Inside
They, Them, Theirs: The Importance of Pronouns and Other Considerations When Caring for Patients who Identify as Gender Diverse
PAGE 8
Moments of Joy can change the world

“Moments of Joy” is a documentary that provides an emotional look at childhood cancer through the eyes of some of its young patients, their family members and professionals who care for them. It also features My Special Aflac Duck®, who throughout the film is a gentle reminder that even the smallest moments of joy, especially when found in the midst of uncertainty, can be true treasures.

A 25-year, $140 million corporate ally to families facing childhood cancer, Aflac, along with the film’s purpose-driven creator, Chispa House, hope ‘Moments of Joy’ inspires others to join in supporting the thousands of courageous children diagnosed with cancer each year.

To view the film, visit aflac.com/joy. To learn more about My Special Aflac Duck visit AflacChildhoodCancer.org.

Aflac herein means American Family Life Assurance Company of Columbus and American Family Life Assurance Company of New York. WWHQ | 1932 Wynnton Road | Columbus, GA 31999.
I first read Bulletin in 2000 as a playroom volunteer at Scott and White Hospital in Temple, Texas. A decade later, I first published in Bulletin, sharing my master’s thesis in Focus. Now, as the end of this decade approaches, here I am composing my last column as executive editor for ACLP Bulletin, reflecting on the role of this space over the years.

In 1999, a year before my time at Scott and White, Bulletin readers were introduced to an insert titled Focus. This insert featured peer-reviewed original research, theoretical descriptions, and literature reviews. It is where I first read our evidence-based practice statements, where I devoured Sweett’s (2009) “Advocacy and its Place in Child Life Work,” and where I read in awe as child life professionals conducted their own studies (some of my favorites include Brinson, 2012; Farrell et al., 2013; and Moore, Bennett, Dietrich, and Wells, 2015). Twenty years and 83 articles later, Focus has continued to publish high-quality evidence contributing substantially to our emerging field of inquiry. While I missed the beginning of the publication’s journey by a year, I have been part of the team and witnessed an ending of a sort. The last publication of Focus was shared with readers in our Fall issue of ACLP Bulletin.

My own training and career path have confirmed the ever true but rarely comforting adage that with endings come beginnings. Focus is migrating to a new home and will assume a new name. The Journal of Child Life: Psychosocial Theory and Practice will be introduced in March 2020, to coincide with Child Life Month. The unknown nature of a beginning may be a source of anxiety, a moment to hold to the comforts of the familiar past; but it is also one of excitement, of possibility for the potential of a fresh canvas. The biannual peer-reviewed publication will be more accessible to those outside the child life community, with the mission to extend the reach of our community’s pivotal but too-often silo-ed research across both disciplinary and national lines.

This exciting beginning also brings inevitable changes to our committee’s editorial structure. I will be moving into the executive editor role of The Journal of Child Life and our current associate editor, Kathleen McCue, MA, LSW, CCLS, will become executive editor of ACLP Bulletin. Come spring 2020, Kathleen will be greeting you from this space in ACLP Bulletin and I will be writing to you from the first issue of The Journal of Child Life. I look forward to sharing the inspiring content we have coming your way in the journal each March and September, and encourage every one of you to consider sharing your work with us as part of this growing movement to spread the evidence-based and innovative care we are dedicated to providing across our community and beyond.

It has been an honor to support ACLP Bulletin and watch Focus emerge as a growing resource. While preparing each issue, I remained inspired by the depth and breadth of our talented community. Thank you for sharing your work.

REFERENCES


Leading the Way in Emotional Safety

What does an emotionally safe experience look like for patients and caregivers, as well as for staff? It may be easier to start to conceptualize the idea of emotional safety if we think about the times we’ve seen a patient or parent emotionally harmed: when appropriate preparation didn’t take place, when information was given at the wrong time and without support, when pain wasn’t mitigated, when a child was held down for a procedure, or when developmental level wasn’t taken into consideration. In all reality, emotional safety happens when all staff look at patient care and the environment through the lens of a child life specialist. My belief is that emotional safety is the basic tenet upon which our profession was created, and is at the core of child life philosophy. This is why it is so important for ACLP to be leading the work to create best practice standards for pediatric healthcare.

When ACLP’s current strategic plan was published with the new vision statement that states, “ACLP advances psychosocial care and the emotional safety of children, youth, and families impacted by healthcare and significant life experiences,” there were questions about the meaning of “emotional safety.” To begin the work to define emotional safety and create a supporting framework, ACLP sponsored an Emotional Safety Summit, held at the beginning of November and hosted by ACLP’s Patient and Family Experience Committee. In preparation for the summit, a basic definition of emotional safety was developed as “intentional and respectful health care delivery that expedites resiliency, healing, and trust in patients and families.” The committee emphasized that emotional safety is ensured through assessment—considering a patient’s developmental level, as well as thoughts, feelings, and experiences as related to their medical encounter—to inform appropriate interventions. The summit sparked invigorating conversations between child life specialists, nurses, physicians, psychologists, parents, quality improvement professionals, and others around the constructs of emotional safety, and then began to lay out the structure to carry the work forward. It is crucial to note that our multidisciplinary partners validated the language being used, as well as the direction we are headed. The four pillars of emotional safety as outlined by the Patient and Family Experience Committee are assessment; intervention; environment/culture; and staff communication, education, and training; each having significant evidence-based research behind them. Summit attendees spent time creating actionable behaviors to identify the work associated with each pillar, and the committee is now going through the process of refining and prioritizing these behaviors and activities.

As thoughts and ideas from the summit begin to come together, it is important to recognize that emotional safety is more than trauma-informed care, or medical traumatic stress, or even patient-and-family-centered care. Those are all pieces within the construct of emotional safety, directly connecting to the greater context of patient safety, which is a priority within pediatric healthcare and beyond. As child life specialists, we are in the unique position of being the resource for the rest of the healthcare team when it comes to the work of emotional safety. Keeping kids emotionally safe is at the heart of who we are as child life professionals. It’s what all of our knowledge, skills, and abilities equip us to do every day in our work. You already know what it means to create emotional safety for patients and families; you work to do it every day, and that’s something to be proud of. 🌟
Putting the “WE” in Welcome

Recently I’ve found myself troubled by the social trends of divisiveness, cancel culture, and an “us vs. them” approach, and I’ve wondered how we shift to appreciate and leverage the value of different perspectives and varying life experiences. Fortunately, I’m not alone in my thoughts, as fellow association professionals join in to focus on diversity and inclusion, and to consider how remaining ignorant or rigid in our status quo prevents opportunity and growth, further solidifying the systemic oppression of many while sustaining the privileged position of a few.

There are many ways one can define diversity and inclusion. Perhaps one of the best ways I’ve seen both defined was by Carrie Ellis of Celestial Consulting, who led our board, staff, and key volunteer leaders in a full-day session focused on diversity and inclusion in the fall of 2019.

*Inclusion* is a dynamic state of operating in which diversity is leveraged to create a fair, healthy, and high-performing organization or community. An inclusive environment ensures equitable access to resources and opportunities for all. It also enables individuals and groups to feel safe, respected, engaged, motivated, and valued for who they are and for their contributions toward organizational and societal goals.

*Diversity* refers to the variety of similarities and differences among people, including but not limited to gender, gender identity, ethnicity, race, native or indigenous origin, age, generation, sexual orientation, culture, religion, belief system, marital status, parental status, socio-economic difference, appearance, language and accent, disability, mental health, education, geography, nationality, work style, work experience, job role and function, thinking style, and personality type. Inclusion of various diversity dimensions may vary by geography or organization.

As ACLP leans in towards solidifying a community that is inclusive of all forms of diversity, it is important that each of us remain engaged and curious about how every individual contributes to experiences of inclusion, exclusion, and/or privilege. For the child life profession, one area of interest lies in academic and clinical training as we encourage diligence in engaging students in discussions around unconscious bias, healthcare disparities, and equitable practice. We are grateful to those who have reached out to offer guidance about where and how to scaffold current academic and clinical curricula to include opportunities to discuss such relevant and important topics.

This work requires increased awareness and reflection of how each of us “shows up” and examination of our engagement with others so that we can further each other’s contributions to closing the gap in health disparities. I encourage leaders across the child life community to support their teams in processing implicit biases and exploring what makes up the space between people, as personal investigation and reflection are necessary components for true growth.

While ACLP is actively working toward creating an updated Diversity Statement to uphold our commitment to welcoming all, each member must decide how they will contribute to keeping the ACLP community accountable in its inclusivity.

Refreshing the community’s interests, raising awareness of how/when/where diversity informs practice, and articulating emotional safety as a natural result of our members’ work; these are all new priorities that ACLP will be focused upon in 2020 and beyond. There will be (more) shifts to our programs and materials as a result of such focused evaluation, but we’re committed to making changes to produce the greatest impact.

Our board, staff, and committees will all be engaged in the courageous work of evaluating ACLP’s practices to highlight where stagnation and status quo exist, and how they implicitly and explicitly exclude engagement of diverse perspectives. ACLP’s greatest asset is its community, and we are committed to reflecting upon the ways that a variety of perspectives can leverage innovation and growth and keep us aligned with ever-changing healthcare trends.

So go on . . . engage your curiosity, listen, reflect, and decide how you will grow. We’re here. *
Child life specialists often express concern about isolation in the hospital setting, but in truth, “isolation” could be referring to several different things. We might be referencing a patient being on isolation precautions as a result of infection control processes. We might be talking about how a patient is physically isolated from peers as a result of a diagnosis. Or we might be referring to the emotional isolation of a patient: the feeling that no one understands what they’re going through and that no one can reach them.

This last type, emotional isolation, often results from the first two, physical isolation and a lack of socialization opportunities. Due to infection prevention practices, patients on isolation precautions are typically restricted from socialization with peers and from participating in developmentally appropriate group activities. Socialization is a key component of mental and overall health. As Pizzignacco and Lima (2006) explain, “One of the coping strategies for children and adolescents with chronic disease is the search for social support from friends, family and professionals, as they consider this is one of the most significant ways to control stressors caused by the disease” (p. 575). Denny and colleagues (2013) found that children and adolescents with chronic health conditions are more likely to have emotional health concerns compared with their healthy counterparts. Koller, Nicholas, Goldie, Gearing, and Selkirk (2006) found that chronically ill children also shared more stories about loneliness, fear, and unpleasant emotions. Isolating ill children may exacerbate or intensify preexisting feelings of loneliness and alienation (Koller et al., 2006).

One of the essential job functions of a child life specialist is to promote developmentally appropriate play and socialization opportunities in the hospital environment. At Children’s Mercy Kansas City, patient activity coordinators also have this essential job function. In December 2016, I partnered with the patient activity coordinator on my inpatient unit to address the emotional impact and lack of socialization opportunities that patients on isolation precautions were experiencing. We explored interventions aimed at combating this common barrier in order to optimize psychosocial and emotional health and development. In our exploration, we discovered telepresence resources from within our hospital’s telem medicine department that we hoped could enable expanded and exciting opportunities for developmentally appropriate activities and social interactions for our patients on isolation precautions.

Telepresence creates a sense of being in another environment. In particular, robotic telepresence offers the means to connect to a remote location via traditional telepresence with the added value of moving and acting in that location (Kristoffersson, Coradeschi, & Loutfi, 2013). The telepresence device we used was a “robot” consisting of an iPad on a stand with wheels. This robot is controlled by a second iPad that allows the user to drive, (i.e., move forward, backward, turn, get taller and shorter), while also maintaining a live video (similar to FaceTime). The driver of the second iPad can see everything the robot sees, and wherever the robot is, people can see the face of the driver and communicate with them. Our institution began its telepresence robot journey by using the robot with individual patients, allowing the patient to “become” the robot, “ambulate” around the unit, socialize with staff, participate in unit playgroup, and attend special events. Equipped with live video and a microphone, the robot allows the patient to fully interact with

continued on page 6
T is for Telepresence: Utilizing Technology to Increase Socialization and Interactive Engagement Among Pediatric Patients on Isolation Precautions

staff, volunteers, and other patients, giving the patient opportunities to socialize and participate in activities that they otherwise would have missed. Patients have used the robot to tell jokes to staff, play Pictionary in the playroom, perform magic tricks for volunteers, attend the hospital’s first annual prom, and so much more! The use of telepresence robots has given our patients an ability to connect and engage in therapeutic group experiences previously hindered by isolation.

After the successful implementation of our telepresence robot program with individual patients, we identified the need for multiple patients on isolation to be able to socialize and engage with their peers and staff members simultaneously. To meet this need, we applied iPad video conferencing technology during various group socialization opportunities and events. To do this, each patient in isolation uses an iPad app to video conference to a single iPad that is utilized at the event or experience. This allows patients to not only participate in the activity, but also to socialize with peers who are present as well as other peers on isolation. Virtual group experiences have included playgroups, therapy dog visits, interactions with professional athletes, and other special events. Prior to the implementation of these virtual opportunities, patients in isolation were unable to participate in these group experiences or interact with other isolated patients at these events.

To assess patient satisfaction and to gather patient feedback on these telepresence experiences, we collected verbal comments from 13 patients (ages 4 to 19 years), who used the robot (16 times total) and used the iPads to video conference into group activities (15 times total). Patients unanimously expressed enjoyment of these experiences and satisfaction with the operation of the telepresence technology. Patient-reported benefits included the ability to connect with peers, meeting patients with a similar diagnosis, engaging in age-appropriate group activities, and focusing on therapeutic interactions in a stressful environment. As one teen patient stated, “It was so nice to get out of my room! I mean… virtually.”

We acknowledge that nothing compares to being able to participate in an event or an experience in person. However, being able to “attend” an event, or “leave their room” in some way is thought to be greatly impactful. A multidisciplinary team at our hospital is planning to conduct formal research and evaluate the best method to assess the impact of using this telepresence technology with patients.

We continue to utilize telepresence technology and are focused on expanding these services to additional patient populations. Our institution has since obtained several more robots dedicated to promoting patients’ psychosocial engagement opportunities, allowing for additional patients to participate in telepresence experiences. We have added a very large touch screen computer monitor to one inpatient unit playroom. This monitor will be used to allow easier access for multiple patients to video conference in and engage in playgroups, teen groups, diagnosis teaching sessions, or even hospital-based school classes. The possibilities for utilizing the monitor are still under discussion and development.

Telepresence opportunities have also expanded from within our hospital environment into the outside community. Patients have been able to use the robot to attend their high school graduations, funerals of family members, and Sporting KC soccer games. Previously, patients who were admitted to the hospital...
would have missed these milestone experiences. Technology has allowed us to connect these patients in a whole new way!

In conjunction with our telemedicine department, we continue to make telepresence plans for the future. One thing is for sure: When a patient gets admitted to the hospital and is labeled “on isolation,” we no longer see this as a barrier, but as an opportunity for a new type of play and engagement. You should see patients’ faces when we ask, “Do you want to drive a robot?”

REFERENCES


Milestones

The child life team at SickKids in Toronto, ON, Canada, lost a valuable member when Amanda English, CCLS, passed away in August 2018 after a lengthy illness. Amanda began working as a child life specialist in SickKids therapeutic recreation program, Marnie's Lounge. Amanda’s passion and commitment led her to work in the neurosurgery and trauma departments, and she was instrumental in the expansion of child life services into the emergency department. Throughout her 15-year career, Amanda was a creative visionary and served on many hospital-wide committees that mirrored her clinical interests, which included pain, preparation, and children's participation in healthcare. Immersing herself in all aspects of child life, Amanda also served on the ACLP Certification Committee, which reflected her commitment to ensuring that the child life profession would continue to thrive and grow. During her career she left a lasting impact on those who knew her and will remember her as a dear friend, a gentle spirit, and a strong advocate for children and families. To honor Amanda, this year the child life department at SickKids commemorated their colleague by naming the annual teddy bear clinic in her memory.
They, Them, Theirs:
THE IMPORTANCE OF PRONOUNS AND OTHER CONSIDERATIONS WHEN CARING FOR PATIENTS WHO IDENTIFY AS GENDER DIVERSE

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CINCINNATI CHILDREN’S HOSPITAL MEDICAL CENTER, CINCINNATI, OH

Aiden* is a 14-year-old patient who was admitted to the hospital for appendicitis. Aiden has recently come out to his family as transgender and asked his family to call him Aiden and refer to him with male pronouns (he/him/his).

Aiden’s legal name, the name he was given at birth, is listed in the medical record. Aiden and his family have shared his gender identity and preferred name and pronouns with the hospital staff. Aiden’s family is supportive of his gender identity but sometimes forget to call him Aiden and accidentally use female pronouns (she/her/hers). You overhear staff discussing Aiden’s gender identity in the breakroom and his nurse repeatedly calls him by his legal name using female pronouns. His nurse states, “If her parents still call her ________ (legal name), why should I bother calling her anything else?” You know that Aiden will be hospitalized for at least a week and will have medical...
procedures in various departments throughout the hospital. As a child life professional, how do you best support Aiden and his family throughout his hospitalization?

People who identify as gender diverse, specifically transgender, have become more visible in recent years. As such, youth who identify as gender diverse are being seen more often within healthcare settings. Medical professionals, including child life specialists, receive little, if any, training related to providing healthcare services to patients who identify as transgender (Rider et al., 2019). The American Academy of Pediatrics recommends that provider education, both medical training and continuing education, include information about best practice for caring for youth who identify as transgender and gender diverse (Rafferty; American Academy of Pediatrics Committee on Psychosocial Aspects of Child and Family Health; American Academy of Pediatrics Committee on Adolescence; & American Academy of Pediatrics Section on Lesbian, Gay, Bisexual, and Transgender Health and Wellness, 2018).

Gender identity is a term that is used to describe a person’s sense of being female, male, a mix of these traditional genders, or having no connection to either gender. Gender diverse is a relatively new term that describes people with a gender identity that is different from the gender assigned to them at birth. People who identify as gender diverse may also identify as transgender or any of a number of other gender identities, including genderqueer, gender fluid, or non-binary (Rafferty et al., 2018). It is always best to ask a person what a specific term means to them as terms and their definitions (see Table 1) change frequently.

Identifying one’s gender begins at the age of 2 or 3 years, and is typically established by the age of 4 (Austin, 2018). Not all children who are gender diverse identify as transgender. Some people may identify as non-binary, or having no connection to the traditional system of gender. Other people prefer to not have a label placed on their gender. Children who identify as transgender or gender diverse are aware of their gender to the same degree as developmentally comparable peers who are cisgender (Rafferty et al., 2018). A child who identifies as transgender is “consistent, insistent, and persistent” about their gender identity being different than the gender they were assigned at birth (Human Rights Campaign, n.d.-b, para. 8). While statistics detailing the number of children who identify as gender diverse are not currently available, according to the Williams Institute’s most recent survey in 2017, approximately 0.7% of youth (150,000 youth) between the ages of 13 and 17 identify as transgender in the United States (Alumit, 2017).

Youth who are gender diverse often face challenges both at home and in the community, but they have shown the ability to be resilient, especially when they receive social support and acceptance. Torres and colleagues (2015) described the importance of three spheres of influence that can create a safe environment for transgender youth (see Figure 1). Parents, schools, and the community can work together to create safe environments for youth who identify as gender diverse. The healthcare environment is included within the community sphere (Torres et al., 2015). Child life professionals can make a difference within this sphere by advocating for supportive healthcare environments, promoting continuing education for staff, and providing resources to patients who identify as gender diverse.

### Table 1: Gender Terminology

<table>
<thead>
<tr>
<th>Gender Terminology</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Agender</td>
<td>Someone who identifies as genderless or outside of the gender continuum</td>
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<tr>
<td>Cisgender</td>
<td>A person whose gender identity and/or expression aligns with their gender assigned at birth</td>
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<tr>
<td>Gender</td>
<td>Societal perception of maleness or femaleness</td>
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<tr>
<td>Genderqueer</td>
<td>Umbrella term for a wide range of gender identities</td>
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<tr>
<td>Gender diverse</td>
<td>General term describing gender behaviors, expressions, or identities that are different than those culturally assigned at birth</td>
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<tr>
<td>Gender dysphoria</td>
<td>Distress or impairment resulting from the difference between one’s experienced or expressed gender and the gender assigned at birth</td>
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<tr>
<td>Gender expression</td>
<td>External display of gender identity through appearance, dress, mannerisms, speech patterns, and social interactions</td>
</tr>
<tr>
<td>Gender fluid</td>
<td>A mix of male and female, a person who may always feel like a mix of the two traditional genders, but may feel more masculine some days and more feminine other days</td>
</tr>
<tr>
<td>Gender identity</td>
<td>Internalized sense of being male, female, or elsewhere along the gender continuum</td>
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<tr>
<td>Gender non-conforming</td>
<td>A person who has a non-traditional gender presentation (masculine woman or feminine man)</td>
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<tr>
<td>Gender neutral/non-binary</td>
<td>A person with no (or very little) connection to the traditional system of gender, no personal alignment with the concepts of either man or woman, and/or someone who sees themselves as existing without gender</td>
</tr>
<tr>
<td>Transgender</td>
<td>A person whose gender identity or expression differs from the gender they were assigned at birth</td>
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continued on page 10
Gender Dysphoria
As defined in the DSM-5, gender dysphoria is the name of the clinical diagnosis given to people who identify as a gender that is different than the gender that was assigned to them at birth (American Psychiatric Association, 2013). Not all people who are gender diverse will be diagnosed with gender dysphoria. Gender dysphoria is only diagnosed if there is distress related to the discrepancy between one’s gender identity and the gender they were assigned at birth (American Psychiatric Association, 2013).

Gender Affirmation Treatment
Some people who identify as gender diverse choose to undergo gender affirmation treatment. The decision to undergo gender affirmation treatment is a very personal decision and treatment will vary depending on the person. Social affirmation occurs when a person adapts their gender identity to be more congruent with their identified gender, not the gender they were assigned at birth. This affirmation may manifest itself most often in choice of clothing, hairstyle, name, and pronouns (Rafferty et al., 2018). According to the World Professional Association for Transgender Health’s Standards of Care (2012), medical affirmation can begin at the start of puberty when an adolescent can receive hormone blockers. This treatment delays the physical changes of puberty. This has been shown to have a significant positive impact on the adolescent’s mental health (Tellier, 2019). A few years after puberty blockers are started, an adolescent can receive gender-affirming hormones. The age at which gender-affirming hormones are first given varies; the decision about when to begin this treatment should be made collaboratively between the adolescent, their family, and the treatment team (World Professional Association for Transgender Health, 2012). Surgical affirmation can be chosen to more closely align a person’s body with their gender identity. Not all people who are gender diverse choose to undergo surgical affirmation. This treatment is usually not done until a person reaches adulthood (Rafferty et al., 2018).

Healthcare Challenges
People who identify as gender diverse often face barriers and challenges related to accessing healthcare and feeling comfortable within the healthcare setting. Youth who identify as gender diverse often have poor access to physical and mental health services. This can be due to a multitude of factors, including incorrect name and pronoun usage, anxiety related to healthcare that is specific to the gender that they were assigned at birth, insurance coverage, lack of family acceptance, lack of knowledge or understanding among healthcare providers, and/or being denied treatment due to their gender identity. Lack of access to physical and mental health services can lead to worsening gender dysphoria and poor mental health outcomes (Rafferty et al., 2018).

Name/Pronoun
People are referred to many times a day using their name and/or pronouns. A person’s name and pronouns are closely tied to that person’s identity. Some pronouns are gendered, such as the use of “she/her” when referring to a female-identified person and “he/him” when referring to a male-identified person (Human Rights Campaign, n.d.-a). Other pronouns, such as “they/them,” are considered gender neutral when referring to a single person. As such, “they” has become the pronoun that is used by many people who do not identify as either male or female (Merriam-Webster, 2019). “They” is also the pronoun that should be used when the gender of the person you are referring to is unknown. “They” has been deemed to be an appropriate singular pronoun when used in writing and speaking by Merriam-Webster (2019) and the American Psychological Association (Lee, 2019) when referring to a person whose gender is unknown or when referring to a known person who uses “they” as their pronoun. While it may initially seem unusual to refer to a single person using the pronoun “they,” this will become easier with time and practice.
The use of the correct name and pronoun are essential to affirming a person’s identity and showing respect. Often the first step that someone who is gender diverse takes to affirm their gender is to choose a name that is different from their birth name. After changing their name, many people refer to their birth name as their “dead name.” When someone accidentally or intentionally refers to a person by their birth name, this is called “deadnaming” (Clements, 2017). Misgendering, or the use of an incorrect name or pronoun, can be extremely upsetting to someone who identifies as gender diverse. If you accidentally misgender someone, the best way to handle this is to apologize and do your best to not allow this to happen again. When you are not sure about a person’s pronouns, ask them which pronouns they want you to use (Human Rights Campaign, n.d.-a).

**Gender-Specific Treatment vs. Identified Gender**

Patients who are gender diverse will arrive in the healthcare environment due to illness or injury that is similar to their peers who are cisgender, but they may also be seen due to an illness or injury related to the gender they were assigned at birth, not the gender with which they identify. For example, someone who identifies as male may be seen due to a gynecological concern, or a female-identified person may seek treatment for testicular pain. Patients who are experiencing medical care that is inconsistent with their identified gender should be approached with sensitivity. Physical examinations can be stressful for patients who have gender dysphoria, regardless of the reason for the examination (Klein, Paradise, & Goodwin, 2018). Child life specialists are in the unique position to provide procedural preparation and support that is sensitive to the patient’s gender identity. Honest, straightforward communication is essential in such situations. Many healthcare professionals become unsure about how to discuss gender identity in relation to gender-specific body parts.

Such conversations should be approached in a sensitive manner, as would be done for any child or adolescent, keeping in mind that the patient knows what body parts they have, whether this is consistent or inconsistent with their gender identity. As with any child or adolescent, patients who identify as gender diverse should be asked what word(s) they use to identify their genitalia. Patients should not be asked about their private body parts unless that is necessary for the treatment or procedure that they are undergoing (Clark, Vealè, & Zaleski, 2018).

**Insurance Coverage**

People who identify as gender diverse often experience difficulty with insurance coverage. Insurance denials for transgender-related services can be a significant barrier to receiving proper healthcare for people who identify as gender diverse. One study found that approximately 25% of people who identified as gender diverse, specifically transgender, were denied insurance coverage based solely on their gender identity (James, Herman, Rankin, Keisling, Mottet, & Anifi, 2008, cited in Rafferty et al., 2018). The denial of treatment for gender dysphoria in pediatric patients is often based on the idea that gender dysphoria is a mental disorder and not a physical disorder. Based on this assumption, gender affirmation treatment, such as hormone therapy, is often deemed to be unnecessary by insurance providers (Rafferty et al., 2018). People who identify as gender diverse may also be denied insurance coverage for examinations and treatments related to the gender that they were assigned at birth, especially if they have changed their gender marker on their legal paperwork. For example, someone who identifies as male but was assigned female at birth and has female genitalia may be denied access to a PAP test. In addition, youth who identify as gender diverse may or may not have parental support related to their gender identity. Those who do not have parental support run the risk of not having access to health insurance and parental consent for healthcare (Torres et al., 2015).

**Uninformed Healthcare Providers**

The healthcare setting can often be an unwelcoming environment for people who identify as gender diverse due to many factors, including providers’ insufficient knowledge or competency regarding care for patients who identify as gender diverse. Many people who are gender diverse report that they have had to educate medical staff on caring for a person who is gender diverse. This is an additional hardship to accessing medical care that should not be the responsibility of the person who is gender diverse (Torres et al., 2015). The American Academy of Pediatrics (Rafferty et al., 2018) recommends that provider education include information about the best practices for the care of youth who identify as gender diverse and their families.

**Healthcare Environment**

People who identify as gender diverse often worry about whether the clinical environment will be a safe place for them (Rafferty et al., 2018). A safe environment is the responsibility of not only the healthcare provider, but all staff within the healthcare setting. Education and training about terminology and other gender diverse topics should be provided to all staff (Klein, Paradise, & Goodwin, 2018).

continued on page 12
They, Them, Theirs: The Importance of Pronouns and Other Considerations When Caring for Patients who Identify as Gender Diverse

People who are gender diverse report that the correct use of name and pronoun is one of the most important aspects that leads to feeling safe within the healthcare environment (Torres et al., 2015). Healthcare settings should ensure that their electronic medical record systems include options for the inclusion of preferred names and pronouns so that all staff have access to this information. Providing access to gender-neutral bathrooms is another way to ensure that people who identify as gender diverse feel safe (Torres et al., 2015). The healthcare environment itself can be more welcoming by including pictures of diverse families and people in public areas and including gender-neutral language on intake forms (Klein, Paradise, & Goodwin, 2018).

Healthcare Avoidance

Due to various healthcare challenges and previous negative experiences, many people who identify as gender diverse avoid healthcare settings. There is limited research regarding youth healthcare avoidance, but one study found that 25% of adults who identified as transgender had avoided going to a necessary doctor’s visit in the last year because they were afraid of being mistreated (James, Herman, Rankin, Keisling, Mottet, & Anifi, 2008, cited in Rafferty et al., 2018). Maintaining a confidential, safe clinical space is an important step to gaining the trust of gender diverse youth and their families (Rafferty et al., 2018). Child life professionals can advocate for and work toward fostering an emotionally safe clinical environment, in both inpatient and outpatient settings. This includes advocating for the use of correct name and pronoun and providing supportive and sensitive care for youth who identify as gender diverse by all members of the healthcare team and clinical staff. Setting the foundation for early successful medical experiences may minimize healthcare trauma and lessen healthcare avoidance later in life.

Ethical Considerations

Most, if not all, healthcare professions have a code of conduct or similar position statement outlining professional responsibility related to the care of patients and families. The Association of Child Life Professionals’ (2019) Code of Ethics outlines this obligation for child life professionals. Care for patients who identify as gender diverse is addressed under Principle 3, which states “Child Life professionals shall have an obligation to serve children and families, regardless of race, gender, religion, sexual orientation, economic status, values, national origin, or disability” (Association of Child Life Professionals, 2019). Additionally, the Joint Commission first asserted in 2011 that accredited organizations must prohibit discrimination based on many factors, including gender identity or expression. Healthcare institutions also have specific policies related to diversity and inclusion, as well as patients’ bills of rights that employees must follow as terms of employment. Within these policies, many healthcare settings include a statement related to the appropriate care of patients regardless of gender identity/expression. Child life professionals should follow their institutions’ policies, as well as the child life code of ethics.

Child Life Support for Youth Who Identify as Gender Diverse

Child life specialists utilize assessment to individualize care for all patients. Information obtained during the child life assessment is essential to providing optimal care to patients who are gender diverse. Child life professionals should do the following to maintain a safe and supportive healthcare environment for patients who are gender diverse and their families:

- Provide preparation and support that is sensitive to the patient’s gender identity and, as with all patients, privacy should always be protected.
- Advocate for consistent use of the patient’s chosen name and pronouns.
- Assure that toys, games, and crafts that are provided to patients are not gendered. Toys should not be seen as “boy toys” and “girl toys” but simply as toys. When hospital staff request toys or activities for a specific gender, child life professionals can educate staff that toys and activities should be provided that are based on the patient’s preferences instead of their gender.
- Playrooms and activity centers should be decorated with regard to diversity and include pictures of different types of families inclusive of diverse gender identities.
- Pamphlets and brochures outlining available hospital and community resources for patients who identify as gender diverse should be made available to all patients and families.
- Advocate for continuing education for staff related to the care of patients who are gender diverse.

The child life profession values diversity in healthcare services, which lends itself to advocacy for a safe and supportive healthcare environment for all patients, including those who are gender diverse.
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OPEN VISITATION POLICIES IN THE ADULT ICU: A Cultural Transformation

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Child life in the adult hospital setting is an ever-increasing sub-specialty within our field. A large percentage of adults hospitalized each year have children or grandchildren in their lives who are impacted by their loved one’s illness or injury. There is a growing demand for psychosocial support geared toward the wellbeing of these children, particularly when an adult has a life-altering illness or injury (Association of Child Life Professionals, 2018; Sutter & Reid, 2012). Working in an adult hospital can bring about unique challenges, particularly in the critical care setting. Child life specialists receive education and training that equip them with the skills to assist children, families, and their support systems in order to minimize the short- and long-term effects of stress and trauma that accompany a medical journey. Additionally, child life professionals assist children and families in striving to reach their full potential during times of stress (Association of Child Life Professionals, 2018; Sutter & Reid, 2012).

The Problem
When I began working as a child life specialist exclusively supporting children of adult patients with life-threatening or life-limiting illnesses and injuries, it became clear to me that there were substantial barriers to overcome in building an environment that welcomed children. Age restriction policies regarding child visitation in adult hospitals, particularly in critical care, are a common occurrence. Recently, there has been increased advocacy for child visitation in adult intensive care units (ICUs). In particular, the use of child life professionals has been recently discussed at length in a new textbook on meeting psychosocial needs in adult ICUs (Bruce & McCue, 2018). At Baylor Scott & White All Saints Medical Center, signage on the doors of our ICUs once stated that “Visitors under age 14 are not permitted.” When exceptions were made, usually in end-of-life situations, staff preferred that children “go through” the child life specialist before being able to visit their loved one. While this hurdle was not shocking, it did prompt lengthy discussions with the system-wide child life manager in efforts to allow child visitation. It became clear that this endeavor would take time, trust, and a shift in the culture of our hospital.

After almost a year of building rapport with staff and querying them on their perspectives towards the visitation policy, I realized that although making modifications would be no easy feat, it would be well worth the effort to evoke a cultural change within the facility. During several staff meetings and individual conversations, ICU staff continued to voice being very uncomfortable with children present at the bedside. Common themes identified in these discussions included
the transmission of germs from the child to the patient, the trauma of seeing a loved one in the hospital, children being exposed to things they were “too young” to understand, and fear that children could cause harm to the patient. Additionally, the staff’s personal experiences or biases contributed to their overall hesitancy to change this policy.

**Developing a Plan, Establishing a Sense of Urgency, Forming a Powerful Coalition, and Creating a Vision**

Kotter (2007) suggests that organizational transformation requires progression through eight stages for the best chance of success (see Figure 1). By keeping these stages in mind during the process of making changes, our plan resulted in successfully opening the visitation policy for our ICUs. The staff was empowered to feel confident in themselves as they entered unfamiliar territory and we were able to help the multidisciplinary team embrace a new policy and enhance patient- and family-centered care.

Our journey started with a meeting between child life, the critical care manager, and our nursing supervisors for each ICU. Our meeting included discussions about staff fears, why we needed to change our visitation policy, the steps we needed to take to implement the change, and how to get the bedside nurses and staff on board with the change. It was agreed that this change was needed based on the 2016 American Association of Critical-Care Nurses (AACN) Practice Alert regarding family visitation policies within adult intensive care units. This statement advocates for facilities to have “unrestricted access of hospitalized patients to a chosen support person (e.g., family member, friend, or trusted individual) who is integral to the provision of emotional and social support 24 hours a day, according to the patient’s preference” (American Association of Critical-Care Nurses, 2016, p. 15). The policy also notes that developed policies should “prohibit discrimination based on age,” and that children should be welcomed with appropriate supervision (American Association of Critical-Care Nurses, 2016, p. 15). Additionally, our system-wide policy promoted open visitation, although there was a clause allowing for unit-based policies. Making this change would align our intensive care units with the rest of the system, as well as with this recommendation from the AACN. Agreeing on the rationale for this new policy gave us a sense of urgency to begin making changes. It was felt that the best method for implementing change would be to begin in our medical ICU because they were exhibiting the least resistance, adjust our implementation processes as needed, and then execute this policy in our cardiovascular ICU.

Each of our critical care units has a unit-based council (UBC), which is part of our nursing leadership hierarchy. UBCs are comprised of nurses from all shifts on the unit and promote a culture of empowerment to improve patient outcomes through evidence-based practice, resulting in safe, quality care. During the planning stages of this new visitation policy, discussions were held with the medical ICU UBC monthly. We discussed the current literature surrounding child visitation, practices implemented at other hospitals within our healthcare system, the role of a child life specialist, and what we felt the best approach would be for our team in this unit.

In these meetings, we also discussed The Change Cycle (Salerno & Brock, 2008; see Figure 2) and took into account the first three stages of loss, doubt, and discomfort. Our leadership team knew there would be individuals who would experience fear and defensive behavior towards the new policy, while others might have difficulty processing and acclimating to this change. Our team believed it would be critical for hesitant staff members to have someone physically beside them to assist in acknowledging and processing through these feelings. In an effort to help move staff towards the adaptation of this new policy, “key players” were identified on each shift who could serve as advocates for policy implementation. These key players were well-versed regarding the process being implemented and served as mentors for those with reluctance or apprehension towards this change.

**Communicating the Vision, Empowering Others, and Short-Term Wins**

After several months of planning, we had a roadmap of how the new visitation policy would be executed. We removed

![Figure 1. Eight steps for organization change (adapted from Kotter, 2007).](attachment://figure1.png)
Open Visitation Policies in the Adult ICU: A Cultural Transformation

every sign in the medical ICU that restricted child visitation, and encouraged each bedside nurse to call for child life support if they were concerned about a child visiting. While most of our staff were open to how this process would be executed since it was coming from their UBC, several staff members still ultimately needed to have a support person physically present next to them to provide validation and model how to work with children when they were present. Whenever these situations occurred during child life hours, the child life specialists on the unit were the ones to provide that support. According to Salerno and Brock (2008), the feelings of skepticism, confusion, and anxiety that some staff members expressed are part of the cyclical nature of change each of us may experience. When these feelings surfaced, the key player had the opportunity to assist their teammate in a shift of perspective, support them in making decisions, and help them feel empowered to be a part of this transformation. Many of the issues we expected to be of concern to some staff members were raised during the initial months, and we used the AACN practice alert as our main source of support for addressing these concerns (see Table 1).

When a staff member had concerns about a child’s presence, child life strove to validate what that nurse was feeling. We discussed what the nurse felt would be helpful (since telling the children they could not come back was not an option), and this appeared to help these staff members feel empowered to find solutions and coping tools for their discomforts with children on the unit. As a child life specialist, these moments can evoke really hard situations and feelings of stress and frustration. While the reasons given by a staff member for not wanting children present may seem irrational to a child life specialist, these are still genuine feelings for that person. It is incredibly important to be patient in these moments, practice kindness, and offer grace to those grappling with change. These actions help gain trust with struggling staff members. One veteran nurse on this unit said, “Initially, I didn’t think it made sense to have a crying child next door to a critically ill patient, but my thoughts have changed. I have seen parents and grandparents light up to see their children. I feel it gives them hope, and therefore gives them something to fight for. I’m so happy to have been a peripheral part of this change.”

Consolidation and Spreading Improvements

After roughly five months, it was time to expand the program by initiating child visitation in the cardiovascular ICU. Child life attended regular staff meetings to review the changes that would occur and address staff concerns. Many of the same concerns from the medical ICU were addressed, and while there was resistance as expected, being physically present with hesitant staff members at the bedside is what seemed to ultimately evoke a shift in culture. One nurse with extensive experience in this unit said, “I was pretty against children in the ICU when we first started all of these changes. However, I will say I have had some really good experiences when the children were properly prepared. One specific instance comes to mind when we had a really, really sick young adult patient and her niece wanted to visit. Because she was allowed visitation, [her parents] were able to spend more time with their loved one during her time in our hospital.”

A particular case illustrate the benefit of hands-on support for staff who need assistance in acclimating to new processes. Child life received a referral for a patient admitted over the weekend following an out-of-hospital cardiac arrest. He had an impella placed over the weekend, and after speaking with his wife, we learned that staff had not allowed their 9-year-old daughter, Casey,* to visit over the weekend due to his placement on an impella machine (a device that helps the heart by providing pumping support to the left ventricle, resulting in increased blood flow) and a ventilator. Casey wanted to visit her dad, and her mother felt this would be beneficial as well. A plan was developed, which included a child life session before the visit to help explain her father’s cardiac arrest and prepare Casey for a bedside visit. This plan was communicated to the bedside nurse, who was open to this visit occurring with

* Pseudonyms are used to protect patient and family privacy.
child life involvement. While Casey visited at bedside, she had many questions about what it meant when someone had a cardiac arrest and how the impella machine was helping her father’s heart. The nurse was able to witness how these questions were answered in a developmentally appropriate way, and how seeing everything in the room helped Casey to understand more about her dad’s illness and hospitalization. This nurse recognized the benefits of child visitation, and continues to be a strong advocate for child life and child visitation.

Institutionalizing New Approaches

Overall, it took approximately two years to truly reach a point of integration, which aligns with the expectations we had from our reading of the work of Salerno and Brock (2008). Due to the cultural shift achieved in the hospital, child life has seen an increase in referrals within all of our ICUs. While this is celebrated as a success, it is essential to remember that the change does not stop here. To this day, we continue to spread change by educating new nurses about our policy, institutionalizing these new approaches, and walking with them if they exhibit resistance. To celebrate small wins, thank you notes or small tokens of appreciation (i.e., piece of candy, points through our hospital recognition program) are given to staff when they make an appropriate child life referral.

Recently, I spoke with a new nurse in our medical-surgical ICU, which opened after this policy change. This nurse shared that she did not even know our hospital previously did not allow children in the ICU because “it’s just part of the culture here.” This is how we knew our efforts of changing the culture to allow children to visit their critically ill loved ones were deemed successful and that a positive transformation had occurred.

<table>
<thead>
<tr>
<th>CONCERN ABOUT CHILD VISITATION</th>
<th>EXPRESSED REASONING</th>
<th>AACN PRACTICE ALERT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Germs</td>
<td>Children are “germy”</td>
<td>“Some ICU nurses believe that family visitation . . . contributes to increased infection; however, the evidence does not support these beliefs.” (AACN, 2016, p. 1)</td>
</tr>
<tr>
<td></td>
<td>Children will bring germs into the room, which could make the patient sicker</td>
<td></td>
</tr>
<tr>
<td>Trauma</td>
<td>Children will be traumatized by what they see in the ICU</td>
<td>“… restrict children’s visits based on the intuition that children will be harmed by what they see . . . these biases are not grounded in evidence or based on the patient’s or the child’s actual needs.” (AACN, 2016, p. 2)</td>
</tr>
<tr>
<td></td>
<td>The hospital is “scary” and children don’t belong here</td>
<td></td>
</tr>
<tr>
<td>Age/Exposure</td>
<td>Kids are too young to understand medical treatment/ machinery, so we shouldn’t expose them to it (i.e., ventilator, dialysis, IV machines)</td>
<td>“… properly prepared children have less negative behavior and fewer emotional changes than those who did not visit.” (AACN, 2016, p. 2)</td>
</tr>
<tr>
<td>Personal Experiences or Bias</td>
<td>Staff visited a loved one when they were a child and remember being scared, so they feel that all children would have this experience</td>
<td>“Supporting a patient’s right to identify individuals whom the patient views as “family” and chooses to be their “partners in care,” without discrimination.” (AACN, 2016, p. 2)</td>
</tr>
<tr>
<td></td>
<td>“I wouldn’t bring my kids up here”</td>
<td></td>
</tr>
<tr>
<td>Cause Harm to The Patient</td>
<td>Children touch/grab things; they might touch a button or pull out a line</td>
<td>“… a concern that [visiting children] would be uncontrollable. These biases are not grounded in evidence or based on the patient’s or the child’s actual needs.” (AACN, 2016, p. 2)</td>
</tr>
</tbody>
</table>

 REFERENCES


When it comes to documentation, we have all heard it said (and many of us have said it ourselves): “If it isn’t in the chart, it didn’t happen.” The medical record serves as an account of a patient’s health conditions and of care provided. It is a legal document and information in a medical record can be used as evidence in a court case. In the legal system, medical record documentation, including child life documentation, is regarded as an essential element of patient care, and failure to document relevant data is considered a significant breach of and deviation from the standard of care (Gutheil, 2004).

Less formally, child life documentation also serves to educate other disciplines about our scope of practice and our skillset. Documentation also offers insight into how the utilization of our skills can impact the patients and families that we support. While no one ever expects their documentation to be summoned for a court case, in the back of our minds we all know it could happen. I can attest to the fact that it really does happen because it happened to me—not just once, but three times.

A legal request for documentation is made by serving a subpoena to the person and/or entity that possesses the documentation. Separate subpoenas are required for documentation requests and for summoning a person to testify. I have been served with subpoenas for documentation on three occasions. For two of those cases, I was also subpoenaed to provide testimony. Though the process of being served a subpoena is not as dramatic as what you might see on television, it can feel a bit overwhelming. Depending on the state, subpoenas can be served by certified mail, hand-delivered, faxed, emailed, or even provided verbally. The server can be a sheriff, constable, or another person authorized by law to serve legal documents. Subpoenas can be served in the workplace or any other location where the person being...
summoned is likely to be found. For all three cases, I was served at work.

What do you do if you are subpoenaed? You are unlikely to have a chance to mentally process what is happening before having to sign the subpoena, acknowledging its receipt. Before doing anything else, talk to your leader and contact an attorney about the next steps. Fortunately, when working in a healthcare institution you likely have access to legal counsel through the healthcare system. Those working in private practice or other settings without a legal team will need to seek their own legal counsel. I immediately contacted our legal department at Baylor Scott & White Health (BSWH). The BSWH attorney reviewed the subpoenas with me and explained what would happen next. All three cases involved custody issues, and child life documentation was the only documentation requested from the patient records. The attorney acquired and delivered all requested documentation, and I reviewed my documentation to prepare to testify. The BSWH attorney prepared me for the hearing and remained with me during the courthouse proceedings. The presence and support of the attorney was comforting and made the process much less scary.

I work with children of seriously ill adult patients, and unfortunately in these three cases, the adults had not fully completed their advanced planning before their deaths. Advanced planning includes making decisions about your own medical care to guide family and medical staff in the event you are unable to express your choices. But for parents, advanced planning includes determining who will assume custody of minor children should one or both parents die. In two of the cases where I was subpoenaed, I supported the adult patient in navigating their children’s grief as they neared the end of their own life. I also directly supported the children prior to and following their loved one’s death. The third case was atypical because not only did I first meet the child after her parent’s death, but it was after the deaths of both of her parents. The following case illustrates a situation that can trigger a court case: I was subpoenaed for documentation and testimony as well as court appearances.

Five-year old Jill* was referred to child life services by her father’s oncologist. At that time, it had been just four days since Jill’s father had died and one day since Jill’s mother had died. Jill’s father died peacefully after a long cancer journey, and her mother died unexpectedly, amid the stress of making funeral arrangements for her husband. Sam and Bonnie (Jill’s grandparents) lived in another state but were by their son’s side when he died. After their daughter-in-law’s untimely death, Sam and Bonnie naturally assumed custody of Jill, as she had no other nearby relatives. Jill had spent lots of time with her grandparents, who stayed with her family for long periods of time during her father’s illness. Based on my observations and interactions with Jill and her grandparents, I believed she felt comfortable and safe with her grandparents. Sam and Bonnie met with an attorney to begin the process of adopting Jill. I supported Jill as she processed her parents’ deaths and began transitioning out of the home they shared and into a new home with her grandparents. Despite the unimaginable circumstances she was experiencing, Jill appeared to be coping in a healthy, age-appropriate manner. Her grandparents were very mindful as they planned for adapting their life and their home to make Jill feel as comfortable as possible. We had our final visit and said our goodbyes about three weeks after our initial meeting.

I was surprised when Bonnie called me a few weeks later and tearfully explained that one of their daughter-in-law’s distant relatives, someone Jill had only met once while a baby, was petitioning the court for custody of Jill. Bonnie believed that this action was likely monetarily driven, and she was worried about how Jill would cope should the relative gain custody. Bonnie told me to expect that my documentation and my testimony would be subpoenaed for the custody hearing. I was served with those subpoenas the following week.

I felt as prepared as I could be when the BSWH attorney and I arrived at the courthouse. To prepare, the most important task for me was to refresh my memory by reviewing all of my documentation, which I did several times. After that, the BSWH attorney asked me questions so I could practice testifying. He evaluated my behaviors and responses and provided some helpful tips for the process. His tips included:

1. Be honest and truthful.
2. Listen carefully to each question and wait until the entire question is asked before responding.
3. Think before answering. Avoid guessing at an answer and instead say “I don’t know” or “I don’t remember” when appropriate.
4. Answer only the question that was asked and avoid volunteering information that was not requested in the question.

* All names and identifying information have been changed to protect the family.

continued on page 20
5. Ask for clarification whenever needed. Avoid trying to make sense of a question and risk providing an incorrect answer.

6. Cooperate and be courteous, but do not allow the opposing attorney to push you toward giving an inaccurate answer.

7. Remain calm throughout the testimony and avoid demonstrating any anger or impatience.

8. Be consistent with all answers.

9. Speak slowly, clearly, and in your own words. When needed, count to ten to clear your mind before answering.

Shortly after arriving at the courthouse, we met with Sam and Bonnie’s attorney who talked about how my documentation might be utilized and at what point in the hearing I might be called to testify. The BSWH attorney and I were there for six long and stressful hours. I listened as Sam and Bonnie’s attorney shared information found in my documentation, including how children grieve, the importance of stability and routine, and the necessity for Jill to have consistent, familiar caregivers as she grieved the loss of her parents while trying to adapt to her new normal. Several people were called to the stand but ultimately, I was not called to testify; I would be fibbing if I said that I was not very relieved by that. The case continued into the following week, but I was not required to appear again. Bonnie called me after it was over and was thrilled to share that the relative had abruptly called off the case without explanation. Jill would remain with her grandparents. The final email I received from Bonnie described how Jill was thriving, and included photos of Jill holding hands and smiling with her new best friend.

Because you cannot anticipate when it might happen, one of the best ways to prepare for the possibility that your documentation might someday be subpoenaed is simply to complete each chart note with that possibility in mind. Ensure that you are documenting on the correct patient; include the elements required by your department and institution; provide reflections based on expert assessments, observations, and interventions with the patient or family; and always be sure to complete and sign it. I strongly believe that the only way to truly incorporate all of these elements is to include a narrative written in professional terminology and tone, free of abbreviations, using proper spelling and grammar. Be objective and focused, thorough yet succinct, and provide first-hand information as opposed to hearsay (Parish and Johnson, 1987). Provide an overview of the visit as opposed to a transcription. Proofread each note at least once before signing it, and while doing so ask yourself, “Did I include enough detail that if I am called to testify about this in three months, or even in three years, will I clearly understand what I meant when I wrote it?” If you don’t feel secure with your documentation, speak with your leader about getting help to improve. Although it’s unlikely that you will ever be served with a subpoena for documentation or testimony about a patient or family that you supported, your best defense is always a strong offense. My best advice is to be proactive and write each note as if it could be subpoenaed someday.

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The Beautiful Journey of Child Life in Taiwan

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“Formosa,” meaning “the beautiful island,” is an ancient Portuguese name of Taiwan, now officially named the Republic of China. Taiwan lies within the tropical and sub-tropical climate, surrounded by waters with lush green mountains and diverse species. Neighboring countries include the People’s Republic of China, Japan, Korea, and the Philippines. The 23.43 million population in Taiwan use Mandarin as the official language and traditional Chinese in writing.

Although Taiwan is a small island compared to other Asian countries, the National Health Insurance System in Taiwan is well known internationally. In Taiwan, 99% of the people are covered under the national healthcare insurance. With fairly low co-payments (those with major illnesses, children under 3 years old, and low income families are even waived of the healthcare co-pay), almost everyone has access to high-quality healthcare, medicine, and medical treatments.

While a high standard of medical care has been fairly accessible and affordable in Taiwan, it is only recently and through years of hard work from the mental health professionals in healthcare that the importance of providing psychosocial support and child-friendly healthcare has started to gain more focus in the field. It was not until the beginning of 2012 that Taiwan added its first Certified Child Life Specialist working in the pediatric cancer unit in Taiwan’s leading children’s hospital, National Taiwan University Children’s Hospital (NTUCH).

Introduction of Child Life to Taiwan

Dr. Frank Leigh Lu, a pediatric intensivist at NTUCH, had a vision that was deeply touched by the concept of child life when it was first introduced to him during his scholar visit to Boston’s Children Hospital from 2003 to 2005. He was inspired by Ms. Myra Fox and her lovely energetic child life team advocating for children’s rights and their support for children facing life challenges. Working hard over several years advocating to the hospital and several nonprofit organizations (NPOs) about the child life concept, his dream of bringing child life practices to children’s medical care in Taiwan finally came true. Child life practices finally started to shed light on this beautiful island of Taiwan in 2012.

Prior to child life practices providing psychosocial support, medical needs and treatments were the main focus when children faced medical care. Psychosocial needs were seldom brought up and support was randomly provided by either caring social workers or nurses who already had heavy case loads, or by volunteers from outside organizations such as religious communities and NPOs. The services were inconsistent and mostly not charted. Play opportunities were not considered a necessity to either medical staff or parents. When a child’s adjustment or psychosocial needs became more challenging issues, they were often referred to the hospital psychiatrists or psychologists that covered hospital-wide units and often had a limited number of visits available for young patients’ psychosocial issues.

continued on page 22
Expressive therapies, such as art therapy and music therapy, provided therapeutic interventions and mental healthcare support in pediatric cancer units earlier than child life. In Taiwan, expressive therapies were mainly limited to pediatric psychiatry and rehabilitation services in the beginning, and expanded to provide care to the pediatric cancer ward around 2007, funded by NPOs.

Raising Children Medical Foundation (RCMF) was the first nonprofit foundation to financially support Taiwanese students’ child life clinical training in the United States and promote the professional practices of child life in Taiwan. The foundation supported pediatric psychosocial services by collaborating with both expressive therapists and child life.

In the fall of 2011, the first child life trainee (the author) began clinical training in the United States, with assistance from Dr. Lu and international child life advocate Ms. Andy Standish from the Standish Foundation, as well as Thomas Hobson, Director of Child life at Le Bonheur Children’s Hospital. RCMF continued to provide the majority of support for three subsequent child life specialists during their internship training phase in the United States and strived to ensure the value of child life was heard by the government, policy makers, and hospital administrators in Taiwan.

Currently Taiwan has four Certified Child Life Specialists working at three different hospitals. The funding for child life practices comes from hospital or governmental projects in combination with donations by the Taiwanese society and generous foundations like RCMF and many other NPOs.

**Early Challenges**

Child life, as a new concept and profession, had a slow introduction into pediatrics in Taiwan in 2012. The first challenge was translation of the term “child life” into Mandarin. In order to introduce the child life specialist role to the medical team, there were many discussions and considerations. Finally, the Chinese terms 嬰幼兒醫療輔導 and 兒童醫療輔導 were settled, which directly translates to English as “child medical counseling” and “child medical counselor.” These terms were utilized as an easier way to recognize and understand child life in the Taiwanese culture. It was also literal for the medical staff and families to understand the role of child life and the psychosocial services provided without much explanation. Currently Mandarin-speaking regions such as Hong Kong, China, and Singapore have followed Taiwan’s footsteps in using the Mandarin term 嬰幼兒醫療輔導 for child life.

During the early stages of developing the child life program, some challenges related to terminologies used when providing child life interventions emerged. One challenge involved translating medical procedures and terms into child-friendly language. This was difficult because some medical procedures have threatening words such as needle (IV), cuts (biopsy), or knife (surgery) in the original Mandarin phrases.
Other challenges included learning how to work with the medical team to promote child life practices to the hospital administration. In the beginning, the pediatric medical professionals were not familiar with new child life team members and were hesitant in allowing child life specialists to be involved in medical procedures or to access patient information or charts. Sometimes staff would mistakenly view child life specialists as volunteers who provide toys or gifts to cheer patients up. For several practical reasons, wearing white medical coats was an unusual but necessary decision for the introduction of child life specialists to help them integrate within the medical team. Many hospital staff in Taiwan, including social workers, dietitians, and case workers, also wear white coats as uniforms.

**Growth of Child Life in Taiwan**

Happily, after seven years of development in Taiwan, child life services have expanded to many hospital units beyond pediatric cancer units. Over these years, we have been able to work with the medical team to set some examples and have directly supported patients and families in pediatric cancer units, surgery, ICU, radiology, general medicine, hospice care, and more. Although the focus in Taiwan for child life services is still mainly in medical teaching and preparation for medical procedures, despite low manpower and resources, child life is putting more emphasis on family and sibling support, adjustments to the medical environment, and play. Medical staff who have worked with child life specialists have experienced and witnessed the impact of child life on families and understand the benefits of child life’s role in focusing on psychosocial support within the medical team. Referrals for child life services are increasing, sent from residents, fellows, attending physicians, nurses, social workers, and even psychologists.

Due to low numbers of child life professionals and few resources, child life specialists in Taiwan have to locate more educational resources to learn about providing clinical care and promoting the importance of supporting patients’ and families’ psychosocial needs to the medical field and the general public. During these seven years, there have been over 10 local psychosocial support/child life-related conferences for medical staff in several hospitals in Taiwan, and two national conferences to help build awareness of patient- and family-centered psychosocial care. The first two child life specialists in Taiwan were nominated as ACLP International Scholarship recipients in 2015 and 2017, and attended ACLP’s annual conference in the United States. Attending ACLP conferences with sponsorships was extremely helpful for child life specialists in Taiwan, not only to advance their own professional skills, but to also to help them bring leading psychosocial concepts back to the medical field and Taiwanese society since we do not have similar platforms in the Eastern part of the world to learn from. The ACLP conferences are also tremendous opportunities for network-

![Photo 4: The first and second child life specialists in Taiwan: Mei-Chi Fang (right) and Hsin-Ju Hsiao (left).](image)

We are hopeful that one day soon child life services will be considered standard medical care for children and families in Taiwan, and even better, that child life will be included in the National Health Insurance System so that all children and families will have the right to receive psychosocial support. It is our dream that in all parts of Taiwan, from the villages in the mountains to any corner of the city clinics or hospitals, child life will continue to shine brighter and brighter for the children and families in this beautiful island Taiwan!

**REFERENCES**

The Perks and Challenges of Working as a PRN Child Life Specialist

Sarah Barrientos, MS, CCLS
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In the fall of 2018, as graduation neared, the daunting task of completing job applications weighed heavy on my mind. If you’re like me, you’ve heard it a million times... “Take whatever you can get,” “This is a competitive field,” “Don’t be too picky; you can always move to your preferred unit later.” I was determined to fulfill my dream of being a child life specialist, so I applied for every opening I found. When I was offered a position in my hometown, I was ecstatic! I accepted the offer and started my first job as a PRN child life specialist. As the medical abbreviation “PRN” implies, I would work “as needed.” I wouldn’t have a specific role in the hospital, but would act as a backup child life specialist, providing coverage in any area of the hospital on days that the department required additional support. There was a lot that I loved about my role, but as with any job, there were some challenging aspects as well. If I had known then what I know now, I think I would have felt better prepared for some of the challenges I faced. My hope is that by sharing the ups and downs of my experience, perhaps I can offer some guidance and insight to help prepare new child life specialists who are considering traveling down the PRN path.

Perks
What first caught my attention about the PRN role was the leisure of having a flexible schedule, and it was undoubtedly one of my favorite parts. It allowed me the time to adjust to life in the hospital while still having time to engage in other jobs and activities that I enjoy. I was also able to plan vacations without having to worry about requesting time off. My schedule looked different from week to week and I loved it. This flexibility made for a good work/life balance; I was afforded the luxury of planning my job around my life instead of planning my life around my job.

Being PRN also meant having flexibility within the hospital, as I worked on many different units. Throughout my time, I provided coverage in the ER, the acute respiratory unit, inpatient rehab, the NICU, hematologic/oncology, and various clinics. As a new child life specialist, this was a great opportunity that allowed me to explore different areas and gain a variable skillset. When I graduated from college, I wasn’t sure which units I preferred, and working PRN allowed me to get a little taste of everything. I was able to learn what I liked and what I didn’t, what came naturally to me and where I needed to build my skills. I’ve learned that I love the fast pace of the ER but yearn for the long-term therapeutic relationships often built on inpatient units. I also learned that although I feel confident in my procedural preparation and support skills, knowing all the right assessment questions to ask is an area that I’ve had to continually develop.

With the ever-changing rotation of units, I was kept on my toes as I was consistently learning something new. I not only grew professionally, but also personally, as being PRN pushed me to explore and to become comfortable with being uncomfortable. On any day that might have been particularly difficult, I was often gifted a breath of relief as I remembered that sooner rather than later, I would be given a day of rest or floated to another unit where I could start over and try again. My role as a PRN specialist taught me a lot about my own resilience and my ability to persevere as it pushed me to believe in my skills and my knowledge. I gained a lot of valuable insight. Some of this insight came to me with ease and some of it was acquired with a bit more difficulty.

Challenges
Despite the flexibility of working PRN, I began to feel a lack of connection with the interdisciplinary team. Because I was constantly moving between units, it was hard to build rapport with staff. As I finally started to get comfortable with one team, the nature of my role had me transitioning to another unit and back to
square one. This was particularly difficult for me as it takes me a while to feel comfortable with new people and new situations. Feeling like I was constantly starting over was a bit discouraging at times. I wanted to gain a sense of belonging, but the very nature of my role made it nearly impossible. My inconsistent presence at the hospital also made it hard to feel like a part of my own child life team. Because I wasn’t present for daily huddles, lunches, meetings, and staff development, I missed out on the quality time it takes to build relationships. When I was working and able to attend these events, I felt like a stranger. Without the consistency to help me feel comfortable, I found that the more days I had off between shifts, the harder it was and the more distant I felt.

The lack of consistency also impacted my confidence in my skills and knowledge. While frequently shifting between units and trying to soak it all in, it was difficult for me to build a sense of competence within any one area. Instead of feeling like I knew a lot about a certain diagnosis, procedure, or population, I felt like I knew just a little about a lot of them. While I clearly realize now that it was an unrealistic goal, I wanted to be an expert in something—anything. I wanted to know the ins and outs and hold the confidence of a child life specialist who had been doing this work for years. I struggled between the high of knowing information about many different topics and the low of realizing that my knowledge only went so far.

Challenges also manifested themselves outside of direct patient care as I became aware of the restraints put on my role at the policy level. For example, PTO and health benefits weren’t a part of my job package. However, at that point in my life, these weren’t huge sacrifices. That being said, I would encourage anyone considering this role to think about how these factors might impact them. When I think about my overall experience as a PRN child life specialist, the thing that I struggled with above all else was the inability to give more. I wanted to engage in a deeper commitment to my role by participating in hospital, unit, and department committees set on making changes to positively impact those we serve. The PRN role makes this difficult when you cannot promise your presence.

Go For It!
I learned a lot of valuable lessons working as a PRN child life specialist, lessons that taught me about myself, helped to build my confidence in my skills, and motivated me to continue moving forward. I was able to slowly dip my toes into child life work without jumping in headfirst and was given the freedom to explore. Looking back now, the flexibility of this role was its greatest gift. When a full-time job finally became available to me, my PRN experience gave me the courage to confidently say, “Yes, I am ready. This is the area where I want to work.”

Although the challenges were hard to swallow at times, I don’t share them with you to deter you from pursuing child life work on a PRN basis. I think it can be a great option for individuals starting out in this field. I felt it was important to be open and honest about the challenges of this role, while also highlighting the perks. My hope is that my insight can offer some preparation as you contemplate whether working PRN is the right choice for you. After all, as we all know, coping is made easier with a little preparation.
Alan Fleischman, MD, has been a pediatrician and newborn specialist for over 50 years and has the pedigree to examine pediatric ethics in his book, *Pediatric Ethics: Protecting the Interests of Children* (2016). In addition to his long-term service to the American Academy of Pediatrics’ Bioethics Committee, Dr. Fleischman co-created the first infant bioethics center in the United States (at Montefiore Medical Center and the Albert Einstein College of Medicine in the Bronx, New York), and was appointed to the first bioethics commission, the New York Governor’s Office Task Force of Life and Law. In this book, Fleischman examines ethical issues relevant to the medical continuum of care for children. There are a vast number of topics within, including 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. The book also offers ethical cases that cover the lifespan of childhood and issues specific to pediatric medical care in general.

Fleischman lays out his chapters as if we are following a child along the lifespan, from ethical issues in creating a child (e.g., issues with reproductive technology), to giving birth (e.g., DNR orders in the delivery room), to genetic testing and screening in children. In addition to the material covering the childhood lifespan, content is also dedicated to ethical issues in end-of-life care (e.g., brain death, organ donation, children as participants in their final days), medical and surgical enhancement (e.g., growth attenuation in children with developmental disabilities, psychotropic drugs, embryo selection), and ethical issues in researching children (e.g., historical background, minimizing risk, parental/guardian permission or child assent). Although he mostly writes to an audience of medical doctors, any member of a psychosocial team will be able to find connections between the cases he discusses and their own work.

In my work as a professor of child life, I find that adolescence is a life stage that can be intimidating to our students who do not have experience working with this age group. Therefore, I found Fleischman’s chapter on ethical concerns facing adolescents particularly insightful; I can mine information within to share in a number of courses. For example, Fleischman discusses what he calls “the adolescent alone,” adolescent patients without parental/caregiver support because they come from dysfunctional family systems, are homeless, runaways, and/or struggling with addiction without community or family support. He urges health-care professionals to be aware of these young patients and advocate for their patient rights, as they can be vulnerable to being ethically exploited due to their ambiguous legal status. Additionally, Fleischman uses an ethical lens to discuss other issues that adolescents can experience, including depression, suicide, and eating disorders.

Fleischman explores current medical issues we see discussed in the media, including ethical issues surrounding parents/caregivers of children with Down syndrome using plastic surgery to erase the physical characteristics of that genetic variation, and religious perspectives on creating babies with medical intervention. Other ethical issues examined include the debate on immunizations, family religious/personal beliefs impacting medical decisions for their children, and prenatal parental behavior that puts a fetus at risk.

Interspersed throughout each chapter are cases relevant to the issues discussed. For example, in the first chapter, there are three cases involving various family compositions facing decisions about parenting: 1) a 58-year-old female and 62-year-old male contemplating reproductive technology to become first-time parents, 2) a couple struggling with the decision to conceive a child so that their 4-year-old son can have a chance of a stem cell match necessary to save the boy’s life, and 3) a mother with multiple medical diagnoses (celiac disease, type 1 diabetes,
lupus) utilizing a surrogate, who eventually changes her mind after the baby is born. Given the context of his professional experience as a pediatrician and his long-time service to the field of pediatric ethics, I found it very beneficial that Fleischman discusses his own views on where he would side with each ethical dilemma, sharing his reasoning and the basis for his decisions. He digs deeper as a given chapter progresses, going beyond the brief details given in the cases to highlight the ethical dilemmas faced by patients and their families. Fleischman ends each chapter with his final thoughts and suggestions for additional reading.

Despite its usefulness, there were some problematic areas in this book. Although the publication date is relatively recent (2016), I found some of the language used to be antiquated. For example, in Chapter 8, which covers ethical issues in adolescents, the word “homosexual” is used quite often. In today’s lexicon, we tend to use more progressive language, (e.g., lesbian/bisexual/gay/transgendered/ queer [LBGTQ]), rather than a homogenizing word like “homosexual.” However, despite the use of that word, Fleischman uses the term “transgendered” and includes discussion of both LBGTQ children and the importance of addressing issues adolescents face as they struggle with support and accurate medical information. As child life specialists understand the importance of mirroring the language used in the discourse by given populations, Fleischman’s inconsistency with language can be distressing. As noted earlier, Fleischman does write with a lens more towards medical doctors, and this can tire a reader outside of this medical profession. Lastly, it’s important to note that this book does not offer steps that healthcare professionals can take when faced with an ethical dilemma, including ways to identify whether a situation does indeed involve ethics, and if so, what models exist to help one work through logical steps in sorting out what can sometimes be very messy situations for professionals, families, and patients themselves.

This book’s connection to the child life profession is strong, as the cases discussed are transferrable to patient and family care provided by child life. Child life professionals and child life students can find the topics and discussions helpful in providing a larger picture of what a patient or family could be facing. This can be a valuable resource on the shelf of child life departments, in teaching child life courses, and in weaving through discussions with colleagues.

Fleischman states, “Pediatric ethics is family-centered, respecting the role of parent and family in the lives of children—roles that are fundamentally different from the role of family in the lives of adults” (2016, p. 11). The sentiments of this statement are what child life is all about. Child life professionals understand the hospital stressors that patients and their families face as they navigate a medical diagnosis. When we are aware of the serious ethical considerations families can face, it adds more complexity to our understanding of these stressors we know so well, giving us a much broader, richer view of patient and family experiences.

REFERENCES

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.

Chabot recommends two excellent resources for further reading on medical ethics:

Supporting the Traumatized Child

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Child life specialists in a range of practice settings encounter and work with children who have experienced a traumatic life event. Exposure to trauma is common; two thirds of individuals have experienced at least one type of potentially traumatic event during childhood (Marsac et al., 2016). There are many different categories of events in which children are exposed to trauma. According to Marsac and colleagues (2016), some children are exposed to trauma in highly publicized, large-scale events (e.g., natural disasters, school shootings), while the vast majority of potentially traumatic childhood events involve lower-profile events such as abuse, community violence, accidental injury, motor vehicle crashes, and exacerbation of chronic illnesses. Whether you have months or moments with children who have experienced trauma, outlined below are resources to help. These resources are for parents, caregivers, and professionals who are helping children understand and process their reactions to traumatic life events, learn coping skills, and ultimately move forward.

REFERENCE


PARENT/CAREGIVER RESOURCES

- This website was created to help parents and caregivers learn about injury and trauma and find ways to help their child recover physically and emotionally. downloadable tipsheets provide information on ways to help children recover, ways children can help themselves cope, how caregivers can practice self care, and how to help children cope with being in the hospital.
- The National Child Traumatic Stress Network is a resource for parents and caregivers as they navigate understanding how traumatic events affect children and reasons behind specific behaviors and emotions in a child after experiencing trauma. This site offers a variety of downloadable resources on topics ranging from bullying to disasters.
- Healthy Children: https://www.healthychildren.org/English/family-life/family-dynamics/adoption-and-foster-care/Pages/Parenting-Foster-Adoptive-Children-After-Trauma.aspx
- Healthy Children, the American Academy of Pediatrics' website for families, offers a section on parenting after trauma that discusses different forms of trauma, how the brain reacts to trauma, learning to trust after trauma, and how parents and caregivers can help. Additionally, this resource provides tips for parents of adoptive and foster children who have experienced trauma.
- This app allows the user to select a disaster (i.e., earthquakes, extreme weather, floods, hurricanes, tornadoes, tsunamis, or wildfires) and provides developmentally appropriate options to explain, prepare, respond, heal, and learn from the the selected event.
- This fact sheet discusses what trauma is, the impact of untreated trauma, understanding a child's behavior, trauma and mental health, PTSD, helping your child, and when to seek help and resources.

RESOURCES FOR CHILDREN

- This book is designed to help school-age children explore their emotions surrounding grief and trauma and help them learn to cope with loss and change.
- This resource was created to help school-age children and adolescents who have experienced a violent trauma or death understand their trauma and grief. It explains common reactions and uses interactive worksheets and drawing exercises to enhance understanding.
- This guide explains feelings, thoughts, and behaviors that school-age children might experience after enduring a trauma and provides strategies to help children return to baseline.
- I Saw It Happen is a workbook full of illustrations and exercises created to foster healing, self-understanding, and optimal growth after a school-age child or adolescent has witnessed violence.
- This book follows several animals that have experienced scary events and have all reacted in different ways. This book aims to help preschool and school-age children understand that they can ask adults for help and can learn different ways to cope with their feelings.

This book is about Whimsy's attempts to deal with the heavy things that are weighing her down. Rather than trying to hide them, she learns that dealing with them one at a time allows them to lift her up rather than weigh her down. This would be a great book for children ages 5 to 11.


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CHILD LIFE/PROFESSIONAL RESOURCES


Children and Trauma teaches readers about the effects that experiencing trauma can have on children. It also provides detailed ways that caregivers can help support a child who has experienced trauma and best ways to help them heal.


This article reports on a cross-sectional study on the outcomes associated with familial presence in the trauma room among structured trauma programs incorporating principles of family-centered care.


This handbook discusses what current professionals do and don’t know about pediatric PTSD and its treatment, considering differing opinions for the diagnosis of PTSD as well as the ways that cultural and socioeconomic factors affect the diagnosis.


This article discusses acute stress disorders, one of the many diagnoses patients may receive after a traumatic event, as well as screening tools and the importance of caring for emotional trauma in children. It also explains ways to minimize potentially traumatic aspects of the child's care, recognize stress symptoms, and provides resources to help parents support their children.


The downloadable guides offered here provide information on what to expect, what to do, and what to look out for during crisis events. All guides are sorted by developmental age for easy searching.


This book explores the biological process that connects traumatic experience to physiological responses and behavior. It highlights the importance of early intervention, the impact on mental and physical health, and the need for psychosocial support.

Kayla Rueter has been a Certified Child Life Specialist for 6 years. She has worked the majority of her career in a level-one trauma center, and recently made the transition to an acute inpatient rehabilitation unit. Kayla has experience working with patients and families who have suffered trauma in both inpatient and outpatient settings. She can be reached at krueter@ascension.org

The Journal of Child Life: Psychosocial Theory and Practice

First Issue: March 2020

“Join us as we celebrate this important step in moving the profession forward during Child Life Month.”

-Jill Koss, President, ACLP

The Journal's Editorial Board is now accepting submissions in the categories of quantitative research, qualitative research, substantive and systematic literature reviews, analysis of theory as applied to child life, and program development with pre- and post-implementation data.

See www.childlife.org for more information on the submission process.
Finding the Cure for My Burnout

Kristin Brown, CCLS
GOLISANO CHILDREN’S HOSPITAL OF SOUTHWEST FLORIDA, FT. MYERS, FL

Three years was all it took. During my third year as an inpatient child life specialist at a downtown level one trauma center, I began to experience an unsettling feeling every morning on the drive to work. But what was it? I was pretty sure I still wanted to practice child life, but maybe just not in that same role, or in that same hospital. So I picked up and moved to a drastically different role and place—an outpatient unit in a small beach town.

When I made the transition to being an outpatient specialist at a new hospital, I dove right in with new energy. I wanted to show that I was a team player, advocating for our profession, supporting patients, and working with the community, but I was leaving work feeling exhausted and unfulfilled. I felt as though, despite everything I had accomplished, I wasn’t making enough of a difference. Was this the experience of my first years of professional practice repeating itself?

If this were a live presentation and I asked for a show of hands of those who have heard the topics of burnout and compassion fatigue mentioned more than once in their career, I can visualize every hand in the air. These are hot topics in our field, a helping profession, for good reason. And while these two terms are often used in the same sentence or even interchangeably, they are actually very different issues that manifest in very different ways.

Compassion fatigue comes about as the result of witnessing human suffering; it can be conceptualized as the emotional cost of empathizing with people in physical or emotional pain. Research centered on this topic notes that compassion fatigue is due in part to the traumatic and stressful situations we witness in our professional practice, such as abuse and neglect, painful treatments, and death (Krog, 2016). Having experienced each of those situations on a daily basis in my first child life job, it’s now easy to look back and identify that I was in fact experiencing compassion fatigue in those first few years of work. But was I right to think that moving to an outpatient procedural unit in a smaller hospital would ease the stress of my job?

In 2001, Maslach, Schaufeli, and Leiter defined burnout as a prolonged response to chronic emotional and interpersonal stressors on the job, or more simply put—burnout is the result of stressful working conditions. As child life specialists, most of us would automatically think of patient care when we hear the phrase “stressful work conditions”; however, in reality that is only a piece of the puzzle that contributes to the risk of burnout.

Burnout research looks at stressors that include role ambiguity, an individual’s workload, lack of control or autonomy in one’s role, and other factors unrelated to patient care. The necessity of learning how to navigate the hospital system and its policies, working with media and the public relations team, or even how to balance the personalities and preferences of all your new coworkers—these are all job requirements, in addition to patient care, and are just the type of stressors that can lead to burnout.

If you were to go the classic route and look up “burnout” in Merriam-Webster and scroll through the definitions, there’s one you might miss that is extremely pertinent to this topic: “to cause to fail, wear out or become exhausted specifically from overwork or overuse” (Burn out, n. d., para. 5). As a practicing child life specialist for over six years, reading that definition was a “stop me in my tracks” moment. Often, healthcare professionals are so focused on providing care to others (patients, coworkers, and the community) that we neglect to take care of ourselves, with the result that we become exhausted from overworking ourselves. I realized that I was overworking myself by trying to do everything, and be everything, to everyone.

In their chapter in The Handbook of Child Life, Thompson, Bennett, and Snow (2018) note that role ambiguity or lack of clarity about the duties and responsibilities of a position is associated with increased levels of burnout. Therefore, just as children develop a personal identity as they learn and grow, we as individual child life specialists must carefully define our role and develop our own profes-
sional identity as we learn and grow through our practice and experience. Those of us established in the profession fully understand the hard work and dedication it takes to succeed in the competitive field of child life, from undergraduate work to practicums and internships, but we must be careful to not kick that dedication into an unhealthy overdrive once a coveted child life position is secured. There are many directions one can go in the field of child life, and burnout can happen quickly when you are overextended, or when you do not clarify the role you want to play (Welch, 2018).

The findings of a 1996 study by Munn, Barber, and Fritz highlight the importance of addressing role ambiguity and its impact on role stress in the work environment. One implication for practice is the provision of clearer work role definitions, or more detailed job descriptions. These may improve not only the child life specialist’s, but also the multidisciplinary team’s understanding of what is expected. Some hospitals have implemented clinical ladders, with more experienced specialists being promoted to higher levels on the ladder than new graduates. Clinical pathways can also be used to clearly define each team member’s responsibilities within specific professional situations. Clinical pathways can look as simple as very clear communication ladders for special events or student programming. Additional studies (see Munn, Barber, & Fritz, 1996, for review) encourage supervisors to foster social support and a sense of belonging within a department to improve job satisfaction through teamwork and open communication about individuals’ professional needs. Building that network creates open lines of communication where a specialist feels secure in going to any other specialist for support or guidance. Open communication with one’s supervisor and peers, rooted in the need to determine one’s social identity, is the start of eliminating role ambiguity.

You are a child life specialist, but what is your specialty? Everyone has different interests, pace preferences, and skill sets. Once you begin to identify yours, then you can position yourself to work within the environment that fits you best. Six years ago my specialty was building those therapeutic relationships while providing support in post-trauma situations. Today, however, when someone asks what my favorite aspect of child life is, my answer would be teaching. After moving across the country to become an outpatient child life specialist, I have found a strong sense of passion and purpose in teaching patients about their upcoming procedures and seeing the resulting sense of mastery they develop through those procedures. Knowing my strengths and limits has allowed me to regain the personal and professional fulfillment that I remember having as a new child life specialist on that trauma unit, and kept me from falling into compassion fatigue and burnout again.

**REFERENCES**


The first two articles in this series addressed finding empirical articles and making sense of them. Knowing that, how do we take a critical eye and determine the quality of an empirical article? No matter whether the research is quantitative (data as numbers) or qualitative (data as words or observations), there are many factors that can be evaluated to determine the quality and usefulness of an article, including whether the methodology is appropriate for the question addressed, the reliability and validity of measures, and the data analysis employed. For those who are not well versed in research, there are less technical factors to consider as well.

This article will delve into three factors that readers might use to evaluate an empirical article: author expertise, the journal impact factor, and the sample.

Author Expertise
Who wrote the article and what are the author’s credentials? Notice if the author is a clinical professional in their field and/or connected with an academic institution. For example, a child life specialist may pay more attention to an article about children’s coping styles when it is written by a developmental psychologist compared with an article written by a psychologist who studies adulthood and aging. A simple search of the author’s name on Google will allow you to investigate the author’s place of work and whether the author has previous publications or affiliations with organizations. The Google search may yield the author’s profile on ResearchGate.net, a common social networking site for researchers. This site allows researchers to publicize (and sometimes provide full-text renderings of) their publications, conference presentations, and current research projects. Through ResearchGate.net, you can connect with other researchers to begin a discussion about your work or their work.

It is important to note that research articles written by less established professionals should not be discounted: Author expertise is just one out of many factors that can be used to critically analyze empirical research articles.

Journal Impact Factor
Where was the article published? Where, or in what journal, an article is published can indicate the quality of the article. Research journals are typically ranked by an impact factor, which is a calculation of the average number of times articles published in the journal over the past year have been cited (Sharma, Sarin, Gupta, Sachdeva, & Desai, 2014). Simply put, when an impact factor is high, there are many researchers and professionals reading and referring to the journal. When an impact factor is low, not as many researchers and professionals are citing articles in the journal as compared with those journals with higher impact factors. For example, child life specialists may read an article in *Pediatrics*, a publication from the American Academy of Pediatrics. Its 2018 impact factor is 5.401, which is considered high. Selected journals relevant to the field of child life and their 2018 impact factors are listed in Table 1.

Sample
The sample size is the number of participants or subjects who participated in a research study, and is typically denoted as “n” in a research article. A sample is a subset of the population to which researchers hope to generalize their study results (Patten & Newhart, 2018). For example, you may read an article on children’s perception of pain during a blood draw that has a sample...
of 35 pediatric patients. The researcher is hoping to generalize the results from this sample of 35 patients to all pediatric patients (the population) receiving a blood draw in the United States; however, there are several reasons why the results of a study using this sample cannot be generalized to the entire population.

In general, the larger the sample size, the more likely it is that the study results will be generalizable to the population. However, a sample must also be representative of the population being studied in order to be generalizable to that population (Miller & Salkind, 2002). For example, let’s say the sample was 110 patients in the Mountain West region of the United States. Can we generalize the results of this study to patients in the entire country? Probably not. There are too many other variables to consider, including the characteristics of children and families, healthcare staff, and the hospital in the Mountain West region. So how could we make this sample more representative of the population? One way is to collect data at multiple sites in the United States: Instead of just collecting data on 110 patients in the Mountain West region, data could be also be collected on 110 patients in the Southeast region. To continue gaining a sample that is representative of the U.S. pediatric population, data could be collected from 110 patients in each region. Thus, the degree to which a sample is representative of a population should always be evaluated when assessing the quality of an empirical article.

This article does not include all of the factors used to critically evaluate research articles. Instead, this article aims to assist child life professionals in becoming critical consumers of research by enhancing their evaluation skills related to three factors: author expertise, journal impact factor, and sample. Critically evaluating research articles takes practice. The more you read research articles, the easier it will be to evaluate them. To gain experience, some child life departments have started journal clubs, where one article is reviewed and discussed among team members each month so that child life specialists can become more familiar with reading and evaluating empirical literature. Perhaps this is something your department can do. Similarly, our ACLP Scientific Advancement of Professional Practice Committee: Evidence-Based Practice/Quality Improvement Awareness and Networking Subcommittee has started a journal club and we will begin writing reviews of relevant empirical articles in our column in the future.

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<th>JOURNAL</th>
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<tr>
<td>Pediatric Emergency Care</td>
<td>1.119</td>
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<tr>
<td>Children’s Health Care</td>
<td>0.519</td>
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**REFERENCES**


2019 International Scholarships: CHILD LIFE ANNUAL CONFERENCE

Tiffany A. Key, CCLS
CHILDREN’S OF MISSISSIPPI, JACKSON, MS

Last spring at the 2019 Child Life Annual Conference, five healthcare professionals from around the world were welcomed to Chicago, Illinois, as recipients of the Association of Child Life Professionals’ international scholarships. Each year, ACLP provides opportunities for selected recipients to attend the annual conference where they are able to network and explore child life principles and components of pediatric psychosocial care at the world’s largest gathering of child life professionals. International scholarship recipients are healthcare professionals outside of North America in positions to introduce or greatly enhance psychosocial care of pediatric patients and their families. The 2019 recipients include Grace Kajuju Maore, coordinator of Crafts for Cure at the Faraja Cancer Support Trust in Nairobi, Kenya; Sonya Kamenskaya, a social educator at Speransky Children’s Hospital Fund in Moscow, Russia; Marcela Valenzuela Bilboa, a speech and language pathologist from Santiago, Chile who is currently working towards a master’s degree in the emotional attention of the hospitalized child at the University of Barcelona in Spain; Tooba Nadeem Akhtar, a children’s mental health counselor at The Indus Hospital in Karachi, Pakistan; and Ndibmun Ningmua Doh MacDonald, an ER head nurse at Yaounde Gynaeco-Obstetric and Pediatric Hospital in Cameroon.

Upon their arrival to the Windy City, scholarship recipients were able to meet face to face with their conference mentors, established ACLP members who offered guidance and insight leading up to and during the conference experience. To kick off conference, recipients toured Comer Children’s Hospital, attended pre-conference intensives, and were recognized at the leadership awards breakfast where they were met with a round of applause from leaders and visionaries within the child life field. Throughout conference, scholarship recipients attended professional development workshops and sessions that appealed to their interests. While reflecting on his experience and the sessions he attended, Ndibmun Ningmua Doh MacDonald gladly welcomed the expertise of the various presenters and noted that “Being the major pediatric hospital in the capital city of Cameroon, psychosocial care cannot be overemphasized.” Furthermore, in her conference reflection essay, Marcela Valenzuela Bilboa described her experience as “incredible” and stated that “Everything I learned in the days...
of the conference is an incentive for me and makes me feel hopeful that with patience and dedication it is possible this profession will develop and grow as a fundamental support for children and their families [in Chile].” Sonya Kamenskaya noted her expectations for conference were “fully confirmed” and enjoyed comparing the similarities and differences that exist in children’s healthcare across the world. In the Exhibit Hall, Tooba Nadeem Akhtar, who works within the only child life department in Pakistan, was able to connect with the San Diego Zoo Kids Channel, which is now being streamed for children and their families at The Indus Hospital. Akhtar summarized that attending conference was “the experience of a lifetime.” It has become abundantly clear that the international conference scholarship program serves as a universal bridge for professionals to connect, build relationships, and share resources across the globe.

Before boarding their flights to return home, scholarship recipients were able to attend the closing session and say farewell to their newfound friends and colleagues. Grace Maore concluded that “The ending ceremony was more of a celebration than a goodbye. It meant I had made new friends and networks that I could work with to forge a better healthcare journey for the children in Kenya.” ACLP and the Awards Committee offer a special thanks to the international scholarship recipients for sharing their stories and their passion to further develop and enhance pediatric healthcare in their countries. ACLP looks forward to extending scholarship opportunities to deserving recipients at the Child Life Annual Conference in San Antonio, Texas, in May 2020.

Get Ready for the 2020 ACLP Conference in San Antonio!

Brittany Blake, MS, CCLS
CHAIR, 2020 ACLP CONFERENCE PROGRAM COMMITTEE

The 2020 ACLP Conference Program Committee looks forward to hosting you in San Antonio, Texas, from May 21 through 24! The 2020 conference program will showcase conference standards representing a broad variety of professional topics and perspectives from colleagues and invited guests. In addition, we are pleased to highlight the following features:

- **Emma Plank Opening Conference Keynote:** James C. Burroughs II, Chief Equity and Inclusion Officer at Children’s Minnesota, will discuss equity, diversity, and inclusion in healthcare and how child life specialists can become Equity Action Champions.

- **“Get Connected” Event:** Previously known as the First Timer/New Member Event, this event is a time to get plugged into all things “conference.” Whether this is your first conference or your thirtieth, make plans to stop by and join us for an engaging, informative discussion, followed by small group networking where you will discover tips on how to make the most out of your conference experience.

- **Innovation Fair:** We are excited to announce that this opportunity is returning for a second year. The innovation fair is designed to showcase the creativity and ingenuity of students and professionals alike. Expect to see original child life hacks made by colleagues in the form of preparation materials, teaching tools, games, and comfort objects, all designed to improve care of patients and families. Do you have something you would like to share? Please submit your innovation to our Call for Innovators by emailing clinnovations@childlife.org. The deadline for innovation submissions is January 31st.

- **Child Life at Play:** Would you like to explore San Antonio? Want to meet new friends over dinner? How about starting your day with morning yoga or a guided stretch? The Conference Program Committee is excited to continue Child Life at Play—facilitated social activities designed to enhance attendees’ conference experience. Be on the lookout for more details on activities, dates, and times as the conference approaches.

- **Closing session:** Jacquie Lloyd Smith, MA, MBA, STR, CMC, is a skilled facilitator and master trainer from Strategic Play Group Ltd. Jacquie is a Registered Art Therapist and is certified in play therapy and creative problem solving and will be sharing her message of play and resiliency.

Learn more about all of the exciting happenings and register for conference on the [ACLP website](http://www.childlife.org). We hope to see you in San Antonio!
It is May of 1994, and many child life specialists are preparing to celebrate, learn, and connect with their community at the annual child life conference in Toronto, Ontario. Meanwhile, members of the Child Life Council’s History Committee are spending their time leading up to conference together; pouring over boxes of donated historical items; sorting letters, tapes, books, and more; and planning for their next steps as a committee to better establish and maintain the history of child life. Within the next year they will have conducted many audio and video interviews with various pioneers and individuals of influence within the field of child life. A question I’m sure that was pondered during this meeting: “Who will house these materials?” At that point there was no permanent space for these items; however, members of the committee knew the value of preserving the history of the child life profession and took turns storing boxes upon boxes in their attics and basements, hoping they would not be damaged along the way.

In 2001, Civita Brown, MSEd, CCLS, became the chair of the Archives Management Group and was given the child life historical item collection to maintain and keep safe at her home during her time in this role. Civita believed that these items deserved a permanent home where they could be accessed and kept safely, and where there was space to expand the collection over the years. Through Civita’s work at Utica College and her partnership with their library’s director, Utica College and the Child Life Council formally named the Frank E. Gannett Memorial Library the permanent home for the Child Life Archives in 2001.

All photos provided by the ACLP Archives Committee.
Twenty-five years have passed, and I find myself standing in the Child Life Archives among the members of ACLP’s Archives Committee looking at these images of the 1994 gathering. Within these last 25 years, the field of child life has experienced exponential growth, and the archives’ expanding collection reflects that. While our group continues to process donations of historical items, we are also spending a significant portion of time considering the need for technological advances in our archives. Accessibility for all ACLP members is a priority, and we are taking action toward creating a digital archive platform. In another effort to increase access, the Archives Committee hosted its first mini-museum at the 2019 ACLP Conference in Chicago, highlighting key photos, letters, and items of prominence to the archives, and will continue to manage displays such as this one at future ACLP conferences.

While we have evolved in many ways, there are a few things that haven’t changed. In 2019 as in 1994, we are sorting donations, discussing the impact of our history, and considering next steps to best support ACLP members. Our committee members are diverse, in terms of geographic location and time in the field, but together, as we review items, we are each reminded of the reason why we choose to dedicate our time to the archives. For some, it is awe-inspiring to learn of an event or person who paved the path for child life today. Others can take one look at an image or read a letter and be transported back to a moment when they were present for a decision or conversation that has led to the profession’s growth. One understanding remains the same for committee members of past and present: The steps we take today as a profession will shape our future, and the history being created is worthy of being preserved for generations to come.
ACLP Calendar

JANUARY

1  CLPDC data entry for 2019 Q4 begins
1-31  Start planning your Child Life Month events and activities for March!
24  Deadline to apply for a One-Person Child Life Program Conference Scholarship
31  Deadline to submit 2020 Annual Certification Maintenance Fee
31  Submission deadline for the Innovation Fair at the 2020 Annual Conference

FEBRUARY

1-28  Continue planning your Child Life Month events and activities for March
7  Deadline for early registration for Child Life Annual Conference
14  Applications available for the Diversity Scholarship for summer 2020

MARCH

1-31  Celebrate Child Life Month!
1-31  First issue of The Journal of Child Life: Psychosocial Theory and Practice published
10  Deadline to apply for the March 2020 administration of the Child Life Professional Certification Exam
15  Deadline to submit internship applications for fall 2020
16  Deadline to submit a Diversity Scholarship application for summer 2020
15-30  Child Life Professional Certification Exam administration testing window

Upcoming Events

MARCH 25-26
Virtual Medicine: Best Practices in Medical Virtual Reality 2020
Los Angeles, CA
Visit the Virtual Medicine website for information.

MARCH 25-28
National Association of Pediatric Nurse Practitioners National Conference
Long Beach, CA
Visit the NAPNAP website for more information.

Webinars

ACLP’s 2020 webinar programming features new and updated ways to enhance your profession education. From search functionality to on-demand recordings, there’s truly something for all learners to enjoy in our new portal. A few new features we don’t want you to miss:

- Targeted learning: Each month ACLP will be hosting two live webinars—one targeted for emerging professionals and the other for established professionals—rooted in the same theme.
- New! Subscription services: Our new subscription services offer learners the chance to join some or all of our live 2020 webinars at a discounted rate. Subscribers will have access to the on-demand recordings for these events in case watching live isn’t convenient.
- Webinar scholarships: To support ACLP’s diversity goals, we will be offering a number of individual registration scholarships to each of our live webinars. Visit the online learning portal to complete the application.

Be sure to visit ACLP’s online learning portal to learn more about our new features and to explore the full 2020 programming schedule.

TECHNOLOGY

Emerging Professionals – Gaming for Good: How to Incorporate Video Games and Digital Technology into Your Therapeutic Practice
Tuesday, January 14, 1-2pm EST

Established Professionals – Incorporating a Technology Professional Within Your Child Life Team
Wednesday, January 22, 2:30-3:30pm EST

COMMUNICATION

Emerging Professionals – Influencing Behaviors: Seven Simple Rules
Wednesday, February 19, 2-3:30pm EST

Established Professionals – Difficult Conversations: How to “Address” for Success in the Professional World
Thursday, February 20, 3-4pm EST

SELF-CARE

Emerging Professionals – Resilience over Balance: Professional Sustainability for the Modern Child Life Specialist
Thursday, March 12, 1-2:30pm EDT

Established Professionals – In for the Long Haul: Exploring Career Longevity Among Child Life Specialists
Tuesday, March 3, 1-2pm EST

If you’d like to share your expertise and facilitate a webinar, please visit ACLP’s webinar proposals page to provide us with information about your presentation. Presenters earn 2 PDUs per hour of presenting. We look forward to partnering with you as a facilitator!
Help Children and Families Thrive with a Master’s Degree from APU

A need exists for qualified, compassionate healthcare professionals to serve children, adolescents, and families in a variety of situations and settings. Prepare to meet this need and impact lives with Azusa Pacific’s master’s programs in psychology.

M.S. in Counseling Psychology with Specialization in Children and Adolescents

Support the mental and behavioral health of children and youth.

- Become equipped to work in a variety of public and private mental health settings
- Graduate ready to pursue LPCC licensure in California
- For Certified Child Life Specialists, expand your scope of practice with this complementary program

apu.edu/counselingpsych

M.S. in Child Life

Help children and families coping with stressful situations.

- Focus on research and therapeutic skills
- Prepare for CCLS certification
- Gain field experience through a practicum and internship
- Complete the program in just 18 months; Advanced Standing option available

apu.edu/childlife

Take the next step and apply today!
apu.edu/gpc/apply
What is equity and inclusion?

What are equity actions?

Besides being very popular buzz words, it seems most organizations understand the value of discussing equity, diversity and inclusion, but few have created sustainable actions with long term strategies and goals to help create positive outcomes.

How do we change culture and strive for health, economic and social equity?

How is success measured and what difference will it make?

How do we hold ourselves accountable?

We will explore #EquityActions and how they lead to transformative change.

We will address these questions and more, creating a child life toolkit and learning how to become an Equity Action Champion!

San Antonio, TX
Marriott Rivercenter
MAY 21-24, 2020

#ChildLife2020