, caregivers, and patients, which elevates two secondary ethical principles of veracity and fidelity. Veracity explores the concept of truth telling within the healthcare context. Truth telling must occur in two realms to achieve ethical decision-making practices: truth telling related to self, and truth telling related to others. Healthcare professionals are mandated to provide patients and their caregivers with unbiased and complete information about their condition and treatment options. The ability for children to comprehend information about their healthcare experience is impacted by chronological age, developmental needs, emotional development, past healthcare experiences, and personal coping mechanisms. Each child's qualities are intensified by their caregivers' personal history and healthcare literacy. Objective truth telling is compounded by a

clinician's ability and willingness to engage in self truth telling. This includes a continuous process of self-evaluation of one's clinical abilities and personal and professional values. A singular focus on objective truth telling with others can lead to a lack of awareness of how one's own healthcare experience and balance of values influences the therapeutic relationship.

Engaging in the principle of veracity leads to the development of fidelity of relationships. When engaging in professional relationships, healthcare clinicians find commonalities in practice and processes and enter into partnership to care for patients and families. Simultaneously, clinicians develop rapport with these patients and families throughout the therapeutic process. The commitment to these relationships reflects the principle of fidelity because ethically motivated clinicians will want to honor implicit and explicit promises made to all individuals engaged in the relationship. As with the previous ethical principles, clinicians may experience conflict when competing needs arise in professional relationships. At any given time, the need of a nurse for procedural support during a challenging acute intervention for one patient may be in direct conflict with the need for extended medical play and exploration of a different patient with a chronic condition prior to an impending surgical intervention. Additionally, clinicians may pose differing opinions about the best course of treatment for a patient, creating potential conflict among team members and between the family and the healthcare team.

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Honoring Children in Healthcare: An Ethics-Based Approach to Acute Decision Making

When this conflict arises, child life specialists may find themselves deliberating between these two sets of relationships as they also explore the concept of truth telling between colleagues and between the family and professional team. While the concept of paternalistic medicine has been predominantly replaced by family-centered care in pediatric hospitals, healthcare teams may inadvertently or purposefully withhold information about treatment options if they hold strong opinions about the validity or feasibility of a specific option. Likewise, families may choose to withhold information from a child regarding his or her treatment process out of fear of reaction from the child. The child life specialist will naturally engage in a process of sorting out the complexities of maintaining a stance of truth telling while meeting the unique needs of each clinical and therapeutic relationship.

As child life professionals explore these ethical principles and how

they relate to their current service delivery, they will benefit from opportunities to practice these concepts prior to making acute decisions. Some methods of practice include debriefing significant cases with a peer or supervisor, actively reviewing professional decisions, and writing a descriptive response weighing the values and limitations of a specific chosen course of action. In order to honor the relationships one develops with clinicians, families, and patients, child life specialists may benefit from completing a personal values assessment or character strengths assessment (see online resources, below). The results of this type of questionnaire will help clinicians identify potential blind spots or personal triggers that may preclude objective delivery of information, services, and compassionate care. Clinicians can also review their own code and guidelines for professional conduct and ethical codes from related clinical fields to gain deeper understanding of how they are expected to

respond to challenging situations and how others may be interpreting a specific situation. Finally, most hospital systems provide at least a basic ethics consultation service, and their professionals are specially trained to engage their colleagues in conversations to explore these ethical concepts with the goal of providing holistic patient care.

The evaluation of child life service delivery from an ethical framework will not create simple answers or concrete justifications for decisions. Instead, this framework provides a tool for clinicians to develop methods to evaluate the complex and competing needs of children, their families, and other healthcare professionals when decisions need to be made quickly in a high intensity environment with significant emotional, physical, and spiritual implications. ✨

Acknowledgment: This author receives ongoing mentorship and support from the [Charles Warren Fairbanks Center for Medical Ethics](#) in Indianapolis, Indiana.

ONLINE RESOURCES:

Personal Values Assessment <http://www.valuescentre.com/our-products/products-individuals/personal-values-assessment-pva>

Character Strengths Assessment <https://www.viacharacter.org/www/Character-Strengths-Survey>

ACLP Code and Guidelines for Professional Conduct <https://www.childlife.org/certification/codes-and-guidelines-for-professional-conduct>

FOR FURTHER READING:

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ALPHABET 2.0



R is for Research Ethics: Humanizing Qualitative Research Methods

Alison J. Chrisler, PhD, CCLS

HOPE FOR HENRY FOUNDATION, WASHINGTON, DC

Child life professionals are increasingly involved in data collection and research activities. Although this is a very positive step for the profession, it brings with it a number of challenges. One of the most important of these challenges is the utilization of ethical practices when conducting research. As in any other part of child life work, researchers must ensure that the research process is ethically appropriate and humanizing for its participants. According to the Belmont Report, three fundamental principles of research ethics must be followed: respect for person, beneficence, and justice (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978). “Respect for person” ensures that participants are aware of their rights and are well informed about the study prior to consenting to participate. The purpose of “beneficence” is, at a minimum, to “do no harm” by minimizing risks and maximizing benefits of those participating in the study. As for “justice,” participants need to be treated fairly. Therefore, the selection of participants needs to be equitable and those participating must likely benefit from the completed study (Owonikoko, 2013).

Every university and healthcare institution is required by law to have an Institutional Review Board (IRB) whose primary task is to protect the welfare of human research participants. The IRB uses all of the traditional tenets of professional ethics in reviewing all research done at that institution. During this review process, the IRB committee, often consisting of a panel of seasoned researchers, reviews the study protocol. The protocol includes the goal of the study, as well as the set of procedures used to complete the work. This includes an overview of the inclusion and exclusion criteria of participants, recruitment strategies, what will be asked of those participating in the study, and the consent process. To ensure individ-

uals understand their rights as participants of the study, before obtaining consent, the research team needs to explain to participants 1) the purpose of the study, 2) the role of participants during the research study, 3) possible risks and benefits of participating, 4) that participation is voluntary, and 5) how data are used and shared with others. The IRB review, ultimately, is conducted to minimize risk and potential harm to participants.

Though this process is necessary to ensure research ethics are upheld, there is little attention placed on whether the research procedures used in the study are “humanizing.” Many qualitative researchers believe that qualitative research methodologies, such as observing and interviewing participants, are inherently humanizing. Paris and Winn (2014) challenge researchers to be “more mindful of how critically important it is to respect the humanity of the people who invite us in their worlds and help us answer questions about education, social, and cultural justice” (p. xv). Therefore, we might ask ourselves when and how often we are interviewing the participant. During the interview, are we offering any feedback or support, or are we simply listening to ensure objectivity of the data being collected? For those of us engaged in research, we need to critically examine how we balance our role as a child life specialist and researcher. It is critical that we continually engage in the act of self-reflection and deconstruct our research methodologies to ensure the needs of patients and families are at the center.

How, as child life specialists, can we engage in humanizing research? Firstly, anticipating ethical dilemmas that might arise during data collection is critical. For example, imagine interviewing a patient about her chronic illness and during

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the conversation, the youth becomes upset and cries about her prognosis. Do we stop the interview, or do we continue? Do we offer support, or do we remain an objective, silent observer for the sake of the study? Continuing with the interview privileges the research process and puts the patient's needs second (Orb, Eisenhauer, & Wynaden, 2001). In anticipation of this dilemma, consider "ongoing consent" rather than a one-time consent process (Richards & Schwartz, 2002). Due to the sensitive nature of data collected from patients and families who are hospitalized, reminding participants they can stop the interview and exit the study at any time is critical.

Secondly, we need to actively engage in self-reflection throughout the research study. Guillemin and Heggen (2009) argue that it takes courage to look within and question ourselves as researchers. When faced with an ethical dilemma, we might ask ourselves and others whether we did or said the right thing, which may warrant criticism and judgement. However, this process of asking for and receiving feedback allows us to refine our research practices to ensure the needs of patients and families are met. Additionally, we need to create a safe space to process the pain stories of others. Though most child life specialists would agree that working alongside children and youth who are hospitalized is a privilege, it is important to recognize the emotional toil of witnessing both physical and psychological pain. Throughout the research process, the researcher might consider journaling or having one-on-one conversations with

peers or mentors as a way to process emerging feelings and discomfort (Kendall and Halliday, 2014).

Lastly, more attention needs to be placed on how we exit the researcher-participant relationship. Within the context of research, we often assert that at the conclusion of the study, we end the relationship with the participant. For some studies, significant time spent with participants is inevitable. During these interactions, participants share their lived experiences, and at times, divulge deep secrets. This sharing can lead to an unexpected level of intimacy between the researcher and participant. Therefore, when the study concludes, how do we end the relationship? At the outset, researchers might consider discussing with participants how they will end the relationship at the conclusion of the study. In addition to encouraging researchers to consider their exit strategy, Figueroa (2014) urges for an institutional change, where IRBs and peer reviewers during the publishing process routinely ask the researcher not only how they gained access to a community but also how they exited the relationship. By doing so, researchers will spend more time developing a plan on how to exit the relationship in a humanizing way.

When engaging in qualitative research, it is critical that we look beyond what is expected in an IRB submission. Anticipating ethical dilemmas, engaging in self-reflection, processing the pain stories of others, and developing a plan of how to exit the researcher-participant relationship ensures the research methodologies being used are not only ethical, but are humanizing and patient- and family-centered. ✨

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Annette Bonjour:

2019 Mary Barkey Clinical Excellence Award Recipient

Ashley Rapske, CCLS

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When describing Annette Bonjour, CCLS, the 2019 Mary Barkey Clinical Excellence Award recipient, her colleagues use words such as determined, spicy, and humorous, which were exemplified in her awards presentation at the 2019 Child Life Annual Conference. Annette's foundation in child life began while growing up as she helped care for her sister with special needs and accompanied her to countless medical appointments. Looking back, Annette describes herself as being her sister's best advocate and personal child life specialist before she even knew what child life was.

Annette currently serves in an innovative role as a Behavior Safety Team (BST) child life specialist at Cincinnati Children's Hospital Medical Center and has developed expertise in helping patients who exhibit aggressive behaviors to safely receive the medical care they need. Annette prioritizes safety and proactively identifies and implements adaptive strategies to prevent potential sources of harm for patients, families, and staff. She is the expert in in-depth pre-visit planning and coordination for complex, high-risk patients,

and she mentors her child life peers in performing comprehensive psychosocial assessments and providing care to meet the unique needs of patients with developmental and behavioral challenges. Annette consistently demonstrates interdisciplinary teamwork and engages in group problem-solving to identify ways to adapt healthcare to meet patient needs. In response to a need for improvement in communication and documentation practices, Annette designed an electronic health record interface to facilitate interdisciplinary communication, collaboration, and pre-visit planning for high-risk patients. This interface allows for key members of the care team to simultaneously document in a shared care plan prior to a patient's healthcare visit. A patient's mother recently wrote a letter to hospital administration after working with Annette, expressing her gratitude for Annette's planning and support. In her letter commending Annette's work the mother states, "We quickly felt a reduction in stress. We felt we were in the hands of highly trained caregivers. Our daughter has a rare syndrome and a complex medical history. She is pro-

foundly delayed in many ways. It was immediately clear to us that every single person entering our room had read our daughter's Adaptive Care Plan so carefully prepared by Annette in child life. It was the first time we had this type of help since her illness began."

In addition to clinical care, Annette has been an integral member on a number of professional inquiry initiatives. Annette consistently demonstrates leadership and seeks out opportunities to participate in research, evidence-based practice (EBP), and quality improvement (QI). Annette is both a Point of Care Scholar and Rapid Cycle Improvement Collaborative graduate, demonstrating her expertise in EBP and QI. Furthermore, Annette is a key member of an ongoing research project, "Adaptive Care in the Perioperative Setting." Annette served as a team member of an EBP project, "Reducing Pain in Children and Adolescents Receiving Injections" that won a hospital award for the Best BEst (Best-Evidence Statement). Since completing the EBP statement, Annette has taken a leadership role in translating the research evidence into practice through her work

The Mary Barkey Clinical Excellence Award

Since 2010, the Association of Child Life Professionals has honored some of child life's most skilled professionals each year with the Mary Barkey Clinical Excellence Award. This award recognizes child life specialists who have demonstrated exemplary child life care and a high level of clinical skill. Award recipients are nominated by their peers in August, and the winner is notified by the ACLP

president later in the year. The recipient is honored at ACLP's Annual Conference, with formal presentation of the award during the Closing General Session. To nominate a deserving child life specialist, watch your email for the call for nominations. To read about previous recipients of the Mary Barkey Clinical Excellence Award, please visit the [ACLP website](#).

with the Pain Task Force. Annette was instrumental in the implementation of J-tip as a pain management option for patients at Cincinnati Children's and the development and roll-out of a procedure comfort plan for staff to document patient and family preferences for comfort measures to utilize during medical procedures.

Annette has presented locally, regionally, and nationally in the areas of adaptive care, working with patients who have developmental and behavioral challenges, the Psychosocial Risk Assessment in Pediatrics (PRAP), and professional inquiry. Annette has published and co-published several articles in *ACLP Bulletin* on topics related to professional inquiry, and recently co-published an article in *Pediatrics* titled "A Collaborative Approach to Improving Health Care for Children with Developmental Disabilities."

According to a colleague, "The child life profession has benefitted from Annette's drive to elevate the level of professional practice for all clinicians."

Due to the work Annette has accomplished, the multidisciplinary team better understands, values, and respects the role of child life. Annette's words of wisdom include: Do not settle, take

advantage of every learning opportunity, collaborate with others, and learn from your mistakes. Annette copes with potential stressors by not taking life too seriously and laughing at the end of each day. Her inspiring story and illustrious career have earned her the 2019 Mary Barkey Clinical Excellence Award. Annette's contributions to the field of child life are far from over, as she continues to work on projects to advance the field of child life at Cincinnati Children's Hospital and beyond. Congratulations on this well-deserved honor, Annette! 🌟

Calling All Mentors and Mentees!

Are you looking for "something more" in your career? A chance to practice new skills, an opportunity to reflect on where you're headed, or a new professional connection?

The ACLP Mentor Program matches Certified Child Life Specialists seeking support to enhance their skills and/or further their careers with child life professionals who wish to be mentors. It operates on the belief that everyone has something to teach, everyone has something to learn, and every child life specialist is a leader.

Since the program's inception, more than 130 pairs have been formed, reviewing skills and practices in support of the mentees' goals, which ranged from serving as a child life advocate to managing limited time, navigating chronic illness, and leading clinical supervision.

Applicants to the program (both mentors and mentees) may work in any area of child life practice, including clinical settings, community-based work, academia, and formal leadership roles. Accepted applicants are matched based on interests and experience, creating the optimal foundation for joint learning. Mentees then set individualized goals related to their clinical skills, leadership abilities, personal effectiveness, or overall career development, while mentors draw upon their own experiences,

knowledge, and leadership skills to provide guidance.

The Mentor Program consists of structured elements over a six-month period, including monthly meetings of mentors and mentees (in person, or via phone/video chat) and monthly professional development webinars. Participants earn PDUs for completing the required webinars, and mentors are eligible for one additional PDU for their overall program participation.

Applications for the 2020 Mentor Program will be released August 26 and must be completed by September 16. Help us spread the word! For additional information about the Mentor Program or to review applicant requirements, check out the [Mentor Program page](#) on the ACLP website today!

The program gave me the opportunity to encourage another child life specialist by simply listening, validating, and then sharing my past experiences to help set her up for success. We navigated together through situations and were able to see progress and growth. I enjoyed how the program created a personal way to connect with another child life specialist from a different program to share honest thoughts and ideas, and solve problems in a safe, encouraging way.

— HOLLY EMERSON, CCLS, 2018 MENTOR

The Ethics Committee of the Child Life Certification Commission

Lucy Raab, MA, CCLS

CHILDREN'S MERCY HOSPITAL, KANSAS CITY, MO

Sherwood Burns-Nader, PhD, CCLS

UNIVERSITY OF ALABAMA, TUSCALOOSA, AL

Child life specialists are ethically responsible to children, youth, families, students, and colleagues. We must be able to advocate for the best interests of patients and families and identify ethical issues as we perform in our daily roles. As we become adept at identifying ethical dilemmas, it is critical to understand the principles and to gain competence in navigating each situation. For example, a child life specialist may experience conflicting feelings regarding aspects of a patient's care and the actions of the member(s) of the medical team. In other words, the specialist is having an ethical conflict between the principles of beneficence and nonmaleficence. Another child life specialist might feel "stuck in the middle" when there is disparity between the team and the wishes of the family (i.e., a conflict between justice and beneficence). Understanding how to navigate such situations is important because developing a proficiency in utilizing ethics as a child life specialist is integral to formulating an assessment and treatment plan when working with patients and families (LeBlanc, 2006).

As professionals, we all have a responsibility to have a fundamental knowledge of our own ethical duties and responsibilities. Most, if not all, professions have a code of ethics which embodies the principles and standards by which their members are to engage in professional practice. These are more than codes of etiquette; they are codes of conduct. The language and formats of codes may vary, but the purpose is the same: to articulate the ethical doctrine of each profession. The child life profession has its own [Code of Ethical Responsibility](#) (Association of Child Life Professionals [ACLP], 2011), and we, as

Certified Child Life Specialists, attest to serve by this code. Who makes sure our codes are up to date? What happens when there is a conflict between one's professional practices and the principles and standards outlined in the Code of Ethical Responsibility (ACLP, 2011)? The Ethics Committee of the Child Life Certification Commission (CLCC) is the group of volunteers who address such questions. The Ethics Committee of the CLCC has a responsibility to members to provide resources, education, and support related to sifting through ethical dilemmas.

In its primary role, the Ethics Committee of the CLCC is charged with evaluating and making recommendations regarding ethical issues and concerns. That is, if someone feels a Certified Child Life Specialist has displayed actions that go against the principles and standards outlined in the Code of Ethical Responsibility (ACLP, 2011), that person would compile a formal complaint using the [Ethics Review Request](#) form located on the ACLP website and submit it to the Ethics Committee. The committee would review the complaint and operate as an impartial review body to consider whether further actions, such as ethics training or suspension of the CCLS credential, are warranted. The committee is led by the Ethics Committee chair; other members of the committee include all of the committee chairs of CLCC (voting members), the ACLP executive director (non-voting member), and the director of certification (non-voting member). The Ethics Committee convenes as needed to respond to formal written complaints determined to be valid and that merit further investigation. Committee members recuse themselves immediately when their ability to remain impartial becomes compromised. All actions of the Ethics Committee are guided by the CLCC Certification Policy 6.0 Ethics Violations and Disciplinary Actions (CLCC, 2019). The investigation and all deliberations conducted by the Ethics Committee are conducted impartially, objectively, and confidentially.

If sanctions are imposed, the sanctions must represent a reasonable response to the nature and severity of the violation. The goal of the sanctions is to change the conduct of the involved individual and deter future violations. A full list of sanctions may be viewed in the [CLCC Certification Policy 6.0 Ethics Violations and Disciplinary Actions](#) (CLCC, 2019).

The Ethics Committee of the CLCC's second role is to provide resources and education regarding ethical practices to child life professionals. The Ethics Committee provides the Code of Ethical Responsibility (ACLP, 2011) to the membership and works with CLCC's Communications Committee to provide professionals with information about ethics through CLCC newsletters. In addition, the Ethics Committee also works with ACLP to provide *Making Ethical Decisions in Child Life Practice* (ACLP, 2000) available in ACLP's Child Life Store.

In the last year, the Ethics Committee has been working diligently on its second role, to provide resources and education to membership about ethical practices. The Ethics Committee worked with ACLP to host "Child Life Collaboration: Ethics in Healthcare" at this year's conference in Chicago. The session included presentations on global ethics, ethical dilemmas in the clinical setting, and ethical practices for providing student clinical training. In addition, a panel of ethics experts and parents shared their perspective on such topics, with emphasis on the ethics of self-care. One of the most exciting tasks coming

In its primary role, the Ethics Committee of the CLCC is charged with evaluating and making recommendations regarding ethical issues and concerns.

out of the Ethics Committee is the updating of *Making Ethical Decisions in Child Life Practice* (ACLP, 2000). The Ethics Committee is working with child life professionals, ethics experts, and ACLP to revise the manual to be current in child life practices and ethical principles and standards. The updated version of the book is expected to be released in 2020. Finally, the Ethics Committee will be partnering with ACLP in hosting a webinar entitled "Ethics 101," as part of the emerging professionals track. The webinar is scheduled for this summer and will be geared toward professionals with fewer than seven years of experience.

As child life specialists, we recognize the importance of making ethical decisions in our daily practice. As a profession, we have the Code of Ethical Responsibility (ACLP, 2011) to help guide us in our practice. The Ethics Committee of the CLCC is an additional support available to child life professionals, serving as a resource for receiving ethical complaints, providing ethical education opportunities, and continuing to keep ethics as a focus of all things related to the CCLS credential. If you have questions, feedback, or an idea that you would like to share with the Ethics Committee, please email the committee at certification@childlife.org. ✨

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THE ACLP CODE OF ETHICAL RESPONSIBILITY: Growing with our Profession

Cora Welsh, MA, CCLS

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You may read elsewhere in this publication that a group of peers is working diligently on updating *Making Ethical Decisions in Child Life Practice* (ACLP, 2000). This is important work. It brings us the opportunity to look deeply at our Code of Ethical Responsibility. The Code of Ethical Responsibility (CoER; part of the much larger document, Child Life Certifying Committee Code of Professional Practice) was developed in 1983, and updated in 2000 and 2011. The updates have been both necessary and useful. The updates ensure our ethical guideless are relevant and address present day challenges, like social media. Our CoER speaks generally to the diverse situations child life specialists experience. However, it is often vague in its guidelines for clinical care and could be strengthened by inclusion of specific ethical language (autonomy, justice, conflict of interest).

When the nuances between privacy and confidentiality are spelled out, the new professionals have a clear set of guidelines to turn toward when they face an ethical dilemma. They can use the code of ethics to help themselves frame what feels so “sticky” or uncomfortable about a situation and seek guidance from a supervisor or teacher.

A brief survey of other related fields illustrates more detailed, specific codes of ethics, ones that speak to the student, as well as the new and seasoned professional. The code of ethics for the Association of Professional Chaplains (2000) highlights the importance of privacy and confidentiality, and includes statements about dignity and worth of persons; inclusivity; nondiscrimination; avoiding emotional, financial, or sexual exploitation or misconduct; and maintaining compe-

tency. The American Counseling Association's code of ethics (2014) has nearly 20 pages focused on how to move ethically within the intimate spaces that develop in a counseling relationship, including a section on how to navigate ethical issues. The code of ethics of the National Association of Social Workers (2018) spends extensive time explaining how to navigate inter- and intra-professional relationships. Social workers are another member of the interdisciplinary team who know very well the importance of ethical practice amongst teams.

Many other professional codes of ethics provide a level of detail and specificity that is helpful to the student and new professional. When the nuances between privacy and confidentiality are spelled out, the new professionals have a clear set of guidelines to turn toward when they face an ethical dilemma. They can use the code of ethics to help themselves frame what feels so “sticky” or uncomfortable about a situation and seek guidance from a supervisor or teacher. When teaching ethics, strong, clear ethical guidelines are imperative.

Ethics are “values in action” (Dolgoff, Harrington, & Loewenberg, 2012; Parsons & Dickinson, 2017). The first principle of the child life CoER states that child life professionals “shall hold paramount the welfare of the children and families whom they serve” (ACLP, 2011, para. 1). Both the National Association of Social Workers' and the American Counseling Association's codes of ethics begin with a similar statement. The latter two organizations, however, follow that statement with more specific instructions: protect self-determination, provide thorough informed consent, and maintain professional boundaries. The field of child life holds these values as central too. Illustrating how these values translate into ethical child life practice is an important next step for our field.

Child life is still a relatively young profession, particularly when compared to social work and counseling. It is natural that as we grow as a profession, both in scope and maturity, our guiding documents will need to grow with us. Our pioneering foremothers could not have predicted the difficult ethical dilemmas that current child life specialists face on a daily basis. The advancement of medical science has opened many new ethical questions. Societal norms shift and the child life CoER

must evolve to reflect those shifts. Should the CoER include more ethical terms? Is there benefit to including methods for handling an ethical dilemma? What challenges develop when including granular details in the CoER?

I do not highlight this need lightly. The time and effort to work on these changes is enormous. No change to ethical guidelines should happen without careful thought and deep consideration of larger implications. Groups of volunteers like The Ethics

Committee of the Child Life Certification Commission are already stretched in their capacity. It may be time for each of us to consider: How am I contributing to the work of the Association of Child Life Professionals? How am I growing ethical practice? The Child Life Certifying Committee Code of Professional Practice is an asset, one of the many tools child life specialists can use. Because of its central importance, it must reflect the best version of our ethical understanding and expectations. ✨

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AN ETHICAL FOCUS ON ACADEMIC PROGRAMS AND CLINICAL INTERNSHIPS:

Increasing Diversity in our Professional Population

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Certified Child Life Specialists provide interventions within an interdisciplinary model of pediatric care, promoting optimal development of pediatric patients while minimizing the adverse effects of stressful life experiences (American Academy of Pediatrics Committee on Hospital Care & Child Life Council, 2014). Child life services focus on the developmental and psychosocial needs of children, facilitating coping with illness and the hospital experience (Kazak, 2006). Given our essential work with children and families, our professional population is in need of a critical evaluation of current demographic characteristics in order to foster a more diverse workforce. In addition to understanding current trends in our professional demographics, we must look at how our membership can reflect the diverse population that we seek to serve. Examining ways in which academic programs and clinical internships can become action-oriented to increase diversity in our field is not only

essential to the sustainability and efficacy of our profession, but also part of our ethical responsibility. We call upon our profession to build a culture of diversity and inclusion, infuse asset-based pedagogy throughout the child life curriculum, and utilize personal and professional knowledge, abilities, and resources in order to prioritize diversity in our field.

A recent member survey conducted by the Association of Child Life Professionals (ACLP) indicated that 91% of the membership identified as Caucasian and 99% as female (ACLP, 2018). In the *2018 Year in Review* report, ACLP recognizes our field as “predominantly white and female” (ACLP, 2018, p.13). According to the latest data from the Institute for Diversity in Health Management (2014), minorities represent 31% of patients nationally in the United States. Another important number to examine is child population by race in the United States, which indicates 49% of children in the United States are not white (Kids Count Data Center, 2018).

On Building a Culture of Diversity and Inclusion

The American Hospital Association reports that building a culture of diversity and inclusion in healthcare will have an impact on quality, attending to health disparities which lead



to more medical errors, longer hospital stays, and avoidable hospital admissions and readmissions (American Hospital Association, 2017). To support this effort, clinical encounter data demonstrates patients bring up more issues with and are more likely to seek advice from healthcare providers who share the same cultural background (Alsan, Garrick, & Graziani, 2018).

In 2018, ACLP provided 14 diversity scholarships to support and encourage “students from a range of underrepresented populations,” the goal being to create “a field that includes more gender and ethnic diversity” (ACLP, 2018, p.13). While the efforts of ACLP are integral in reaching such a goal, the profession at large is ethically responsible. What else can be done to address the problematic homogenous make-up of our professional field? Numbers alone are not sufficient to provide a landscape in which we can move forward in advancing our field. We must address the child life professional pipeline to identify areas of restriction and facilitate inclusion.

The Association of American Colleges and Universities (n.d.) defines inclusion as an intentional, active, and ongoing engagement with diversity. According to this view, child life academics and child life clinicians need to examine how our field commits to understanding *why* the disproportionate number of Caucasian females continues to exist. The Center for Urban Education at the University of Southern California adds another dimension in which we understand historically underrepresented populations to have equal access, with the term “equity-mindedness.” This refers to a perspective that calls on individuals to be personally responsible to critically reassess their own practices and the historical context of exclusionary practices in higher education (Center for Urban Education, n.d.).

Infusion of Asset-Based Pedagogy

Asset-Based Pedagogy is an instructional approach that views students’ culture as a strength (Lopez, 2017), and requires teachers to incorporate students’ culture into the curriculum to affirm it as worthy content to be taught (Gay, 2000). This cultural content integration should be occurring in both academic and clinical education. Academics and those in the field will need to identify ways in which their current practices of instructional design align with this approach, since there is evidence that this approach improves academic outcomes of historically marginalized students (Cabrera, Milem, Jacquette, & Marx, 2014; Dee & Penner, 2016). Medina (2013) proposes that white consciousness must shift to a kaleidoscope consciousness, forever open and to be expanded, that includes the multiplicity of perspectives required for genuine open-mindedness.

In addition to a culturally oriented curriculum, an emphasis on the provision of a non-threatening environment is also needed to avoid making providers feel ashamed of having racial, ethnic, or cultural stereotypes. Such an environment will address social dissimilarities and the psychological basis of bias (Burgess, van Ryn, Dovidio, & Saha, 2007). Implicit biases are discriminatory tendencies that stem from cognition that exists outside of our conscious awareness, making them difficult to acknowledge and control, and producing behavior that diverges from a person’s endorsed beliefs (Greenwald & Kreiger, 2006). We must seek to understand whether implicit bias is a contributing factor to our canvassed problem, so that change can be achieved by treating unintentional bias as an unwanted habit that can be broken through a combination of awareness, effort, and motivation

[continued on page 20](#)

An Ethical Focus on Academic Programs and Clinical Internships: Increasing Diversity in our Professional Population

(Devine, 1989). A culturally oriented individual believes that the system may not be equitable, but the classroom can be, acknowledging a disposition for social justice that includes command for the complexities of power and privilege (Whitaker & Valtierra, 2018).

On Becoming Your Own Chief Diversity Officer

Research indicates that interviewers rate candidates whom they perceive to be similar to them higher than those who are dissimilar to them, with gender and racial biases similarly impacting interviewer assessment of interviewees (Alder & Gilbert, 2006). In the context of our profession, we must seek to know if and how social dissimilarity influences the pathway to our profession. We must focus on collecting and analyzing data, engaging in research that can examine why our field continues to be predominately white and female. The Institute for Diversity in Health Management utilizes the following to benchmark gaps: race, ethnicity, gender, primary language, religion, disability status, sexual orientation, and veteran status (Institute for Diversity in Health Management, 2014). We should follow suit, with an open mind to expand and modify as necessary. While a robust research agenda needs to be developed, there are actions we can take today that we believe will be productive and forward moving.

We need to be deliberate, not intuitive, thinkers. Deliberative responders are placed at a meta-cognitive advantage, having both the knowledge of what the correct answer is, and being aware of compelling intuition (Mata, Ferreria, & Sherman, 2013). We should hold regular meetings that focus on ecological frameworks and the narratives of underrepresented populations in our field, and develop recruitment procedures that promote a more diverse workforce. We can look for the presence of implicit bias in ourselves and in our colleagues, with a keen and understanding presence. Other options include turning a journal club into an equity-minded club and connecting with our institutions' admissions office and office of human resources to survey what is being done to address inequity and disparities. We will do this together, moving forward with an awareness of pervasive inequalities that appear unbreakable, with a steady and collective force.

Prioritizing Diversity is Our Ethical Responsibility

It is our claim that this topic necessitates our most ethical attention within the following principles from our Code of Ethical Responsibility:

Principle 5: Individuals shall promote the effectiveness of the child life profession by continuous efforts to improve professional services and practices provided in the diverse settings in which they work and in the community at large.

Principle 7: Individuals engaged in study and research shall be guided by the conversations of scholarly inquiry and shall recognize their responsibility in ethical practice in research. (ACLP, 2011)

We have a moral obligation to examine our field and seek ways to promote a more diverse workforce. This includes a conscientious duty to examine barriers and restrictions that may or may not be in our view. We believe this will have a direct impact on the effectiveness and quality of our services that are dedicated to promoting the health and well-being of children and families facing stressful life circumstances.

Moving Forward: Key Questions for Consideration

If we, as a profession, value diversity, why are we not seeing it in our profession? We hope this article encourages an ongoing conversation at all levels. In addition to creating your own questions, we provide a short list here for your consideration:

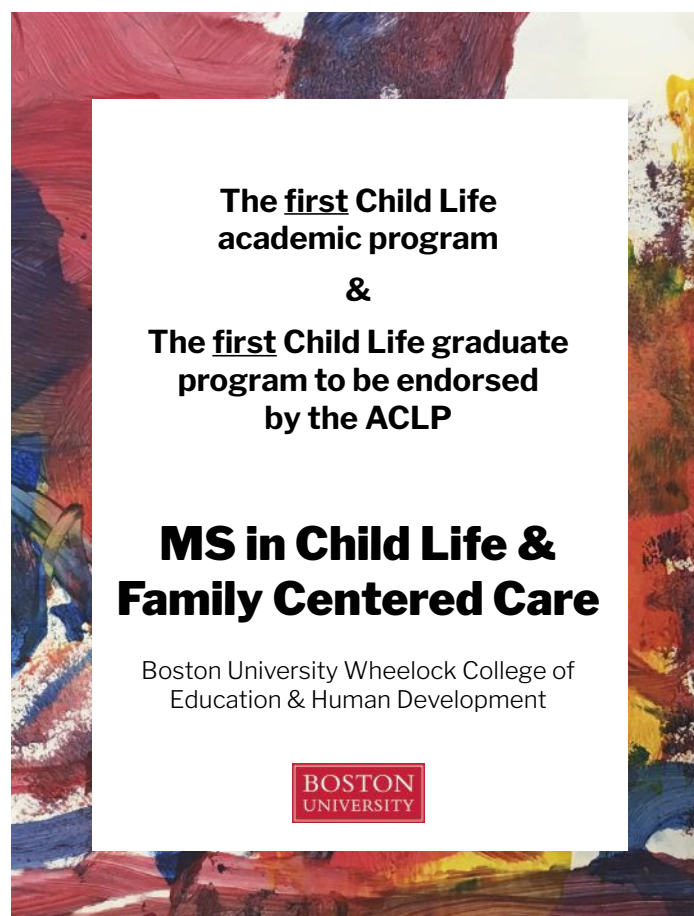
Where is diversity most severely restricted in the pathway to becoming a Certified Child Life Specialist?

- How do Certified Child Life Specialists who identify as members of an underrepresented population in our field view and experience the disproportionate matrix?
- What kind of research will assist us in examining factors that contribute to our disproportionately white and female field?
- How does a diversified child life profession impact health outcomes?
- What are the experiences, knowledge, and resources that facilitate student interest in the child life field?

Recognizing that child life specialists often work in silos, a call for authentic collaboration created by unavoidable exertion is now our call. Our global community is a resource, and we must seek each other out to create space for dialogue and action. It is only through our work that we will continue to advance our profession by creating academic and clinical environments where underrepresented populations can not only thrive and contribute, but also strengthen our profession. ✨

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CHANGING PERSPECTIVES

Reflective Practice in Child Life

The Cost of Child Life

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It is no secret that the journey to becoming a Certified Child Life Specialist is one that requires commitment, resilience, and the ability to overcome challenges. But what is the true cost of child life? I found through my own journey as a student that there are many challenges and hurdles to jump through, especially those related to expenses. I would like to highlight some of the financial barriers that current students are facing when considering a career in child life, with the hopes that practicum and internship programs can consider modifications that would make their programs more accessible for a wider range of valuable applicants.

Volunteering and Practicum

There are countless unpaid hours that go into simply being eligible for a child life internship, from mandatory volunteer experiences to practicums. This is an initial barrier that prevents many students from considering child life as a possibility. Many students cannot afford to volunteer hundreds of hours of their time, but have gained valuable experience working with children through other avenues such as paid experience.

Consideration for internship program coordinators: Can your program consider the value of paid experience rather than just volunteer experience?

Applying for Internship

The cost of applying to internships was one of the most intimidating aspects of pursuing child life for me. The costs add up quickly and include, but are not limited to:

- Application fees
- Applications requiring official transcripts, which often have a fee associated with them
- Shipping costs of required mailed applications versus emailed applications
- Travel costs associated with traveling for required in-person interviews

Considerations for internship program coordinators: Are you able to accept unofficial transcripts, since students have already submitted official transcripts for their eligibility assessment? Are you able to accept emailed applications to eliminate printing and shipping expenses?

Costs During Internship

Aside from completing a 600-hour unpaid internship, there are other costs that spring up unexpectedly during an internship. From buying appropriate clothing to paying for parking to traveling for site visits, the costs can be prohibitive and vary among internship sites. Are we following the Child Life Standards of Clinical Practice (Child Life Council, 2011), which state that we must treat all students in the same manner, if the burden of these additional expenses is greater for some students than others?

Considerations for internship program coordinators: Are you able to work with your site to find free or discounted parking for your intern? Additionally, could we learn from other psychosocial fields, like social work, where part-time, year-long internships are available? This option provides their students with time to work a part-time job if necessary.

Many students are unable to pursue child life because of these obstacles, particularly students who have already encountered obstacles in pursuing higher education such as first-generation students, low-income students, and students of color. The financial barriers in child life have been a contributing factor in the lack of diversity among child life professionals, which can have serious implications for patients and families. Our field is dominated primarily by a homogenous population of child life specialists that is often not reflective of the populations we serve. Patients come from a wide range of cultural, religious, and socioeconomic backgrounds and for these patients and their families, it may be isolating to look around a room and not see one person with whom they can identify. As stated in Principle 1

of our Code of Ethical Responsibility (Child Life Council, 2011), as child life specialists we are to hold paramount the welfare of the children and families we serve. One of the best ways to ensure that families' needs are being met is to have healthcare professionals who reflect the populations served; this can increase comfort and communication between the patient and healthcare staff and create an overall inclusive environment.

ACLP has already recognized the field's financial barriers and has taken steps towards promoting the success of diverse professionals. ACLP's Diversity Scholarship for internship students is a prime example of this. It has helped ease the burden for students who otherwise would have had great difficulty pursuing our field. While this is a step in the right direction that has

significantly benefitted students such as myself, I am challenging the field to do more.

I recognize that some changes are easier to implement than others, but I encourage student programs to begin to have conversations about the requirements set for their applicants. Ask your program the hard questions, starting with "Are our student requirements limiting our applicants to financially secure students?" First-generation, low-income, and/or students of color should not be discouraged from pursuing child life due to financial barriers. I encourage future students to continue embracing their diversity and the unique lens it brings as a healthcare professional, and I encourage student programs to consider what changes they can implement for their applicants. 🌟

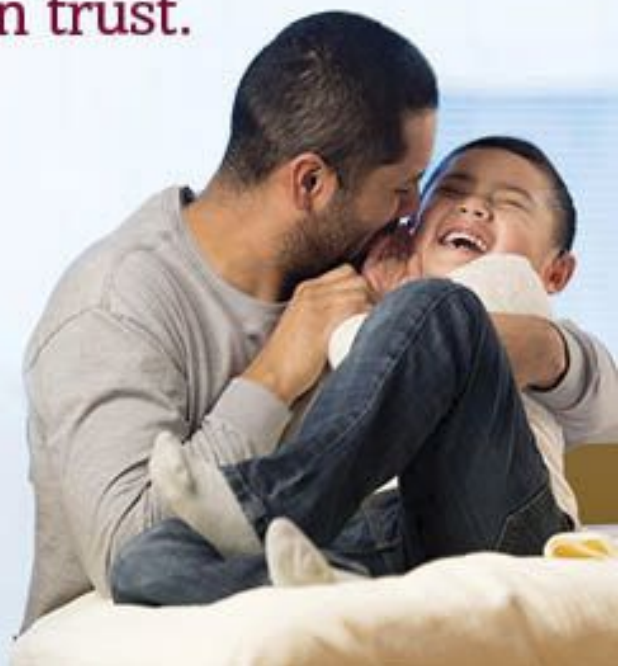
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Families facing pediatric cancer
need a resource they can trust.



Learn More



Who's the Boss?

Ethical Considerations when Parents Decline Preparation

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Parents have the ultimate decision-making authority when it comes to the care of their child, so how can a child life specialist balance parental autonomy with our professional assessment and expertise when a parent refuses preparation for their child?

It is well known to child life professionals that preparation is beneficial to a child's coping, and strong research supports this knowledge. A number of studies have shown that children who are appropriately prepared for an upcoming medical procedure experience minimized distress and pain intensity and have better treatment outcomes and recovery times than children who are not adequately prepared (see review in Jaaniste, Hayes, & von Baeyer, 2007). In addition to benefits for the child, provision of preparatory information in a timely and appropriate manner has the potential to benefit the patient's caregivers and healthcare providers as well (Jaaniste et al., 2007).

At the same time, it is important to consider that preparation may not be appropriate for all patients. While the aforementioned benefits of preparation are significant, research has also revealed some potential risks. For example, McCaul (1980, cited in Jaaniste et al., 2007) found that the distress of patients who are very anxious may be intensified with the provision of sensory preparatory information. Kligman and colleagues (1984, cited in Jaaniste et al., 2007) reported that information about an upcoming procedure may sensitize children with prior negative experiences. Jaaniste and colleagues (2007) further added that some children may develop a sense of helplessness when informed of a procedure they perceive as an unavoidable aversive experience. When supporting such children, it may be helpful to focus on emotional support and normalization.

Special considerations also need to be taken into account when the patient being offered preparation has a developmental disability. Keeping in mind the ethical tenet of justice—the duty to fairly distribute resources and provide equal treatment—the child life specialist should not assume

preparation is inappropriate upon learning a patient has a developmental disability or behavioral challenge. However, an additional layer of factors may need to be considered in the assessment. For example,

- stress may increase with social interaction and/or novel people,
- auditory stimulation, including hearing adults speaking, may be stressful,
- silence may be the best intervention, or
- short-term memory deficits may be present, causing preparation not to be beneficial.

Preparation will often need to be adapted for this population. Simple pictures or a hands-on experience may be helpful even when verbal explanation is not.

Armed with the above knowledge and after a thorough assessment, most child life specialists have experienced entering a room to offer preparation and having parents decline, stating that preparation would not be helpful for their child. Parents know their children best, but are not necessarily experts in coping theory, development, or healthcare. With this in mind, what can we do?

CASE SCENARIO: *Elle is a Certified Child Life Specialist. She enters a patient's room to offer preparation and procedural support for an IV placement that is scheduled to take place shortly. The patient is a typically-developing four-year-old, Ian. When she introduces the intervention to Ian's parents, his father says, "Oh no thanks. He hates all this medical stuff. We don't want him to get upset before it's even time to get it done." Ian's mom nods. Elle has a decision to make: Should she push back, educating Ian's parents*

about what preparation can look like and citing reasons she thinks preparation will benefit Ian, or should she defer to their wishes?

With a decision like this, several ethical tenets come into play. First is autonomy, which refers to the right of patients to make decisions about their medical care. In pediatrics, autonomy involves obtaining informed permission from a child's parent or legal guardian (Committee on Bioethics, 1995) as well as facilitating and supporting patient and family decisions about care (Brosco, 2015). A second and sometimes competing tenet is beneficence, or acting in the best interest of the patient. We want patients to benefit from the provision of child life interventions (such as preparation) that we know to be effective. Finally, we have the ethical tenet of non-maleficence. Non-maleficence refers to our obligation to do no harm or minimize possible sources of harm for patients. As child life specialists, we never want to harm either the rapport we have built with a family or the efficacy of other interventions we provide to patients. However, we also want to avoid causing potential harm to patients by withholding a potentially beneficial intervention. As with most ethical dilemmas, there is no clear-cut best choice, particularly when the various ethical tenets come into conflict with one another. As clinicians, we must weigh the pros and cons of each possible path of action as we decide how to respond.

CASE SCENARIO RESPONSE A: Elle replies, "I hear you. You don't want to risk increasing his stress. I will have his nurse let me know when she's ready to place his IV. I'll be happy to come support him through that. See you then."

With this response, Elle is respecting parental autonomy and practicing non-maleficence by avoiding any possible harm to her rapport with the patient and family. However, Ian will miss out on the potential benefits of preparation and could experience harm as a result of not being adequately prepared for the procedure.

CASE SCENARIO RESPONSE B: Elle replies, "I hear you. You don't want to risk increasing his stress. A lot of the time, it's amazing how much it actually helps children to have some preparation before things like getting an IV. Preparation can decrease the fear of the unknown, address any misconceptions he may have about the process, and build confidence that he can handle it through explanation, demonstration, and rehearsal. Everything I do with him will be at the right level for a kid his age, and it won't take very long. At the end, we can work together to make a plan for the procedure, thinking about things like what he wants to focus on during it,

positioning him for comfort, and what he can look forward to afterward. What do you think?"

With this response, Elle is advocating to benefit the patient through appropriate preparation and to avoid possible patient harm as a result of not being adequately prepared for the procedure. However, she is challenging the parents' decision about preparation, which could result in harm to her therapeutic relationship with them.

What are some things you can assess for when facing these kinds of decisions?

- **Patient's Temperament:** Look for cues in the patient's body language as to whether they seem to have a vigilant or avoidant coping response while you are speaking with their parents.
- **Past Experiences:** Has preparation gone poorly in the past? Has the child had a traumatic experience with a healthcare encounter?
- **Adamancy of Parents:** Are they open to a statement like, "What if we just try preparation this one time, so that if it does help, we know that for the future?" (Parents can be reassured that, if the child shows signs of increased distress or behavioral escalation, the child life specialist will, of course, embrace a change of plans.)

These assessments will help inform a decision on how much to push, or what kind of education to provide.

As you can see, there may be no clear path to determine whether and how much to advocate for preparation when parents refuse it prior to procedures. However, after careful patient and family assessment and consideration of each relevant ethical tenet, child life specialists should feel empowered to trust their professional judgment and offer families what they think is best in each individual situation. ✨

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THE ETHICS OF WORKING IN PATIENTS' HOMES: Different Considerations for Community-Based Child Life

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The Child Life Code of Ethical Responsibility guides our practice both in clinical hospital settings and in the community, where our clinical practice includes family homes (Association of Child Life Professionals, 2011).

However, the ethics of our work with patients and families in their homes naturally presents some changes and different considerations given the intimacy of the setting. It is a challenge to find the right balance of openness to this intimacy and maintenance of our standards of ethical practice that makes this complex for each individual child life specialist.

Ethics are something that affect people every day, in all aspects of life, including at work, at home, and in interactions with colleagues, friends, and family. In healthcare, ethical standards are important moral principles that govern behavior

and were designed to protect us and patients from dangers including harm to the therapeutic relationship, dependency, misinterpretation of a professional relationship as friendship, and uneven distribution of care.

Home-based child life sessions present many special opportunities, such as the chance to meet important members of the family, friends, and community who are not likely to be present in the cramped hospital environment. The honor of being invited into a family's home allows a child life specialist to get a first-hand view of the family living situation, which can mean exposure to aspects of a family's life one would not directly understand or experience within the hospital. Observing conditions such as overcrowding, poverty, disorganization, and food insecurity can add insight into the patient's life and challenges. The privilege of observing the

family's culture as it presents itself in food, icons, music, and child-rearing practices deserves great respect and appreciation and can have a profound positive impact on child life sessions.

The opportunities that accompany the privilege of working in patients' homes present ethical dilemmas that are unique to this setting. By exploring different situations faced by many home-based child life specialists, we can examine the application of appropriate personal and professional ethics. Although the list of situations that require special attention is long, three will be explored here: invitations to join families in events, gifts, and safety.

Celebrations of Patients' Accomplishments, Rituals, and Life Transitions

Celebrating and otherwise affirming patients' lives and accomplishments can be important validation. This is especially true for patients who may face numerous challenges feeling successful and who lack external validation or celebrations beyond their medical experiences. An example of such a celebration is the invitation to attend the first performance in a school play of an adolescent girl who, with the help of child life supports, overcame her fear of attending school after years of treatment and long hospitalizations.

Similarly, when special religious or cultural ceremonies take place, child life specialists inevitably are invited to join families in some of their sacred rituals: Latino families in Quinceanera, Catholic families at confirmations, or Jewish families for bar or bat mitzvahs (Kertész, 2002). In making the decision whether to attend such celebrations, it is important to keep in mind that refusing to do so when invited, in certain cultures, could cause damage to the therapeutic alliance, nullify trust, and create barriers to effective child life support (Schacht, Tafoya, & Mirabla, 1989). When attending events, it is important to maintain the role of child life professional. The clinical and ethical guidelines for interaction with children and families within the child life profession remain the same, even at these events. This distinction can be challenging for some when taking part in significant celebrations.

By joining young patients and their families in celebrations and rituals, child life specialists actively support, affirm, and celebrate their achievements and enhance the therapeutic alliance. Such special efforts on the part of clinicians in

the community have been reported to significantly increase therapeutic alliance and effectiveness (Lazarus & Zur, 2002; Zur, 2007).

By joining young patients and their families in celebrations and rituals, child life specialists actively support, affirm, and celebrate their achievements and enhance the therapeutic alliance. Such special efforts on the part of clinician in the community have been reported to significantly increase therapeutic alliance and effectiveness.

Meals with Families/Gifts from Families

There are no clear guidelines about the ethics of accepting food or gifts from families you work with in their homes, but there are a number of different considerations that one should ponder when deciding how to proceed. While some specialists feel that accepting gifts from a family can influence their clinical judgement, others feel that accepting such gifts can enhance the patient-specialist relationship (American Medical Association, 2016). One thing to consider regarding small gifts and meals is whether it is likely to cause any financial hardship for the family.

When working in a family's home, consider the timing of a visit. There are many times throughout the day when a child will need some snacks and light refreshment, or even a full meal to have enough energy to participate in a session. Regardless of a family's culture, it is often natural for them to prepare and share meals, drinks, or snacks during your stay. These snacks can also be a part of the support needs for some patients, so consider whether the value and appropriateness of enjoying this food and drink may even be therapeutic. For some families, if a session ends right before a mealtime, it is customary to invite you to join them. Sometimes these meals may be to show appreciation for your time with them, or because meal sharing is a cultural or religious practice that they enjoy.

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The Ethics of Working in Patients' Homes: Different Considerations for Community-Based Child Life

Declining food due to diet and allergy restrictions may seem benign, but can actually make a family feel they did something wrong in not offering you the appropriate food, leading them to change what they offer in the next visit to accommodate you. Many specialists will pack a small snack that they can enjoy with a patient to avoid any discomfort.

Similarly, with gifts, it is important to consider how accepting or declining small thoughtful items or some seasonal baked goods will impact the relationship. Extremely valuable gifts should be declined.

Safety Issues and Challenges in the Home or Neighborhood Environment

Illness and trauma do not discriminate, and patients at all levels of socioeconomic status are impacted. Visiting an unsafe neighborhood that experiences crime may pose a potential physical danger to specialists, especially if they are unfamiliar with the neighborhood. Declining to provide a home session due to a patient's neighborhood would be unethical, but these visits are complicated when the personal safety of the child life specialist is potentially at risk. While back-ups and contingency plans are often available and established ahead of time in the hospital setting, more careful plans must be constructed for encounters outside the hospital. Booking home visits during daylight hours can be a part of safety planning, as can coordinating overlapping sessions with another member of the community team to provide services together, when possible. In larger apartment complexes, requesting a family member's assistance once you arrive at the building can be reassuring and give you guidance on the best way to reach the family dwelling safely. For example, they can direct you to the stairs when more appropriate, or to elevator #3 since it never breaks down.

Visiting a patient in the home may arouse concerns about the patient's safety, but these must be viewed through the lens of the family's culture and parenting style. It is essential to recognize and respect each family's unique culture and parenting style within the home. For example, finding that a family of four is sharing a small one-bedroom apartment with one family bed is important information, and can help or hinder your child life plan and the delivery of supports, depending on how you see the situation. For a young oncology patient in active treatment, ensuring that they get enough rest and preventing infection is essential to their care. Often clinicians inappropriately assume that a family bed is not appropriate for a patient, because it robs the child of their own space and a quiet environment to rest, and because this sleep arrangement also exposes them to potentially greater risk for infection. By learning more about this family and the patient's pre-illness experience, a specialist may determine that these are the preferred sleeping arrangements and have always been through the child's lifetime. To separate the child from the closeness of the family bed would create undue distress for all family members. Instead, focusing on educating the family about appropriate infection control practices within the family home and bedroom will help them to safely continue the family bed.

Ethics: Both Personal and Professional

Child life specialists are increasingly providing support in the home as healthcare branches out beyond the hospital. Learning how to appropriately extend professional ethics and boundaries into homes takes time, thoughtful consideration, and ongoing self-assessment. Traditional house calls were about relationships. These modern house calls are too, and can create deep bonds within the therapeutic alliance (Adams & Mylander, 1998). ✨

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Child Life Focus



Voice and Choice: Upholding Autonomy and Other Critical Ethical Constructs in Pediatrics

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A review of ethics in pediatrics brings up a multitude of healthcare related ethical dilemmas regarding topics such as decision making, informed consent, treatment planning, and research.

The four most frequently cited ethical constructs in health related ethics are: autonomy, or the right to self-determination; beneficence, which is doing good; non-maleficence,

which is focused upon preventing harm; and justice, which is how society allocates benefits and burdens (Rollins, Bolig, & Mahan, 2005). Allied health professionals, particu-

larly child life professionals, do not need to conduct a literature search to validate the prominence of ethical constructs in their daily clinical work with children, youth, and families. For example, close examination of one's clinical work would reveal such constructs as truthfulness, quality of life, privacy, equity, and least harm. Issues of confidentiality and privacy are quickly identified when child life

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professionals consider their contributions in interdisciplinary medical team conversations, documentation in the patient record, and collaboration with colleagues. Concerns about quality of life are explored while engaged in conversations with patients and families about treatment planning and the trajectory of care. Professionals often consider the ethics of equality and equity when determining how and where play materials are stored, which patients receive priority time and attention when the professional's hours are finite, and which patients receive pet or music therapy visits. Concepts of truthfulness and full disclosure are expectations of medical education and preparation sessions as a child life professional works with families to determine how and when to discuss upcoming medical interventions with pediatric patients.

One ethical subject to receive renewed attention and consideration in pediatrics is the ethical construct of autonomy, which can be defined as "self-determination, self-rule, being able to make free choices" (Dolgoft et al., 2009, p. 293). A frequent scenario in which autonomy is challenged is in the context of decision making. *Who gets to decide* is a central ethical question and concern in healthcare. The recognition and practice of autonomy varies in different parts of the world. This is because autonomy, like all other ethical principles, is context dependent and is based upon cultural and societal values (Dolgoft et al., 2009). Child life professionals are on the front line of healthcare delivery and through their work frequently witness the ethical dilemma of upholding or diminishing the autonomy of pediatric patients. This paper will explore some of the contexts that impact autonomy in various healthcare environments through the use of a case study and content regarding centeredness, consent, assent, and the role of the child life professional as advocate and developmental expert.

Case Study

To better appreciate what autonomy looks like in the pediatrics, let us consider the following case study as described by Kenny, Downie, and Harrison (2008):

H is a bright, loving, 11-year-old child who has been treated for osteosarcoma. Her left arm has been amputated and she was given a course of chemotherapy. She has been cancer free for 18 months and is doing well in school. She is self-conscious about her prosthesis and sad because she had to give away her cat, Snowy, to decrease her risk of infection. Recent tests indicate that the cancer has recurred and metastasized to her lungs. Her family is devastated by this news but do not want to give up hope. However, even with aggressive treatment, H's chances for remission are less than 20%. H adamantly refuses further treatment. In the first round of treatment, she had initially acquiesced to the treatment but ultimately struggled violently when it was administered. She distrusts her healthcare providers and is angry with them and her parents. She protests, "You already made me give up Snowy and my arm. What more do you want?" Her parents insist that treatment must continue. At the request of her physician, a psychologist and psychiatrist conduct a capacity assessment. They agree that H is incapable of making treatment decisions; her understanding of death is immature and her anxiety level very high. Nursing staff are reluctant to impose treatment. In the past, H's struggling and the need to restrain her caused them serious concern. (Kenny et al., 2008, p. 121)

This case study demonstrates a conflict that is not unusual in pediatrics. The medical team has recommended a treatment, the parents insist that the treatment continue, the child is refusing the treatment, and the nurses are reluctant to administer the treatment because they have had to restrain the child in the past. Should the medical team honor the dissenting opinion of the 11-year-old patient and allow the treatment to be discontinued? Or, should the medical team overlook the objections of the 11-year-old patient and honor the decision of the "legal caregiver" (hereafter referred to as "parent") to continue with the treatment?

For children, decision making defaults to their parents, with very few exceptions. This is because in many societies, children are not recognized as being competent or eligible to consent for their own medical procedures and treatments, until they reach the legal age of the majority (Kodish 2003). According to Sibley, Pollard, Fitzpatrick, and Sheehan (2016), when it comes to medical decision making, "many children and perhaps all who are under the age of 10 are not considered to be sufficiently competent to make their own decisions regarding their participation" (p.2). To fully understand how the autonomy of the pediatric patient is impacted when parents provide permission for their child's medical care, it is important to first explore the process of informed consent.

Informed Consent

Informed consent gives permission for medical intervention for an individual's body, and is practiced with adult patients. For the exchange of information to be considered informed consent, certain criteria must be met. While the criteria may differ slightly between professions, most will agree that comprehension, engagement in treatment that is voluntary, and competence are critical components of informed consent (Parsons & Dickinson, 2017). To support comprehension, information must be provided to a patient in a language that the patient can understand. The patient must be informed of risks associated with participating in the proposed medical intervention and be made aware of alternative intervention options and the risks associated with declining the suggested medical intervention. In order to be considered informed consent, the patient cannot be coerced during the consent process. This means that the patient must feel that they are agreeing to the medical treatment in a voluntary capacity. Therefore, true informed consent affords the opportunity for the adult patient to feel that they have received complete and clear information about their treatment options and then choose, without pressure or persuasion, to agree or decline the medical treatment for their body. This process assumes the patient is competent or has the ability to make a decision for him- or

herself. Determining and respecting a patient's competency upholds that individual's autonomy. Prior to obtaining informed consent, a physician can evaluate an individual's ability to: express their choice, understand the information that they receive from the medical team, have a realistic understanding of the situation (what is reversible and what is permanent, for example), and rationally use the information they are receiving (Grisso & Appelbaum, 1998). If it is determined that a patient lacks the ability to make their own decisions, a surrogate decision maker is identified.

The unique reality in pediatrics is that with children, there is no agreement about how old a child must be before he or she is considered competent to make their own decisions regarding participation in medical interventions or clinical research (Dolgoft et al., 2009; Sibley et al., 2016). Instead, the information, options, and risks are provided to the parents of the pediatric patient. When parents give consent for medical interventions for their children, they are not providing true informed consent; rather they are providing their "informed permission" for medical treatment and care for someone else's body (American Academy of Pediatrics Committee on Bioethics, 2016; National Cancer Institute, 2016). In the example of the case study, the medical team requested that a psychologist and psychiatrist conduct a capacity assessment and it was determined that the 11-year-old patient was incapable of making medical decisions and, consequently, the decision making in the case study then defaulted to the patient's parents.

Assent and Consent

Just because a pediatric patient is recognized as not being competent to make their own decisions and cannot exercise their own authority and autonomy in decision making, it does not mean that they are required to be excluded from decision making altogether. In fact, psychological research supports the involvement of children in decisions that impact their own welfare as it reduces anxiety, improves self-esteem, and creates an opportunity to practice making decisions

(Diekema, 2003). To conceptualize ways in which a child, like H in the case study, can be included in medical decision making it is important to consider the differences between consent and assent.

Consent is used for adults; it is based upon autonomy and it focuses upon *competency and comprehension*. From this perspective, autonomy can be understood as a central tenant to the practice of informed consent (Parsons & Dickinson, 2017). Legally, in the United States of America, "children are not able to give true informed consent until they turn 18" (National Cancer Institute, 2016) and therefore, are asked to provide assent.

Assent is generally defined as a child's agreement to participate in medical treatment or research (Sibley et al., 2016; Unguru, 2011). Assent is an intentional process of engaging and involving an individual in the decision-making process who lacks the competency to make autonomous decisions for themselves so that they have an opportunity to express their perspective (Sibley et al., 2016). While consent focuses upon competency and comprehension, assent is focused upon the *capacity* to understand. The exercise of assent acknowledges that there may be the potential for an individual to gain the skills necessary to establish competency and participate more fully in consent at a later time in development (American Academy of Pediatrics Committee on Bioethics, 2016). In the United States, children as young as 7 years old are eligible for assent (National Cancer Institute, 2016). Internationally, there are many laws and guidelines that promote and encourage respect for the developing autonomy of children and minors and the practice of assent (Grootens-Wiegers, Hein, van den Broek, & de Vries, 2017). Assent can be interpreted as respectful involvement in decision making. This is distinctly different from consent, which is recognized as an opportunity for a patient to exercise their full autonomy.

Assent in Pediatrics

The concept of assent is not new. Professionals across different healthcare disciplines recognize and promote assent in varying

degrees. Many professionals who are aware of consent and assent point to the United Nations Committee on the Rights of the Child (UNCRC) as an influential document that began meaningful conversations contributing to the formation of assent as a construct in pediatric decision making. The UNCRC maintains a report that consists of 54 articles delineating the rights of children and informs governments around the globe on such matters. Article 12 of the document was established in 1989 and obligates states to take the wishes and opinions of children into consideration because every child has a right to be heard, regardless of age. This article was revised in 2006 and states:

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It is the expressed intention of Child Life Focus to provide a venue for professional sharing on clinical issues, programs, and interventions. The views presented in any article are those of the author. All submissions are reviewed for content, relevance, and accuracy prior to publication.

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The new and deeper meaning of Article 12 is that it should establish a new social contract. One by which children are fully recognized as rights-holders who are not only entitled to receive protection but also have the right to participate in all matters affecting them. (UNCRC, 2006, p. 2)

The American Academy of Pediatrics (AAP) Committee on Bioethics published a document in 1995 that called for changes in pediatric medical decision making and provided guidance for pediatric assent. The AAP Committee on Bioethics encourages a developmental approach and delineates three categories of consent that are based upon a child's capacity to understand information. Based upon the child's capacity, the role and the extent to which they participate in decision making is then determined. The three categories are described in Table 1.

In 2016, this same committee revised their document in the form of a technical report. The purpose of this revision was to further encourage, promote, and emphasize the inclusion of children in medical decision making. According to the AAP Committee on Bioethics in the 2016 guidelines, assent in pediatrics should include these elements:

1. helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition;
2. telling the patient what he or she can expect with tests and treatments;
3. making a clinical assessment of the patient's understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy); and
4. soliciting an expression of the patient's willingness to accept the proposed care.

The provision of assent may be considered ideal by many professional voices that advocate for the experiences and the rights of children. However, the involvement of children in pediatric decision making is complicated, and disagreements or conflict between patients, healthcare professionals, and parents can occur. There may even be situations in which assent is offered to

Table 1.

Three Categories of Consent Recommended by the AAP Committee on Bioethics, 1995.

STATUS OF THE CHILD	PARTICIPATION OF THE ADULT
1. The child lacks decisional capacity.	Parents make the decision unless there is evidence of parental abuse or neglect.
2. The child has a developing, but not yet sufficient capacity for decision making—assent should be obtained from the child.	Parents give permission.
3. The child has decisional capacity and should be approached for consent—refusal or consent will be honored.	Parents are consultants to the child.

children even when refusal of care is not an option. While it is important to encourage healthcare providers to have an awareness of assent and guidelines for its provision, there are also cautionary tales expressed in a recent publication through the Hastings Center about the potential misuse of assent. According to Navin and Wasserman (2019) the AAP guidelines underestimate the ethical complexity of pediatric decision making. Their report cautions providers to evaluate their motivation to promote and support pediatric assent. For example, pediatric assent should not be offered to avoid conflict or to make the healthcare provider feel better. Furthermore, the report warns that the healthcare team should only solicit preferences from a patient if some elements of refusal will be accepted.

Let us consider this in the context of the case study. It has been determined that H is not competent to make her own decisions. The medical team may feel guilty about the consent the parents have provided to move forward with the medical treatment considering the fact that H has strongly refused and has a history of requiring restraint during her treatments in the past. Taking into consideration H's age and information about assent offered by the National Cancer Institute (2016) and the AAP Committee on Bioethics (2016), it would be appropriate to involve H in the process of assent. It would be acceptable to offer age appropriate information and to support her developing capacity to make decisions. While practitioners will respect that H has been evaluated and deemed incapable of making medical decisions, some healthcare providers may still feel compelled

to offer an opportunity to participate in the decision making and express her assent and dissent. However, while intentionally engaging H in discussions regarding her medical treatment, the medical team must take care to avoid conveying a false sense of hope that her refusal to receive treatment will be honored. An additional complicating and compelling factor in this particular case study is the fact that H has extensive medical experience as she has been undergoing treatment, surgical interventions, and routine care for her cancer diagnosis for several years. Some could argue that H's refusal should carry more weight than the medical team is allowing considering her experience and the fact that even with aggressive treatment her chances for remission are less than 20%. Adolescent and child refusals are controversial and becoming increasingly challenging in ethical and emotional ways for families and clinicians (AAP Committee on Bioethics, 2016). This is especially true when context, knowledge of child development, culture, and the philosophy and values of healthcare systems are considered.

Context and Centeredness

A complicating contextual factor in healthcare decision making is centeredness, or the approach to providing healthcare that determines the focus of care (Coyne, Dip, Homström, & Söderbäck, 2018). There are several types of centeredness that appear in health systems and health-related literature and include such approaches as: family-centered care, which encourages the family's active participation in care and decision making

Table 2.
Four Core Concepts of PFCC from Johnson et al. (2008).

DIGNITY AND RESPECT	INFORMATION SHARING	PARTICIPATION	COLLABORATION
Healthcare practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.	Healthcare practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information to effectively participate in care and decision making.	Patients and families are encouraged and supported in participating in care and decision making at the level they choose.	Patients, families, healthcare practitioners, and healthcare leaders collaborate in policy and program development, implementation, and evaluation; in facility design; and in professional education; as well as in the delivery of care.

(Abraham & Moretz, 2012); child-centered care, which places the interests of children at the center of healthcare practice (Carter & Ford, 2013); patient- or person-centered care, which appears occasionally in the literature and focuses on delivering care that is respectful, individualized, and empowering for the recipient of care (Morgan & Yoder, 2012); and patient- and family-centered care, which intentionally recognizes the capacity of children to participate in their own healthcare (Abraham & Moretz, 2012).

Family-centered care (FCC) is a healthcare delivery model in which planning care for a child incorporates the entire family and all family members are recognized as care recipients (Feeg, Paraszczuk, Cavusoglu, Shields, Pars, & Mamun, 2016). The principles of FCC were first formally articulated by the Association for the Care of Children's Health in 1987 (Shelton, Jeppson, & Johnson, 1987). FCC is an approach to providing care to the pediatric patient that focuses upon the unique attributes of the patient's family, inclusion of their values, and family involvement in the delivery of healthcare and medical decision making (Bell, Johnson, Desai, & McLeod, 2009). The implementation of family-centered care has encouraged important changes to children's hospital policies and mission statements. For example, visitation policies now allow for 24-hour visitation. Increased participation of family in medical rounds and medical care can be observed in hospitals and clinics that have adopted family-centered care policies. Newly constructed or renovated hospitals have adopted changes to the physical structure of healthcare environments to allow for families to have consistent and comfortable access to their hospitalized child. Consequently, policies, procedures, and practice

in pediatrics have centered the family in medical conversations and the delivery of care. International studies indicate that the practice of FCC is ubiquitous and has been delivered all around the world to varying extents (Shields, 2018; Feeg, et al., 2016).

Patient- and family-centered care (PFCC) is an approach that has been adopted by increasing numbers of healthcare systems since the late 1980s (Abraham & Moretz, 2012). More healthcare systems have begun to make this shift to PFCC to intentionally include the patient along with the family in the center of healthcare delivery, "recognizing the role that developmentally capable children can play in their own care" (Abraham & Moretz, 2012, p. 45). Despite the fact that PFCC promotes a positive partnership amongst patients, providers, and parents (see Table 2), PFCC has not been universally accepted and implemented in all pediatric healthcare systems or settings (Abraham & Moretz, 2012).

Child-centered care (CCC) is a newer model and as such is not as clearly defined as FCC and PFCC. CCC is an emerging approach and has slowly been gaining momentum due in part to the previously mentioned United Nations Committee on the Rights of the Child (2006).

CCC shifts the child to the center and focus of care delivery. According to Ford and colleagues (2018), CCC "acknowledges that children's competence and participation will change over time and be influenced by their environment, culture and the previous position and actions of health care providers. It does not exclude the family but places the child as central to all care decisions and practices" (p. 41). Currently, there is ongoing

work amongst academics and pediatric nurse scientists to articulate the details of CCC (Shields, 2018).

All of these centering perspectives can be confusing for healthcare practitioners. Coyne and colleagues (2018) have studied each through a concept analysis in the literature and can point out that there are similarities and differences. Mostly, their research points to the importance of respecting a person's dignity and knowing which approach to apply in different situations. In considering the case study, one can imagine that if H was being cared for in a healthcare system that recognized FCC, the opinion of H's family could potentially carry more weight and attention in the decision-making process. In contrast, if H was receiving care in a facility that had adopted CCC, then H's dissent may carry more weight in the decision-making process. Likewise, if the environmental context supports PFCC, then H and her parent's opinions would hold equal weight and consideration in the decision-making process. In this context, assent could be encouraged and additional conversation could be supported, even if it was determined that H lacked competency.

The child life professional, as a flexible, responsive advocate in all contexts, is poised to be able to navigate successfully in healthcare systems that practice variations of centeredness. Child life professionals are naturally child-centered in their training and in the delivery of care. Child life professionals are also trained to be inclusive of family members in the education, preparation, and advocacy for the needs of children, youth, and families. Child life professionals are employed in various cultural contexts and

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healthcare environments. However, a child life professional, like any other healthcare provider, may feel challenged in recognizing, respecting, and upholding the autonomy of a pediatric patient in their care. Consider the involvement of a child life professional in the case example. As experts in development and the education and preparation of children and youth for medical interventions, supporting assent may result in placing the child life professional in a conflicting position with the parents or the medical team, particularly if the child has a dissenting position. This could be especially challenging if the child life professional surmises that the child has a greater capacity to understand their medical care than the medical provider has determined. It becomes increasingly important for the child life professional to understand the culture and policies within the healthcare environment that determine centeredness. Without this understanding from the medical team, it can quickly become challenging for the child life professional to know what they should advocate for and how they should align themselves with the patient, the family, and the medical team. Should the child life professional advocate for the wishes of the child and encourage assent if the system supports CCC or PFCC? Should the child life professional be supportive of the cohesion of the family unit in the context of FCC and refrain from advocating for the dissenting voice of the child? If there is conflict and supporting assent is not an option, are there other aspects of care that can be supported by the child life professional?

Ethical Dilemmas

When it has been established by the medical team that a child is not competent and therefore the team is unable to uphold a pediatric patient's autonomy, allied health professionals can choose to focus upon supporting other ethical aspects in the provision of care. Many human service professionals regularly experience these types of distress and ethical dilemmas in their work. An ethical dilemma can be defined as a choice by a human service provider "between two or more relevant but contradictory ethical directives or when every alternative results in an undesirable outcome" (Dolgoff et al., 2009, p. 294).

Table 3.
Ethical Principle Screen as discussed in Dolgoff, Harrington, and Loewenberg (2009).

RANK	ETHICAL PRINCIPLE SCREEN
1	Protection of Life: applies to all persons
2	Social Justice: all persons in the same circumstances should be treated the same way
3	Self Determination, Autonomy, Freedom: an individual's right to make their own decisions
4	Least Harm: when faced with options that have the potential for causing harm, chose the option that will cause the least harm, the least permanent harm, and the most easily reversible harm
5	Quality of Life: the option that promotes the best welfare for an individual
6	Privacy and Confidentiality: duty to protect the private and protected information of others
7	Truthfulness and Full Disclosure: the obligation to speak the truth and promote honest dealings with others

When confronted with a dilemma in clinical practice, human service professionals should first consult their professional code of ethics and then consider utilizing a decision-making tool for additional guidance (Parsons & Dickinson, 2017). While the Association of Child Life Professionals Code and Guidelines for Professional Conduct (n.d.) provides some guidance for ethical professional behavior, other professional codes of ethics, such as the National Association of Social Workers (NASW) Code of Ethics (2018), provide more extensive content about ethical decision making. This example of a comprehensive professional code of ethics is truly intended to be used for guidance when making ethical decisions in professional practice. The NASW Code of Ethics (2018) can be considered a living document, as the NASW organization regularly updates the code to be reflective of specific shifts in societal values and ethics. Therefore, the document is responsive and current, which affords the human service professional an opportunity to feel confident about the guidance they receive from this particular code.

After reviewing a professional code of ethics, the next best step when navigating an ethical dilemma is to consult a decision-making tool. While a rank ordering of ethical constructs has not universally been agreed upon, Dolgoff and colleagues (2009) propose the Ethical Principle Screen (EPS; see Table 3) as one

suggestion of the prioritization of seven ethical practice issues that human service professionals are often contemplating while engaged in clinical decision making. A child life professional should feel encouraged to consider all of the ways in which they can be ethically supportive of the children, youth, and families that they are serving. This is particularly true when they perceive a barrier or a conflict in their practice decisions. An examination of the EPS could empower the child life professional to prioritize other ethical attributes of their care. In the scenario of a medical decision in which a child is not able to utilize assent and as a consequence the professional is unable to uphold that individual's autonomy, the professional should feel encouraged to shift their focus to ensuring other ethical principles such as social justice, quality of life, and truthfulness.

In the case of H, if autonomy is an aspect of care that is not able to be upheld, the child life professional could focus their interventions and support on quality of life. For example, the child life professional could work closely with the child to support coping strategies, connections with friends and family, and offer activities that are expressive, engaging, and enjoyable. The child life professional could also advocate for truthfulness through the provision of age-appropriate education and preparation for medical treatment.

Amplifying Voice and Offering Choice

Child life professionals have the potential to play a significant role in the development of children's and youths' decision making in healthcare by creating an opportunity to practice decision making while still under the protection of caregivers (Sibley et al., 2016). As with most aspects of human development, the capacity for decision making is not a fixed phenomenon (Unguru, 2011). Child life professionals are positioned to provide age-appropriate preparation and education to children, youth, and their families, and to create spaces that allow for the opportunity to participate in the expression of feelings, opinions, and questions. Sibley and colleagues (2016) contend that "the process of assent utilizes [a child's] developing capacities and gives him a voice in matters which affect him, but most importantly it allows him to practice his decision-making skills in order to further enhance his development and become a better decision-maker as an adult" (p. 5). As developmental experts, it is well within the professional scope of care for child life professionals to encourage and support the development of the necessary skills to foster later competency in older teenagers and adults.

There are a multitude of ways in which the child life professional can amplify a child's voice and offer age-appropriate and circumstance-appropriate choices, even in situations where one feels there are no inherent choices. For example, when a child needs to have an IV placed, they do not necessarily have the option to refuse the IV. However, the child can be invited to express an opinion about where they would like for the IV nurse to look first. A child may not have an option to decline physical therapy and exercise, but the child can be offered choices about where they would like to ambulate while out of their room for their daily walk. Child life professionals can also support children in gaining and developing their capacity to express autonomy through the provision of therapeutic play. Medical play and therapeutic play experiences can afford the hospitalized child the opportunity to gain competency and a sense of

mastery over medical interventions they are experiencing (Burns-Nader & Hernandez-Reif, 2016). Through these engaged activities, misconceptions can be addressed, trust can be established, stress can be alleviated, and the skills necessary for competency, expression, and autonomy can be gained.

A masterful way in which a child life professional can be an advocate for the development of the skills necessary for a child to ultimately gain the capacity and competency to fully exercise their autonomy is to enhance and support the development and sustainment of shared, family-centered decision making which is a process that is increasingly being used for pediatric medical decision making (AAP Committee on Bioethics, 2016). Kieckhefer and Trahms (2000) propose that over time, the parent who starts out completely in charge of their child's medical care must gradually transfer some of the self-care responsibility to their child. This takes time and requires support, patience, and scaffolding, but the ultimate goal is a transfer of leadership and autonomy from the parent to the child. Child life professionals can support this transfer of leadership, self-determination, independence, and autonomy regularly in clinical work, perhaps without even recognizing that is what they are doing.

Child life professionals have an opportunity to target specific skill development in each age group and intentionally involve parents in the recognition, support, and growth of these skills. For example, imagine an infant with a diagnosis of asthma. In the beginning, the parents of the child are completely in control of all medical decisions because during this stage of development a child lacks the cognitive skills and fine motor skills required to manage their chronic health condition. A family could be encouraged to support the development of positive coping and self-regulation at this very young age through the reinforcement of clear cues in infants. A child life professional can intentionally involve parents in recognizing and responding to their infant's cues, which will create trust and attachment between the parent and the child. As this child enters toddlerhood and preschool, the child life professional can

encourage cooperative participation in medical care. Parents can be supported in doing this through the creation of routines and the delineation of roles during care. For example, perhaps the parent prepares the nebulizer treatment and sings a perfectly timed song that lasts the duration of the treatment while the child assists by holding the tubing. As children gain cognitive and language skills, the young school-age child can learn the names of body parts and medical equipment, and parents can be encouraged to include the child in discussions about symptom management at school, modeling how to talk about their condition with peers, teachers, coaches, and school nurses. Older children can be encouraged to notice and document their symptoms and symptom management in a medical journal that is shared with medical providers at appointments. Parents of adolescents can begin to transfer various aspects of their care, such as filling prescriptions and scheduling appointments. Older adolescents can be encouraged to practice independent communication with providers while the parent continues to monitor their condition. Shadowing, encouraging, and engaging in this process is the child life professional with a keen eye on the development of lifelong skills and positive coping strategies that will ultimately culminate in the older adolescent's autonomous participation in medical decision making.

Conclusion

The provision of ethical clinical care and the ability to uphold autonomy in pediatrics can pose challenges and create conflict between pediatric patients, parents, and health-care providers. Child life professionals are prepared and possess the necessary skills to promote, encourage, and support voice and choice in pediatrics through the growth and development of the emerging capacities in children so that they can more fully exercise their autonomy as older adolescents and young adults. ✨

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IN THE NEWS

Connections to Child Life

The Border Crisis: Our Ethical Responsibility

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CHILD LIFE DISASTER RELIEF

The ongoing crisis at the US-Mexico border has been filled with political tension, to say the least. There are drastically opposing opinions, controversial proposed solutions, and strong feelings surrounding conflicting moral ideals. It is difficult, if not impossible, to avoid getting swept up in the emotions of that controversy. Many, but not all, feel it is our human responsibility to get involved in the politics to impact positive change. For the purposes of this article, however, I'd like for us to step aside from the divisiveness of the issues and take a closer look at what unifies child life specialists on this topic.

There are several points in the child life Code of Ethical Responsibility (Association of Child Life Professionals [ACLP], 2011) that can be applicable to the current border crisis. Two of them in particular speak the loudest on this topic and are a unifying force for our profession regardless of one's political stance. They are Principle 2: "Individuals shall strive to maintain objectivity, integrity, and competence in fulfilling the mission, vision, values and operating principles of their profession" (ACLP, 2011, p. 1) and Principle 3: "Individuals shall have an obligation to serve children and families, regardless of race, gender, religion, sexual orientation, economic status, values, national origin or disability (ACLP, 2011, p. 1)." When it comes to our professional responsibility on this issue, these ethical commitments require us to look beyond the disagreements and unite together in our focus of serving *all* children and families equally, without exception, and with objectivity and integrity. That is our professional and ethical responsibility.

Ten child life specialists have deployed through Child Life Disaster Relief partnerships to work with the children impacted by this crisis. Many more child life specialists have worked with

children and families affected by the border crisis within their healthcare settings. There are cultural dynamics and differences that play a role in the way we choose to implement services based on our assessment of the child and family's individual needs at any given moment. But one thing stays consistent: All children are vulnerable to trauma and all children need adults in their lives who understand child development, coping, and resilience and who are trained to help.



One of the stories that I have heard from those deployed for the border crisis that has left a deep impression on me is an example of the respect the volunteers in the respite center show all of the guests. Arriving by bus, the refugees unload at the respite center as they follow government processes. They file into the building, at which time the volunteers pause their tasks for a moment and stand up, applauding and shouting "Welcome!" The child life specialists in the respite center report that this greeting is met with surprised expressions and gradual smiles, as the new arrivals relax a little with a collective sigh of relief.

Leah Nawrocki, CCLS, from Helen DeVos Children's Hospital in Grand Rapids, MI, described one powerful interaction she had with a preteen

continued on page 38

The Border Crisis: Our Ethical Responsibility

boy during her border crisis deployment. Although Leah speaks Spanish, this particular boy spoke a different dialect and her communication with him was a challenge. Even with that difficulty, she was able to provide significant support for him as he processed through all of the hobbies and norms of his previous life and how those things might be different in this new country. “Despite the simplicity of the conversation, it was clear that my words would have an impact.” Leah later reflected, “No one had been able to fully answer his questions about the United States; how schools are organized and other unique aspects of living here.” Leah was able to live out our child life professional responsibility of serving children and families regardless of who they are, where they have come from, or how they have arrived.

Kat Leibbrandt, CCLS, from Johns Hopkins All Children’s Hospital in St. Petersburg, FL, is another child life specialist who deployed for the border crisis.


She describes her experience and her commitment to objectivity during her deployment as well as in her daily professional work within healthcare:

I remember feeling the nerves and adrenaline in the hours leading up to my travels. For weeks, the conflicting opinions and divisiveness from all news outlets, social media posts, and in daily dialogue was often overwhelming, especially considering I was preparing to go to ground zero of the issue. I think as child life specialists we are often faced with challenges in regard to objectivity. When a non-accidental trauma is flighted in, or when working with a premie in the NICU who is battling withdrawal, you have to offer support to the family. There truly are countless examples. When your job is to care for these children and advocate for their well-being, remaining objective can often be an internal battle. I think that this trip was no different. No matter where you stood on that subject matter, seeing a woman who is eight months pregnant, knowing that she just put herself and her unborn child in harm’s way to enter the walls of this welcome center is not easy. To hear a child speak of his firsthand experience riding standing room only in an aluminum trailer with dozens of other people from city to city to be able to arrive a hikeable distance to the border is heart wrenching. However, through it all, when I am sitting with this mother or this child, personal emotions must be placed aside, and compassion must shine through. In that moment, they do not need to see pity; they do not need me asking questions so I can better understand what made this treacherous journey worth it. They need love. They need kindness. They need someone who says, “Welcome. We are so happy that you are safe. I feel so thankful to have this time to sit with you.”

Objectivity, integrity, and a commitment to serving all children and families is our responsibility without exception. It is an honor for us to unite together and use our child life skills despite any other differences of opinion we might have on this or any other issue. ✨

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BEYOND THE CLASSROOM

Views of Emerging Professionals

SOCIAL MEDIA BOUNDARIES: Attitudes and Actions of Beginning Professionals

Kristen R. Lumley

STUDENT, BOSTON UNIVERSITY, BOSTON, MA

As an emerging child life professional, how does one learn to navigate professional boundaries in social media? Is one taught by a supervisor or does one learn from personal mistakes or the mistakes of others? Learning about social media boundaries can be challenging for beginning professionals. This article examines the professional boundaries surrounding social relations with patients and families, especially in the era of prevalence of social media. For example, is befriending a family on Facebook a serious boundary violation? The answer is yes, and we know this because of the standards and policies that exist at our places of work and also those provided by the Association of Child Life Professionals (ACLP). However, beginning professionals might have clarifying questions about this violation depending on the status or situation of the family; for instance, do the same rules apply if the family is still under your current care or they have been discharged? This article aims to explore these nuances in an effort to spark conversation and critical thinking surrounding professional boundaries and social media in child life.

The ACLP Code of Ethical Responsibility (ACLP, 2011) states that child life specialists should examine their social media exchanges to assess whether they may interfere with professional effectiveness or negatively impact the children and families they serve. These policies are intended to promote self-reflection in order to maintain a healthy therapeutic role. There are many reasons for having boundaries in place, but as Blanchette states, “These boundaries provide a safety measure for both professionals and families. They serve to

protect confidentiality and the therapeutic relationship... Therapeutic boundaries further respect that each family has its own life beyond the healthcare setting” (Blanchette, 2016, para. 3). It is important to note that there are consequences for boundary violations, and these can be implemented whether the violation was intentional or not. This is why it is critical to familiarize ourselves with the existing standards and policies that are provided to us, as well as to engage in critical thinking and conversation.

Technology and social media are so prevalent in society today that they tend to bleed into all aspects of life, daily routines, socialization, and work. Therefore, people think nothing of sending or accepting a friend or follow request. However, in professional practice, it is important to constantly reassess practices and take into account unexpected consequences of social media. Due to the nature of a child life specialist’s work of establishing unique relationships with patients and families during stressful events, it may be tempting to keep in touch via social media. As Abril, Levin, and Riego (2010) state, social media sites blur the line between the private and public, the home and the workplace. Private information can easily become accessible to patients and families. This knowledge should be factored into the decision making about whether or not to send or accept a friend or follow request.

Hospital and ACLP standards are a helpful starting point for boundary navigation, but oftentimes these policies just tell professionals what not to do, rather than provide a framework for decision making when faced with a slew of situations. For beginning professionals especially, concrete response plans may prove to be very helpful. For example, Duncan-Daston, Hunter-Sloan, and

[continued on page 40](#)

Social Media Boundaries: Attitudes of Beginning Professionals

Fullmer (2013) move from a simplistic prohibition of using social media altogether to concrete suggestions to use only an institution profile or site that is separate from one's personal profile.

In an effort to understand budding child life professionals' attitudes and beliefs about professional boundaries and social media, 30 undergraduate and graduate child life students at Wheelock College of Education and Human Development at Boston University were given a questionnaire to assess their attitudes and professional responses to concrete situations. The questionnaire consisted of ten open-ended questions. The results of the survey are summarized below:

Question 1: *Have you or anyone you know or work with used social media to keep in contact with children and families you have worked with?*

50% = no
30% = unsure
20% = yes

Mitigating factors for those who were unsure included whether they had a prior relationship to the child or family or were following their public patient care pages.

Question 2: *To your knowledge, which three social media outlets are most frequently used to "befriend" or keep in contact with families?*

The top three responses were Facebook, Instagram, and Twitter, though a few noted using email, Snapchat, and LinkedIn.

Question 3: *In what instances, if any, do you feel it is unacceptable to seek out or accept a friend/follow request from children or families you have worked with?*

70% = it is always unacceptable
30% = some exceptions

Exceptions included whether the patient was still in the hospital or actively being treated.

Question 4: *In what instances, if any, do you feel it is acceptable to seek out or accept a friend/follow request from children or families you've worked with?*

30% = it is never acceptable,
70% = some exceptions

Exceptions included after treatment, if the person moves on to a new profession or retires, if there was a previous relationship, if the patient passed away, and if the following is done on the hospital account or patient public pages.

Note: It is possible that the results of this question differ so drastically from question 3 results because of the way students read the questions. It is believed that in question 3 students answered it is always unacceptable because that is what they are taught, but responded in question 4 that there could be some exceptions because they have not grappled with different situations.

Question 5: *What is your personal attitude toward the policy in the child life code of ethics that states 'a minimum of two years following the conclusion of a professional role shall lapse before any personal relationship is permitted to develop with children or family members'?*

40% = timeframe appropriate
20% = timeframe too short
40% = some exceptions

Exceptions included patient death.

Question 6: *How do you feel the use of social media impacts the adherence to this rule with children and families you currently/will work with?*

60% = social media makes adherence more difficult

Comments:

- With name badges it is easy to find and look someone up.
- Social media is the norm in society today.

Question 7: *Do you feel the policies in the child life code of ethics and standards should be updated/revised surrounding the use of social media and boundaries? Why or why not?*

50% = should be updated or revised,
30% = should be made stricter,
20% = unsure

Comments:

- Professional accounts should be taken into consideration as part of the policy to allow a professional account as an acceptable form of contact.
- Policies should be more specific and kept up to date with the advancements of the world of technology and the influence of social media.

Question 8: *Do you feel being friends/followers of someone on social media while they are in your care would impact the therapeutic/supportive relationship you've created? Why or why not?*

70% = yes
13% = probably
17% = no, but still unprofessional

Comments:

- It would negatively impact the perception of the child life specialist as being seen as someone who is a professional and/or confidential source.
- It would be uncomfortable if a family mentioned something they saw online about you.
- Oversharing on social media, such as having different political, religious, or life views which could then create transference and/or countertransference.

- It could become a slippery slope with direct messaging on social media.
- It complicates the idea that as a child life specialist you are a mandated reporter; what if you see something they post that you know isn't compliant for their health or medical directive?

Question 9: *Think about a time where you had an experience with a child or family that you've worked with where you formed a deep connection with them, more so than the other patients. How did you handle that situation when your professional relationship with them ended? Have you ever thought about looking them up?*

36% = wanted to and/or thought about looking the child/family up

33% = terminated the relationship

13% = followed up

Question 10: *Do you feel the question "Would you do this for every patient?" is a good rule of thumb to use for this decision making? Explain.*

44% = yes

37% = unsure—"too much gray area"

18% = not a good rule

Comments:

- Matters whether or not the child or family has anyone with them or is in foster care.

- Each family should be treated differently based on their needs and as unique individuals. There are always exceptions to the rule.

- This rule would keep relationships fair and equal without showing favoritism and running that risk of hurting other families' feelings.

- This is an unrealistic standard.

How do these results impact the world of child life? One could posit that these results present an opportunity to develop a model for teaching decision making in students, interns, and beginning professionals. This survey of undergraduate and graduate students indicates that despite clear policies, there is still a good amount of diversity of opinion about how to handle specific situations that arise in professional practice. Especially for beginning professionals, a multi-faceted model is needed that addresses policies, ethical reasoning, and concrete options for responding to particular situations. Beginning professionals need to be familiar with hospital policies as well as codes of professional ethics. They need to engage in discussions with supervisors about why policies exist, how they have handled relationships with patients and families, and how they themselves can make ethical decisions that will foster the therapeutic relationship that has been built.

As professionals, we work to empower patients and families by giving them the tools to understand, advocate for themselves, navigate their medical experience, and more. If we applied these same principles to giving interns and young student professionals the tools for boundary navigation and decision making, we very well could see different results and attitudes. Seasoned professionals play an important role in helping beginning professionals navigate complex interactions. They need to share their professional experiences and training to pass along decision-making skills and options that obtain therapeutic results and respect boundaries. This survey provides a starting point for the issues we need to learn and talk more about with young professionals. However, work still needs to be done to sort out whether we teach that these situations are black and white, or we acknowledge the gray areas from the very beginning. Technology is constantly evolving, just like the world of child life. If we can take these issues and confront the challenges of depth and nuances in policy, ethics, and decision making, we can begin to inform not only policy, supervision, and teaching, but action and change. ✨

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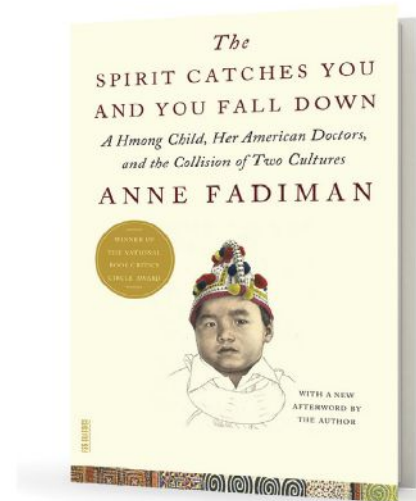
BOOK REVIEW

Samantha Davis, MS, CCLS

PRISMA HEALTH CHILDREN'S HOSPITAL—MIDLANDS, COLUMBIA, SC

The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures

Anne Fadiman



Originally written in 1997 and a recipient of the National Book Critics Circle Award, the Los Angeles Times

Book Prize for Current Interest, and the Salon Book Award, *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures*, by Anne Fadiman, has become a staple case study in healthcare ethics. This non-fiction work recounts the disturbing story of Lia Lee, a young girl of Hmong descent diagnosed with epilepsy, and how Western medicine viewed her family and culture. The book touches on cultural displacement, limitations in medicine, and ineffectual 'good' intentions. Written with an in-depth background of the Hmong culture, the author's personal interactions with the family, and an opposing point of view from American physicians, this text can be considered intricate. However, Fadiman's journalism background and the complex chapter structure enhance the dichotomy between two vastly different cultures and healthcare experiences. This narrative is an excellent account of the clash between Western medicine and Eastern cultural beliefs, which exemplifies the importance of family-centered care principles, individualized interventions, and psychosocial care throughout one's healthcare journey.

Before jumping into the analysis of this book, one must first understand what happened to Lia Lee. Throughout the narrative, there are two separate stories. A significant portion of this book is spent reviewing the Hmong culture and the Hmong peoples' forced relocation to America. This sets the tone for how the Lees react to Western medicine. Nao Kao and Foua Lee are Hmong refugees who have nine children. Starting at 3 months old, their daughter, Lia, began to have frequent seizures. The onset of seizures is blamed on her older sister, who slammed a door just before the first seizure began. Due to their cultural beliefs, the family's perception is that Lia's soul was scared out of her body. In Hmong culture, epilepsy is known as "the spirit catches you and you fall down." Most Hmong people believe that seizures are positive, as many shamans utilize seizures to communicate with the spiritual realm. Lia's parents are proud of this unique ability, but also take her to the hospital each time she seizes. Nao Kao and Foua do not speak English, which makes communicating with physicians difficult. Eventually, the difficulties in communication and lack of cultural understanding led to the family's non-adherence to medical instructions, and the doctors had Lia placed in foster care. Lia's seizures continued regularly and, eventually, a severe seizure left Lia brain dead. Ultimately, the Lees blamed Lia's doctors for their daughter's condition and demise.

Surprisingly, Fadiman is able to keep a mostly unbiased view throughout her reporting of this story, regardless of her deep interest in the friction between Western medicine and the Hmong culture. One strength of this literary work is that Fadiman is able to analyze the background of the Hmong culture, take knowledge from Western medicine, and view the Lees' story to come to the conclusion that the main difference between Hmong and Western views of medicine is quite simple: The Hmong aim to treat the soul, whereas Western medicine aims to treat the body. Fadiman explains that Western medicine physicians are taught to detach and desensitize from patients. In contrast, the Hmong culture aims to treat the soul and espouses the belief that most ailments have a psychogenic element or cause. The most important suggestion throughout the narrative is conjoint treatment, where there is an integration of Western allopathic medicine and the traditional healing arts of the Hmong culture. This suggestion appears to be a phenomenal case for psychosocial and family-centered care. In the end, Fadiman is unable to place blame on either side as she begins to think more like the Hmong culture, allowing her to have a balanced view between the Western and Eastern belief systems.

The main weakness of this text was the complex and confusing structure of the chapters created by Fadiman's unique

writing style. The timeline is out of order and can feel disorganized, as it jumps back and forth from the experiences of the Lee family to the cultural history of the Hmong people. For some readers, this may cause difficulty in following the entire storyline from start to finish and is why this book might not be classified as easy to read. This text could benefit from a timeline for reference, perhaps as an appendix.

Another constructive criticism of this text is of the chapter in which the author meets the Lee family. It appears as if this chapter is the only time throughout the book where bias may be detected. Fadiman claims to have spent hundreds of hours at the Lees' home, but it is never mentioned that she spent an equal amount of time with the American physicians. Additionally, Foua takes a strong interest in Anne and her personal life and love life and even goes to the extreme of dressing her as a Hmong bride. This provides evidence that Fadiman immersed herself into the Lee family and was trusted and respected, creating the appearance that Fadiman got closer to the Lees than to the physicians who treated Lia.

The topic of ethics should be at the forefront of Certified Child Life Specialists' minds, enabling the provision of the most objective, all-encompassing, and therapeutic interventions to patients and families. The Child Life Code of Ethical Responsibility requires

We as child life professionals must also recognize and accept the diversity of each family on an individual basis in order to promote patient- and family-centered care and help other healthcare providers reframe the “typical” view of the family to build a more inclusive perspective.

us to “hold paramount [to] the welfare of the children and families whom [we] serve,” “maintain objectivity, integrity and competence,” and “serve all children and families, regardless of race, gender, religion, sexual orientation, economic status, values, national origin, or disability” (Association of Child Life Professionals, 2011, p. 1). In any culturally diverse situation, child life specialists must uphold these ethical principles. With training and educational background in family dynamics and cultural considerations in healthcare, child life specialists must hold the entire team to high standards of ethical conduct by modeling this kind of behavior for the team. We as child life professionals must also recognize and accept the diversity of each family on an individual basis in order to promote patient- and family-centered care and help other healthcare providers reframe the “typical” view of the family to build a more inclusive perspective. If a child life specialist was actively involved in the Lees' case, perhaps he or she could have advocated for the

patient and family in their role on the interdisciplinary team.

All healthcare employees could benefit from reviewing this book, as it is an invaluable resource that illustrates the contrasting values of ethics and moral compasses of two cultures. This text discusses ethical considerations via a non-fiction account of one family's struggles through the healthcare system in the United States. Informed by this book, child life practitioners can apply a multicultural perspective in their patient and family interactions and be impelled to ask questions, safely collaborate with staff, utilize interpreters, advocate for psychosocial interventions, take a family-centered care approach, and reach out to cultural experts. This can ensure that when these situations arise, we can provide the smoothest and most respectful collaboration between Western medicine and various cultural views. ✨

Opinions about the books reviewed in ACLP Bulletin are those of the individual reviewer, and do not reflect endorsement by the Association of Child Life Specialists.

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HIGHLIGHTS 2019 CHILD LIFE ANNUAL CONFERENCE

APRIL 11-14 | CHICAGO, IL

THURSDAY

PRE-CONFERENCE INTENSIVE

Attendees engaged in a team-building experience.



REGISTRATION

Attendees selected their ribbons.



STUDENT EVENT
Students participated in interactive learning.

LEADERSHIP DEVELOPMENT
New committee chairs participated in an orientation session.



"With so many opportunities for professional development and networking, it's a great way to take your child life career to the next level."

- Mark Compas, CCLS,
Tech Specialist, Northwell,
Attendee Survey

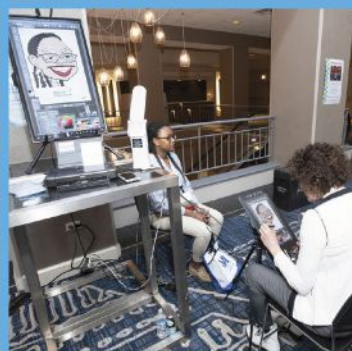


WELCOME RECEPTION

Attendees enjoyed the opportunity to catch up with friends, visit the ACLP booth, have their caricature drawn, and meet with exhibitors.

"This conference, the variety of topics, and those aimed at seasoned child life specialists really ignited my child life passion."

- Conference Attendee,
Attendee Survey





FRIDAY

OPENING GENERAL SESSION

More than 1,170 child life professionals attended the Child Life Annual Conference.



The Opening General Session was generously sponsored by Aflac and Disney.



Stephanie Hopkinson, MA, CCLS, President ACLP, presented Deborah Vilas, MS, CCLS, LMSW, with the Distinguished Service Award.



AWARDS BREAKFAST

International scholarship winners attended the Awards Breakfast.

"Deb was amazing and incredibly inspiring. She was able to reignite my passion for child life and reminded me why I chose this profession...Great choice for this award! "

- Conference Attendee, Attendee Survey

Jason Wolf, PhD, CPXP, President, The Beryl Institute, gave the Opening Keynote Address.



96%

ATTENDEES RECOMMEND CONFERENCE AS A QUALITY EDUCATIONAL EXPERIENCE

- Attendee Survey

"As a new one-person program, the conference was an unparalleled source of knowledge and new ideas."

- Conference Attendee, Attendee Survey



"I was reminded so much of the kinds of energy and creativity we have as a field, and that was represented well with the Child Life at Play events."

- Conference Attendee, Attendee Survey



SATURDAY

The Conference Program Subcommittee provided opportunities for Child Life at Play, including morning yoga sessions.

Attendees had multiple opportunities to meet with 67 exhibitors in the exhibit hall.



The Archives Committee shared history of ACLP with an archives museum display in the exhibit hall.



"The Innovation Fair was a highlight - really cool to see the large turnout. I had some great discussions with other child life specialists at this event."

- Conference Attendee, Attendee Survey

Attendees sorted colors for THE CRAYON INITIATIVE.



The inaugural INNOVATION FAIR, conceived and developed by the Conference Program Subcommittee, was a huge success.



Attendees participated in POSTER PRESENTATIONS.

Stephanie Hopkinson, MA, CCLS, President ACLP, presented Annette Bonjour, MS, CCLS, with the Mary Barkey Clinical Excellence Award.



SUNDAY

CLOSING GENERAL SESSION

Generously sponsored by San Diego Zoo Kids



"I came away from conference energized and with new ideas to implement at my facility."

- Sarah Kress, Lead CCLS, Carilion Children's, Attendee Survey

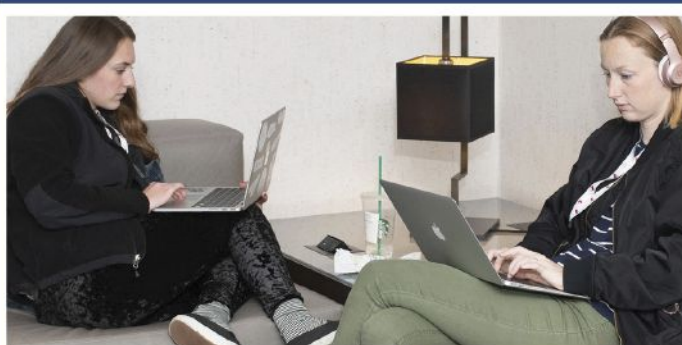
Stephanie Hopkinson, MA, CCLS, President ACLP, 2018-2019, passed the baton of leadership to Jill Koss, MS, CCLS, President, ACLP, 2019-2020.



SPECIAL EXHIBITOR ADVERTISEMENT SECTION

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SPECIALIZED RESOURCES



Specialized Resources is a column designed to share books, websites, apps, and other resources that may be helpful for child life specialists working with a specific population. This column represents only the personal views of the author, and the 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.

Medical Ethics in Child Life

Jennifer “Jenny” Chabot, PhD, CCLS

OHIO UNIVERSITY, ATHENS, OH

Today’s societal and political culture has created interesting and important dialogues regarding medical ethics. One can simply log on to favorite online news sources and social media pages and see headline after headline that bring up ethical dilemmas in healthcare. As we read, we may ask ourselves, “Is this even *ethical*?” Looking at some recent headlines, we can see an increase, for example, in videos and pictures from local police feeds of opioid overdoses for all of the public to see. From a child life lens, what implications do these public pictures have for patients and families with whom we work who are impacted by the opioid crisis?

Beyond social media, there are other interesting ethical dilemmas discussed in today’s society, such as families taking medical treatment into their own hands instead of reaching out to medical professionals, the unattainable costs of life saving/life maintaining medicine for children and families in the U.S., and the growing controversy over pediatric vaccination policies.

As child life professionals, it is important that we have discussions on the impact that these ethical issues and dilemmas have for patients and families in our daily work. We need to explore what our responsibilities are and how ethical principles of child life intersect with medical ethics in the stories we see and experience in our professional work. What are the implications in these cases for child life professionals? Where may these stories occur in child life practice? What is the perspective or role of child life in cases that impact medical ethics? How does a child life specialist maintain objectivity, provide developmentally supportive care, and remain a supportive presence in an environment of conflict in opinion? In order to begin and maintain dialogue regarding medical ethics in today’s society, below are some great resources that can be utilized as primers in medical ethics and provide guidance in examining the above questions.

READINGS: BOOKS

- Doherty, R. F. & Purlito, R. B. (2015). *Ethical dimensions in the health professions* (6th ed.). St. Louis, MO: Elsevier.
Doherty and Purlito offer a foundation on basic ethical theory, relevant case studies, discussions on issues that impact today’s healthcare, and key terms and concepts related to medical ethical considerations. This is a wonderful resource for current and future healthcare professionals, particularly child life professionals teaching in the area of medical ethics, as it provides a foundation of relevant, in-depth content that can be built upon in a classroom setting or within child life in-service training.
- Fleischman, A. R. (2016). *Pediatric ethics: Protecting the interests of children*. New York, NY: Oxford University Press.
Fleischman focuses on pediatric ethics, providing chapters that include a discussion of the field of pediatric ethics and an examination of the impact of today’s societal context for the current generation of children. This book also offers ethical cases that cover the lifespan of childhood, from reproductive issues to those that impact adolescence. There is also coverage on decision-making models to use when faced with a medical ethical dilemma.
- Pence, G. E. (2016). *Medical ethics: Accounts of ground-breaking cases* (8th ed.). New York, NY: McGraw-Hill Education.
The case studies in this book are fascinating and very relevant with today’s societal dilemmas and tensions. Case study topics include the right to die; the treatment of transex and transgender individuals; addiction; psychiatric diagnoses; medical research; and ethical issues related to the American with Disabilities Act, the Affordable Care Act, and the Patient Protection Act. The potential to integrate a child life lens into each case study is very strong, and centering discussions around each case could be a course assignment, staff in-service, or of use in training future child life professionals. Each case could be examined with questions including, “In what way would a child life professional work with a patient/family involved in a case like this?” “How would child life roles and responsibilities intersect with the ethical dilemmas the case raises?” and “Are there any ethical principles of the child life profession that are impacted in each case?”

READINGS: JOURNAL ARTICLES

- Gagnon, K. & Sabus, C. (2015). Professionalism in the digital age: Opportunities and considerations for using social media in health care. *Physical Therapy*, 95(3), 406-414.
Examining ethics from the lens of the physical therapy profession, the authors discuss ways to maintain professionalism in the age of social media, which is very transferrable to child life work.
- Gardner, J. M. & Allen, T. C. (2019). Keep calm and tweet on: Legal and ethical considerations for pathologists using social media. *Archives of Pathology & Laboratory Medicine*, 143(1), 75-80.
Although this article focuses on pathologists, it raises interesting issues related to medical professionals taking and sharing medical photographs and images on social media, all transferrable concerns for any member of the interdisciplinary team, including those in child life. Laws in place are examined, as well as the legal risk for pathologists and potential patient harm in sharing images, including those that are deidentified.
- Harbut, R. F. (2019). AMA polices and codes of medical ethics' opinions related to health care for patients who are immigrants, refugees, or asylees. *AMA Journal of Ethics*, 21(1), 73-77.
This article discusses how the American Medical Association's Code of Medical Ethics addresses the healthcare needs of patients facing limited healthcare resources, including immigrants, refugees, and individuals seeking asylum in the United States. The reference list includes a diverse group of articles addressing specific populations at risk for access to healthcare.
- Hendrix, K. S., Sturm, L. A., Zimet, G. D., & Meslin, E. M. (2016). Ethics and childhood vaccination policy in the United States. *American Journal of Public Health*, 106(2), 273-278.
In their work, child life professionals no doubt come across families who are, as the authors describe in this article, "vaccine-hesitant and vaccine-opposing families" (p.276). What are the ethical issues that arise in the growing pediatric vaccination debate in the U.S.? This article examines both sides and discusses the importance of communication between health professionals and families regarding ethical concerns related to vaccination policies.
- Leider, J. P., DeBruin, D., Reynolds, N., Koch, A., & Seaberg, J. (2015). Ethical guidance for disaster response, specifically around crisis standards of care: A systematic review. *American Journal of Public Health*, 107(9), 1-9.
As disaster relief work is a growing area focus for child life professionals, this is a great article to review regarding what ethical standards exist for disaster relief responses by healthcare professionals. In addition to identifying the most often used standards of ethical care found in the literature, the authors also present the implications for public health.
- Westin, A. (2018). 'Despite circumstance': The principles of medical ethics and the role of hope. *The New Bioethics*, 24(3), 258-267.
The author examines the role of hope and how our understanding of hope informs our care as health professionals. The key concept she discusses is rooted in valuing the patient-professional relationship, which child life professionals do so well.

TED TALKS

There are several TED talks available that cover specific medical ethical issues, and some that are more general regarding medical ethics overall. Here are a few of my favorites:

- Paul Rosen, MD: "The next revolution in health care? Empathy": <https://www.youtube.com/watch?v=8BKN7RFhdq4>
Rosen is a pediatric rheumatologist with Nemours Children's Hospital in Delaware. He discusses the role of empathy in healthcare, and how we can lose our way regarding empathy. Child life professionals will recognize so much of what Dr. Rosen says in his examples of empathy that is often seen in pediatrics. He gives an impassioned speech on how we need to restore empathy, which provides a great kick-off for any discussion on empathy and its place in medical ethics.
- Charles Foster, PhD: "Identity and authenticity in medical ethics": <https://www.youtube.com/watch?v=LRLgH7XYZk>
Foster is a professor of law at Oxford University, and has dealt with many legal cases involving medical ethics. He provides an interesting talk on how the personal identity of patients—their authentic selves versus the self as a diagnosed patient—impacts the patient-medical professional relationship. He uses stories of patient cases (patients with anorexia, Alzheimer's, or Huntington's Disease, for example) to convey his premise that we must understand the relationship each patient has with his or her diagnosis and make every attempt to understand each patient as a whole being and not only within the identity of his/her diagnosis.
- Michael D. Burroughs, PhD: "The significance of ethics and ethics education in daily life": https://www.youtube.com/watch?v=8juebyo_Z4
Burroughs is the director of the Kegley Institute of Ethics at Cal State University, Bakersfield. He provides a fascinating talk on the ways we face ethical issues in our daily lives, and how these struggles within ourselves can strengthen our personal and professional understanding of ethics, helping us make better decisions.

Jenny Chabot has been a professor of child and family studies/child life for over 20 years at Ohio University. She is in the process of creating a course, Medical and Clinical Ethics for the Health Professional, for students pursuing a degree in health-related disciplines at OU. She can be reached at chabot@ohio.edu. Note that the citations discussed above can be found in the ACLP Resource Library via the search tool.



PATHWAYS TO PROFESSIONAL INQUIRY

Locating, Navigating, and Evaluating Empirical Literature

This article begins a three-part series about finding and utilizing journal articles in your child life practice.

Just Like Where's Waldo: The Search for Journal Articles

Dottie Barnhart, M.S., CCLS

CHILDREN'S MEMORIAL HERMANN HOSPITAL, HOUSTON, TX

Finding full-text journal articles sometimes feels like searching for a guy in a red and white striped shirt on a beach full of people in red and white striped outfits. The constant flow of newly-published journal articles is a great resource to a child life specialist who has access to them. Odds are, articles are within your grasp. It can feel like a daunting task, but if you do a little digging, finding and using journal articles can be as easy as grabbing a light-up wand on a distraction shelf. This article will discuss the different types of journal articles and their purpose, searching effectively, hospital- and university-based resources, and resources available no matter your institutional connection.

Types of Journal Articles

Journal articles typically include empirical research articles and review articles. Empirical research articles describe an original research study that has collected data to (a) explain a certain phenomenon (e.g. interdisciplinary understanding of the child life role) or (b) test specific interventions (e.g., efficacy of a child life preparation program for surgery). Empirical research articles use research terms, such as “research question,” “hypothesis,” “method,” and “results” (Thomas, 2017). In contrast, review articles include literature reviews of specific topics, which means they will likely reference multiple research

articles and often compare and contrast these studies. This type of article can be helpful for finding larger amounts of information about specific concepts, usually over a certain amount of time. For example, you may find a review of articles related to trauma-informed care over the last decade more useful than searching for all empirical research articles on trauma-informed care.

Without a doubt, supporting evidence-based practice (EBP) through journal articles can help you “speak the language” of other-disciplined peers. Creating a solid defense for J-tips, campaigning for parental presence in surgical inductions, or advocating for lower noise levels in the NICU can all be strengthened with the support of current journal articles.

The field of child life has advanced because scientific-based work has provided evidence for concepts related to attachment's impact on development (Bretherton, 1992) and the necessity of developmental play for growth (Brown, 2009). EBP has led the way for child life's inclusion in the American Academy of Pediatrics' hospital standards (American Academy of Pediatrics Committee on Hospital Care & Child Life Council, 2014), which set the bar for children's hospitals nationwide. Even if EBP is not part of your “tool-kit” at the moment, it is largely why you are able to be a child life specialist in the first place!

Search Tools

If you are not even sure where to start, the *ACLP Monthly* member email highlights research relevant to child life and family-centered care. Also, posts on the ACLP Forum often highlight beneficial articles related to current practice. Of course, you could ask a co-worker or student if they know of any worthwhile reads.

Using search engines like Google Scholar or PubMed, you can search for journal articles, as well as organize articles you find. While these sites do not provide access to articles, they are an easy way to stay up to date or find more of what interests you.

For more in-depth searches, reference management software and apps, such as Mendeley.com or EndNote, provide research support by highlighting recent articles based on your searches, or sending weekly “reading suggestions” to keep you informed of current research (Thomas, 2017).

Search Methods

The first step to finding relevant journal articles is to use search terms relevant to the information needed. Let's say you are looking for interventions for working with adolescents dealing with pain management as part of their diagnosis. Step two is to decide on key words from that question. Step three is to use these key words in a search (JSTOR, 2018a).

Example:

- Step one: Ask your question. What child life interventions are beneficial for adolescents in pain?
- Step two: Highlight the key words. What **child life** interventions are beneficial for **adolescents** in **pain**?
- Step three: **child life**, **adolescents**, and/or **pain** become the search terms

If a search using these terms finds thousands of articles, be more specific. Narrow the search to within the last 5 to 10 years, or search a specific diagnosis or setting (JSTOR, 2018b). For the above example, adding terms like “sickle cell” or “inpatient” could provide a smaller and more defined group of articles. A search can also be narrowed down by type of publication in order to draw from worthwhile sources. For example, using EBSCO’s search engine, it would be beneficial to opt to search CINAHL and Cochrane Database of Systematic Reviews because both are related to medical research. Table 1 includes some words and symbols to utilize when searching for journal articles.

Hospital-Based Resources

Hospital and clinic-based child life specialists may have journal article access available within their institution.

Many hospitals offer access to journals through large medical databases, such as EBSCO or PubMed. Ask your manager or other staff, such as your team’s nurse educator, a nurse scientist, or medical librarian, about their knowledge of access to journal articles. Medical librarians may even assist you with more in-depth searches.

University Library Resources

Outside of a hospital, public or university librarians are great resources because they are knowledgeable about journals and motivated to educate others on how to find journal articles. If you are post-graduation, know that some universities offer access to journal article databases as part of their alumni benefits. This may require a “donation” to your alumni association. Depending on the university, current students have access to many journal articles through the campus library or on the library’s online portal. Sometimes it is not even necessary to be an alum to gain university library access, but most require that you physically go on campus to register.

Public Library Resources

A public library can potentially provide journal article access, depending on the library’s subscriptions. You will likely need to register for a library card. Just like university librarians, public

librarians may be able to support your search efforts and give guidance. Many libraries even collaborate in order to broaden their resources. For example, many public libraries in Texas are part of a program called TexShare, which allows registered members access to research materials (books, magazines, e-content) at multiple libraries and through multiple online databases (Texas State Libraries and Archives Commission, 2017).

As child life specialists, we already have the skill set to access quality journal articles. We know how to prioritize information, use the resources around us, and cope with frustration. Like searching for Waldo (or Wally if you’re across the pond), the searching can take time, but there are multiple resources available along the way. When you do find useful articles, it can feel like that moment where you finally spot Waldo and breathe a sigh of relief. Best of luck in your searching! 🌟

Table 1
Helpful words and symbols to use in searching for journal articles.

WORD/SYMBOL	PURPOSE	EXAMPLE
AND	Using AND between terms will find articles that include both terms.	J-tip AND lidocaine will find articles that include both j-tips and lidocaine in the article.
OR	Using OR between terms will find articles that include at least one of the terms, and possibly both.	Emergency OR inpatient will find articles about emergency settings and inpatient settings, and possibly emergency and inpatient settings in the same article.
“ ”	Using quotes around terms will find that exact phrase in articles.	“child life” will find articles that include the exact phrase “child life.”
*	Using an asterisk will find variations of a word or phrase.	teen* will find articles that include the words teen, teens, and teenager.

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MOMENTS FROM THE PAST

New Beginnings

Civita Brown, MS, CCLS

ARCHIVES MANAGEMENT COMMITTEE

A photograph, a news article, a letter, or another document can give us a glimpse into the past, including the “firsts” of the child life profession. Each item represents a brick in the foundation of child life, showing us how the profession has become stronger. One such item is a document from the first year of the Child Life Council, 1982-1983. Although a child life study section had been meeting as part of the Association for the Care of Children’s Health (ACCH) for several years, it was in that transition year that new members were recruited from the field of child life, recreation, and related disciplines in anticipation of a new and more independent organization. This recruitment was carried out through direct mailings and in the *ACCH News*. By May 18, 1983, there were 235 members. The first official mailing included ballots for the by-laws, officers, and the Child Life Position Paper. Committees were formed to address issues involving joint accreditation, core curriculum, competencies, philosophy, code of ethics, membership, bylaws, certification, program review, identity (including names and common goals), and theoretical framework.

The first Child Life Council annual meeting was held from May 24 to May 25, 1983, on the campus of Kendall College in Evanston, IL. As the 2019 ACLP conference was held in Chicago, it seems appropriate to reflect on that initial meeting. It was agreed at that time that the Child Life Council’s yearly meetings would be held preceding the ACCH annual conference. About 125 Child Life

Council members attended this first meeting, including the Child Life Council officers: Jerriann Wilson, President; Ruth Snider, President-Elect; Susan Kleinberg, Treasurer; Ruth Kettner, Secretary; and Leigh Parish and Evelyn Oremland, Members-at-Large. A great deal was accomplished, including the approval of a code of ethics and theoretical framework by straw vote, which were then sent to the full membership for vote by mail. It was also decided that future conferences would include one day for professional issues and one day for educational presentations specific to the child life profession. Because of the ACCH conference immediately following this meeting, members were careful to avoid conflicts with the ACCH workshops and presentations.

Another glimpse of this time period in the history of child life can be found in the first *Child Life Council Bulletin*, edited by Evelyn Hausslein in August of 1983. In that first *Bulletin*, the First Annual Council Meeting was declared a success

1983 CHILD LIFE COUNCIL MEETING ON CHILD LIFE PROFESSIONAL ISSUES

**May 24-25, 1983
Kendall College, Evanston, Illinois**

The Child Life Council Executive Committee in conjunction with the Child Life Planning Committee are pleased to invite Child Life/Recreational professionals to our first meeting. Your attendance and valuable contribution in the early stages of our growth will ensure the future progress of your profession. We strongly urge you to attend both days of the Council meeting as the continuity is important.

Kendall College, located north of Chicago, will be the site of lodging as well as meetings. It is located two blocks from Lake Michigan which provides the opportunity for outdoor recreation. It is adjacent to the Northwestern University Campus and the Evanston Art Center.

PLANNING COMMITTEE

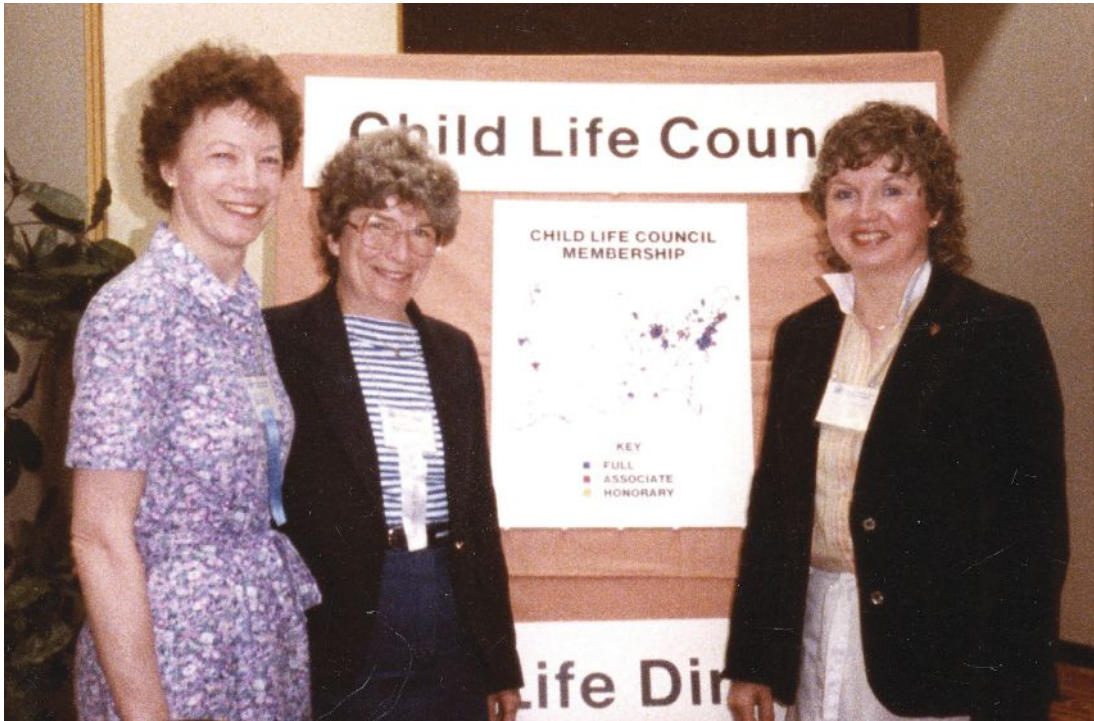
Mary Jo Guglielmo
Rush-Presbyterian-St. Lukes Hospital
Chicago, Illinois

Jerriann Wilson
Johns Hopkins Hospital
Baltimore, Maryland

Janet Larson
Children’s Memorial Hospital
Chicago, Illinois

Ruth Snider
Chedoke-McMaster Hospital
Hamilton, Ontario

Part of the program from the first meeting of the Child Life Council.



The Child Life Council's first president, Jerriann Wilson, with Ruth Snider and Marcia Potruff at an early meeting.

and described as “two days of work with some fun thrown in.” The *Bulletin* goes on to mention that after nearly two days of meetings, members attended a workshop in drama by the creative Piven Group and viewed the premiere of the new videotape, *Emma Plank, An Oral History*. Of course, Mrs. Plank’s presence at this showing really made this a special occasion for the members. The *Bulletin* went on to give a summary of each committee’s report and the actions taken. This first issue also had an article reporting the election of Mary Brooks as the second honorary lifetime member of the Child Life Council. Mary Brooks was one of the original founders of the ACCH in 1965, as well as former director of the child life department at Children’s Hospital of Philadelphia. Mary was well known for her work there in the late 1950s and 1960s before her retirement in the early 1970s. She was also the author of many articles on play in the hospital and had a special role in the history of child life as historian for ACCH.

The first “Presidential Profile” in the *Bulletin* was that of Jerriann Wilson, the Child Life Council’s first President. It went on to highlight Jerriann’s many accomplishments in the field since 1962, including the beginning of her career in child life at Johns Hopkins Hospital as a teacher in the child life department, her role as the first director of the child life program at Baltimore City Hospital, and her return, five years later, to Johns Hopkins as the director of their child life department. It also discussed her involvement with ACCH as co-chair of the 1978 ACCH Conference in Washington, DC, National Executive Board member, frequent speaker, and ACCH child life study section chair.

Thus, the bricks were laid and the foundation became stronger with each meeting and with each *Bulletin* documenting the growth of the Child Life Council and profession. ✨



ACLCP Calendar

AUGUST

- 7 Initial [Distinguished Service Award](#) nominations due
- 7 Initial [Mary Barkey Clinical Excellence Award](#) nominations due
- 10 Deadline to register for the August administration of the [Child Life Professional Certification Exam](#)
- 22 Deadline to submit transcripts and other documentation in time to apply for the [2020 Winter/Spring Internship](#)
- 15-30 [Child Life Professional Certification Exam](#) Administration Testing Window

SEPTEMBER

- 5 Supporting documentation for [Mary Barkey Clinical Excellence Award](#) nominations due
- 5 Supporting documentation for [Distinguished Service Award](#) nominations due
- 5 Application deadline for the [2020 Winter/Spring Internship](#)
- 16 Application deadline for [Mentor Program](#)

OCTOBER

- 1 Submission deadline for [ACLCP Bulletin articles](#) for consideration in the Winter 2020 issue
- 18 Deadline to submit your coursework documents for review in time to register for the November [Child Life Professional Certification Exam](#)
- 27 Deadline to register for the November administration of the [Child Life Professional Certification Exam](#)
- 31 [2019 International Scholarship applications](#) due
- 31 Deadline to apply to [recertify through PDUs](#)

NOVEMBER

- 1 [Research Award applications](#) available
- 1-15 [Child Life Professional Certification Exam](#) Administration Testing Window
- 15 [Application due for 2020 winter/spring Diversity Scholarships](#)

DECEMBER

- 20 Deadline to submit transcripts and other documentation in time to apply for the [2020 Summer Internship](#)
- 31 Last day to [reinstate lapsed CCLS credential](#)



Upcoming Events

SEPTEMBER 6-8

Florida Association of Child Life Professionals (FACLP) – 27th Annual Conference

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

SEPTEMBER 14

Southeastern Association of Child Life Professionals – 2nd Annual Conference

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

OCTOBER 26

Texas Association of Child Life Professionals – 3rd Annual Conference

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

NOVEMBER 2

Great Lakes Association of Child Life Professionals (GLACLP) – 14th Annual Conference

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

NOVEMBER 9-10

24th Annual Midwest Child Life Conference

[Visit the online registration](#) page for more information.



Webinars

ACLP's 2019 webinar programming is well underway, but there are plenty of opportunities to join some exciting sessions in the coming months. Visit our new [professional development page](#) to learn more about our offerings, and complete your professional development plan for 2019.

ACLP is committed to offering our members relevant, high-quality, and accessible professional development. Our 2019 webinar lineup provides members the opportunity to access content that aligns with their background and experience. Whether you're an emerging professional who is new to the field, or an established professional who wants to stay sharp, our updated webinar programming has something for you.

JULY 18, JULY 25, and AUGUST 1

3-Part Webinar Series: Keeping Your Balance While Climbing the Ladder of Cultural Competence

This webinar series is intended for both emerging and established professionals. This series is a great way to start, join, or elevate the conversation on diversity, equity, and inclusion within yourself and across your team. It's not to be missed!

MONDAY, AUGUST 12

You Can't Pour from an Empty Bucket: Stress and Self-Care in the Child Life Profession

This webinar is intended for emerging professionals with 0-7 years of experience.

WEDNESDAY, AUGUST 28

Supporting Infants at Risk of Neonatal Abstinence Syndrome: A Two-Generation Care Model

This webinar is intended for established professionals with 7+ years of experience.

MONDAY, SEPTEMBER 16

Helping Kids Succeed: Communication Between Home and School when Children have a Chronic Illness

This webinar is intended for emerging professionals with 0-7 years of experience.

Your passion for professional development drives our programming. Please help us continue to provide high-quality, relevant programming by sharing your expertise and facilitating a webinar. If you have an idea for a webinar, please visit [ACLP's webinar proposals page](#) to provide us with information about your presentation. In addition to the satisfaction that comes from sharing your passion, presenters earn 2 PDUs per hour of presenting. We look forward to partnering with you as a facilitator!

WEDNESDAY, SEPTEMBER 18

Child Life and Qualitative Research: A Perfect Partnership

This webinar is intended for established professionals with 7+ years of experience.

MONDAY, OCTOBER 14

A Call for Culture Change and Re-Prioritization of Our Most Vulnerable Patient: Establishing Neurodevelopmental Protection for the Neonate

This webinar is intended for emerging professionals with 0-7 years of experience.

MONDAY, OCTOBER 21

Ethical Concerns Regarding Diagnosis Disclosure: A Case Study Discussion

This webinar is intended for established professionals with 7+ years of experience.

MONDAY, NOVEMBER 4

Process Improvements: Applying "Elf" Teamwork to Manage Holiday Donations

This webinar is intended for emerging professionals with 0-7 years of experience.

MONDAY, DECEMBER 9

Supporting Patients, Families, and Staff at End of Life: A Framework for Success

This webinar is intended for emerging professionals with 0-7 years of experience.

WEDNESDAY, DECEMBER 11

Efficient Inquiry: Painless Research Methods for Busy Clinicians

This webinar is intended for established professionals with 7+ years of experience.

2019 Conference Sponsors

ACLP and the child life community appreciate the support of our 2019 Child Life Annual Conference sponsors.

