ACLPBulletin

In Focus:

The Role of Child Life Specialists in the Successful Transition to Self-Management of Adolescent Chronic Illness

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CHILD LIFE FOCUS:

New Year, New Transitions

We learn in our training that transitions never cease, for ourselves as well as for the patients we serve. With every new developmental level, new move, new health status, and new change in insurance, we relearn how to be patients, vulnerably sitting with our health in the hands of someone else. Once adolescents transition to adult healthcare, it is not simply crossing over a finish line with smooth sailing on the other side; instead, it is an adjustment that constantly evolves as they age. As both patients and child life professionals, our lens on this experience is hyper-attuned to the learning pains of each shift in care. Sometimes too attuned. This fall I transitioned from my clinical training in child psychology to a new academic position. The transition was accompanied by many losses, including losing my cozy office with shelves and shelves of toys (my new office has as many insects as I once had dolls), a friendly team of coworkers who made my days zoom by, and, most noticeably, my health insurance. With my change in insurance, I lost my previous medical providers that I spent years getting to know, gaining more trust and rapport with each visit.

The medical facility that my new insurance requires me to use is bigger than my previous digs, and the hustle and bustle of the facility's culture is a pace I struggle to match as a patient. I have been lost over a dozen times just trying to navigate the massive buildings with sticky floors, often showing up to the wrong location and having to run to make it to my appointment on time. There was that time I had what must have been liters of blood drawn from my body only to find out a week later it was mislabeled and I had to repeat the process. And that one time they told me I was going to have an ultrasound but they booked me instead for a CT. And throughout all of this, as I change my schedule and cancel my lectures, my new doctors keep calling me Julie. Who is Julie? I am frequently turning to

my husband and asking, "Where is my child life specialist?" and then slumping my head low as I mourn my previous clinic with its ample parking and magazine-filled waiting room. As developmental clinicians, we are skilled in making transitions in life easier. But I feel as though my new facility thinks of this process as complete at 18 and assumes I should know by now how to find a mysterious clinic without maps, signage, or a logical design.

When you read this issue, it will be a new year and similarly, adjusting to 2019 will be an ongoing process instead of a singular event. I guarantee that in May I will still be inadvertently writing 2018 on my paperwork, like I do each year, only feeling confident in the number around October. As I have been reflecting on the number of transitions I have encountered in 2018, I keep returning to this issue's *Focus* article to learn of ways to cope with the adjustment. Written by Britta Johnson, MEd, CCLS, "The Role of Child Life Specialists in the Successful Transition to Self-Management of Adolescent Chronic Illness" is a broad look at how we can help adolescents (and ourselves) self-manage health experiences and prepare for adult healthcare. Her article demonstrates the breadth of our work and the variety of ways we show up to assist, educate, and

New Year, New Transitions

rehearse with patients and families to ensure that they are ready for their next experiences.

The remainder of the issue also highlights the variety of ways we support adjustment to life transitions. Erin Munn, MS, CCLS, wrote this issue's Alphabet piece titled "P is for the Power in Words," which provides context for the importance of intentionally choosing language that reflects the power and autonomy of patients. This issue's Research Corner, written by Jenny Chabot, PhD, CCLS, is a helpful overview of qualitative research, another way we honor patient stories and validate their experiences. Later in the issue, Meaghan Andrews, MS, CCLS, authors our Specialized Resources column titled "Supporting the NICU Preemie Family," which provides a curated list of valuable resources for clinicians working with families adjusting to the NICU setting.

The new year will also welcome new changes to *ACLP Bulletin*. Observing family separation at the border, natural disasters, and mass shootings frequently discussed in the news, many of our readers have asked about a standing space in *ACLP Bulletin* where they can discuss the intersection of child life and current events. Our new column, "In the News: Connections to Child Life," will be just that space. We encourage you to *share your perspectives* on how the transitions occurring outside your window have impacted the way you help families with their own adjustments. As we search for ways to make sense of our changing world, we hope the column will be a valuable resource for you and your colleagues.

With the new year comes new transitions and adjustments. Skilled as we may be in helping others adapt, it can be troubling when our own changes are sometimes met with a lack of guidance or support. My hope is that your new year is accompanied with surprisingly smooth sailings, and if not, perhaps this issue can offer a much-needed map when lost amidst the hustle and bustle of 2019. Happy New Year! 🏃

Gratitude and Leading the Way

2018 has been a year of incredible work, thinking, and progression! Our progress is an ongoing reminder of the dedicated, passionate ACLP community that continues to make an impact in the lives of children, youth, and families, and how each of you leads the way in psychosocial care and emotional safety across healthcare and community-based settings. ACLP is sought after for our expertise and our profound understanding of what impacts and influences all that children and families experience as they cope with healthcare and other challenging life events. We are participating in conversations and sitting at tables to have dialogues that continue to inform and impact children, youth, and families.

At the board meeting in November, the board was impressed with how the work of ACLP's committees illustrated the thinking and dedication that will move us forward, impacting and influencing the growth of the organization. Our strategic direction, the process that will take us into the next three years, will continue to focus on our strengths and on growing in our areas of need as a community. As we prepare to finalize the strategic plan heading into 2019, there is a deep focus on the needs of the membership. The process and intentionality in strategic planning is critical as we assess where we are and determine the direction we are going. Taking the time to dig deep into the "why" informs our decisions, and engaging in the opportunity to reflect on what informs us is so critical. Our strength as we implement our new strategic plan comes from this place: understanding the journey that got us to this point, while allowing the past to inform where we are going, and taking the risk in innovation to move us forward.

I am inspired by the passion, vision, and profound commitment of our community!

Our strength as we implement our new strategic plan comes from this place: understanding the journey that got us to this point, while allowing the past to inform where we are going, and taking the risk in innovation to move us forward.

Thank you to each group, individual, board member, and staff member for moving ACLP forward and for the commitment to what we are doing and where we are going.

We are ACLP! Vision, Community, and Action Together!

CEO Shares
Jennifer Lipsey, MA

Strategy

(\ˈstra-də-jē\)   A high level plan to achieve one or more goals under conditions of uncertainty (Strategy, 2018)

While Wikipedia isn't considered the best source, I think their definition of strategy best fits our strategic planning process. As we pursue standardization, predictability, and precedence, we cannot ignore the inevitable uncertainty that comes from growth and expansion. As our members are well aware, the healthcare environment requires agility, resourcefulness, and flexibility, especially when providing individualized care and a humanistic approach that necessitates a refined attunement to others' state of being. There's constant ebb and flow, give and take; and those who thrive are those who can embrace the tides to walk along the current, rather than battle to go upstream or stay in place.

Our new *strategic plan* gives us, ACLP, direction over the next three years. Members may shift the currents of the plan with their input or they may contribute in ways that make it stronger; either adjustment requires engagement. I would be remiss if I ignored the uncertainty that surrounds us, but rather than shirk in fear, we must rise to persevere. Budget cuts, healthcare policy, diminishing academic enrollment numbers—they stare our members in the face. It is time to provide support and resources to our members that are updated, relevant, and inclusive of outcomes to demonstrate that no one else can do, can make the same impact, as child life professionals. Money is great, technology is useful, gadgets are fun; but nothing can compete with the art of child life practice. Our members' value is not only in what they do but in who they are.

I hold great confidence that the pendulum that has been swinging in the direction of technology, tools, and gadgets is beginning to swing back towards a balance with classic, interpersonal engagement as the means to connect. Yes, technology addiction is real and growing; the art of meaningful, face-to-face conversation is being threatened by text, email, and insta-everything … and people are burning out. Those who can and have retained the art and skill of personal engagement as a means to create impact will leave lasting impressions on a society that has come to rely on technology to communicate and connect. Therein lies our opportunity to demonstrate our members'

value to patients, families, and fellow colleagues. The understanding of and advocacy for preserving the classic means of communicating and connecting—play, empathy, attunement, normalization—is fundamental to child life professionals' approach to their work, regardless of diagnosis, age, or setting. I have faith that such heart cannot be suffocated by gadgets and distractions. Patients, families—people—will seek interpersonal connection for its ability to truly impact an experience.

As we prioritize member engagement and connection, we do so with recognition that diversity within our leadership positions and membership composition would strengthen our association's integrity, and acknowledge the impact such diversification might have on advocacy efforts for access to healthcare by vulnerable populations. We must investigate where and how we are positioned to impact health equity and seek knowledge beyond our membership, and we must engage experts in cultural humility and equity of access to healthcare to help us assess how we might adjust our infrastructure to encourage greater engagement from diverse perspectives.

As an organization, ACLP must provide the support and stability needed by our members as we change the flow of our direction to accommodate the uncertainty inherent in the healthcare environment. As a small community, one of our primary strengths is the connectivity of our members. It is rare to find an assembly of individuals who are willing and wanting to provide help and support to each other, and yet, that is exactly what our ACLP community embodies—a safe space, a place to be vulnerable—when our daily lives require us to demonstrate courage, competence, and direction. We all need a place to turn and people to rely on for collective wisdom, empathy, and cheerleading. We aim to make ACLP that resource for our members.

We are your ACLP, ready to serve because our members matter most. 🏃

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ACLP Conference Program Committee News

Cat Leung, CCLS
CHAIR, 2019 ACLP CONFERENCE PROGRAM COMMITTEE

The 2019 ACLP Conference Program Committee looks forward to hosting you in Chicago from April 11 to 14! The 2019 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:

- **Conference Keynote:** Jason Wolf, PhD, CPXP, President of the Beryl Institute, will share his expertise and perspective as a recognized expert on patient experience improvement, organizational culture and change, and sustaining high performance in healthcare.

- **Collaborative Sessions:** These facilitated deep-dive sessions will address topics geared toward academic professionals, program leaders, and child life clinicians. Topic areas for

clinicians include mentorship, social justice, and ethics. There is no extra cost associated with participation.

- **First Timer/New Member Event:** Whether this is your first conference or your thirtieth, make plans to stop by and get plugged into all things "conference." 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:** This new opportunity 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 31.

- **Child Life at Play:** Would you like to explore Chicago? 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 introduce *"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:** Funny Bones Improv group is a charitable organization whose mission is to share the gifts and benefits of laughter with sick children, their families, and caregivers in hospitals across Chicago and New Orleans.

We hope to see you in Chicago! 🏃

P is for the Power in Words

Erin K. Munn, MS, CCLS

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

"Good words are worth much, and cost little." (Herbert, 1651/1846, p. 302)

Words matter. As child life specialists, we have been taught throughout our education and training about the *power of words* to influence or "produce an effect" ("Power," 2018). In our practice, we use person-first language to convey respect and to recognize that individuals are much more than just their illness or disability. We teach others to choose clear, unambiguous words that help children and families understand complex information. We advocate for an avoidance of words that can be unfamiliar, confusing, or threatening to children. We choose our own words carefully when preparing and supporting children and families during stressful experiences, using "the softest language that is honest" (Goldberger, Thompson, & Mohl, 2018, p. 295) to promote more manageable appraisal.

Just as our education and training informs our word choices, our colleagues and professional culture also shape the words we use. We may adopt specific words because these are the terms most commonly used in our professional setting, and we hope to connect and communicate more easily and concisely by using the same language. The words we adopt in this way may communicate more than we intend, however. As Plutarch, a Greek philosopher and author, wrote, "…speech must be considered as it were the exposing of the mind… For in words are seen the state of mind and character and disposition of the speaker" (Plutarch, c.100/2007, p. 78).

Despite the shift toward patient- and family-centered care, some terms persist in pediatrics as holdovers from the traditional medical model of care. The traditional medical model, often described as paternalistic, views the physician and other healthcare professionals as the experts, retaining power and control over the care process, while patients are viewed as dependent and passive recipients of care (Anderson, 1995). Patient- and family-centered healthcare approaches maintain that partnership between professionals, patients, and families is essential in shifting away from doing "to" or "for" patients and families toward working "with"

them in the planning, delivery, and evaluation of care (Institute for Patient- and Family-Centered Care, n.d.). With this paradigm shift, the construct of power in the relationship between professionals and patients and families moves from simply the view of power as authority, or power "over" to power "with," or shared power and empowerment.

When we use terms rooted in the traditional model of care, we risk aligning ourselves with the underlying values and perspectives of that paternalistic, professional-centered model rather than the values and tenets of patient- and family-centered care that form much of the foundation for child life practice. Because we understand the power *of* words, we must also consider the power *in* words. Are the words we use empowering or are they paternalistic, with an inherent, unspoken construct of power as "control, authority or influence over others" ("Power," 2018)?

Consider the terms *compliance* and *noncompliance*, still commonly used in referring to patients taking medications or following through with other health regimens. The dictionary definition of compliance is "the act or process of complying to a desire, demand, proposal, or regimen or to coercion" ("Compliance," 2018); the definition of the root word comply is "to conform, submit, or adapt (as to a regulation or to another's wishes) as required or requested" ("Comply," 2018). The definition alludes to the power inherent in the outside influence or pressure that leads to a person's conforming behavior. In medical use, compliance has been defined by Haynes, Taylor, and Sackett as "the extent to which a person's behavior coincides with medical or health advice" (as cited in Lutfey & Wishner, 1999, p. 635). As a concept, even the medical definition of compliance implies a difference in power. The underlying connotation is that the patient's behavior is important only in relation to the advice of the professional as the expert and authority; the patient's task is to obey the instructions of the professionals.

When patients' behavior does not "coincide" with medical advice, the term used is noncompliance, defined as "failure or refusal to comply with something (such as a rule or regulation); a state of not being in compliance" ("Noncompliance," 2018). With the focus on patient behavior as the source of noncompliance (in failing or refusing to comply), patients receive the label "noncompliant" which often carries many negative, even blaming, connotations about the patient—that they are difficult, uncooperative, irresponsible, disobedient.

In recognition of the shift in the 1990's and 2000's away from the paternalistic healthcare paradigm toward more patient-centered paradigms, the concept of *adherence* began to take prominence as an alternative to compliance. Adherence is defined as "the act, action, or quality of adhering (adhere: to hold fast or stick)" ("Adherence," 2018), and nonadherence is defined simply as "the lack of adherence" ("Nonadherence," 2018). With fewer connotations of blame, there is more room within the concept of adherence to acknowledge

and consider barriers beyond the patient's behavior, placing patients and professionals in a more neutral power construct. This shift in terms has been noted in the medical literature as well, with adherence becoming the preferred term in publications in recognition of the changes in patient-professional relationships to reflect partnership and collaboration (Aronson, 2007; Bissonnette, 2008; Hicks & Davitt, 2018; Lutfey & Wishner, 1999; McKay & Verhagen, 2016; Tilson, 2004).

Much attention to the concepts of compliance and adherence has occurred in the field of diabetes care. Researchers and educators in diabetes care contend that, as a conceptual framework, adherence doesn't go far enough to recognize the essential component of collaboration in the process of developing individualized care plans and ongoing management of diabetes (Anderson & Funnell, 2000; Glasgow & Anderson, 1999). They proposed the term self-management as a

Words that are:
Traditional
Paternalistic
Power lies with professionals
Disempowering

DISEMPOWER: to deprive of power, authority, or influence; make weak, ineffectual, or unimportant (Disempower, 2018)

"But if thought corrupts language, language can also corrupt thought. A bad usage can spread by tradition and imitation even among people who should and do know better. . .

What is above all needed is to let the meaning choose the word, and not the other way around."

Orwell, 1946, par. 15 & 17

Words that are:
Patient- and family-centered
Collaborative
Power shared in partnership
Empowering

EMPOWER: to give official authority or legal power to; to enable; to promote the self-actualization or influence of (Empower, 2018)

Compliance	Adherence	Self-management
Noncompliance	Nonadherence	
Distraction		Planned alternate focus
Comply		Cooperate, Cooperation[1]
Allow[2]	Enable[3]	Encourage[4], Promote[5]

1 Cooperate: *to act or work with another or other;* Cooperation: *the actions of someone who is being helpful by doing what is wanted or asked for: common effort* ("Cooperate," 2018)

2 Allow: *to permit [permit: to consent to, to give leave, authorize; to make possible]* ("Allow," 2018)

3 Enable: *to provide with the means or opportunity* ("Enable," 2018)

4 Encourage: *to inspire with courage, spirit, or hope; to spur on; to foster* ("Encourage," 2018). See Cross et al., 2018, for a discussion of the juxtaposition of "encourage" versus "allow."

5 Promote: *to advance; to help bring (something, such as an enterprise) into being* ("Promote," 2018)
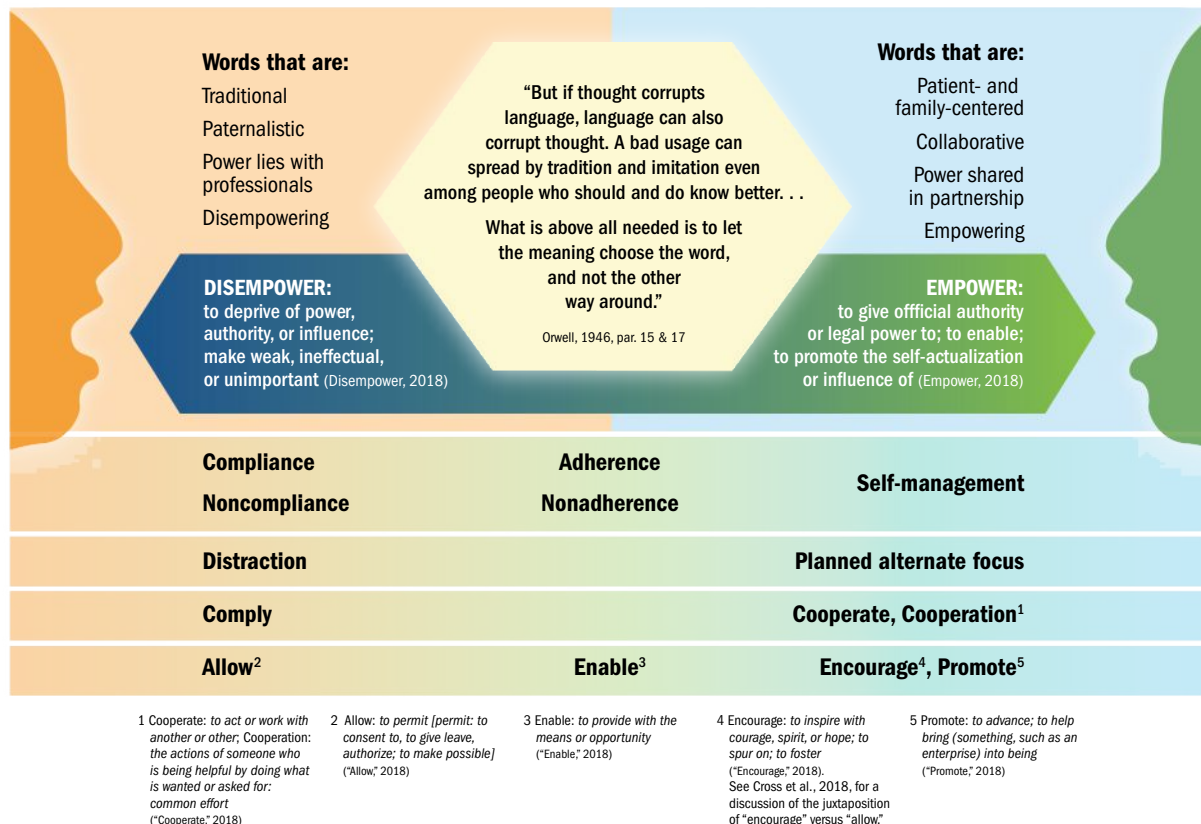
Figure 1. Power assumptions in the words we use.

P is for the Power in Words

more appropriate conceptual framework for the range of behaviors patients must perform on a daily basis in managing life with diabetes, an approach that has been described as a patient empowerment model. Though self-management, as a term, has been adopted by many in the field of diabetes, including the American Diabetes Association (Glasgow & Anderson, 1999), adherence continues to be more widely used in the general medical literature.

Though the terms compliance/noncompliance and adherence/nonadherence have received the most attention in the medical literature, other words may also be identified as having connotations of power that align more with a paternalistic viewpoint and less with the values and principles of patient- and family-centered care (see Figure 1).

In a previous Child Life Alphabet article, "V is for Volition," Mohl and Goldberger (2014) touched on this in their examination of the distinctions between the terms "distraction" and "planned alternate focus" in describing child life procedural support interventions. The authors explained that by engaging children's volition in the process of identifying coping strategies, child life specialists transform distraction into planned alternate focus. They argued that the term distraction holds the professional at the center of care with the patient as a passive recipient, while the term "planned alternate focus" positions the patient and family as active agents at the center of their experience. In choosing the term "planned alternate focus," we can communicate more clearly our fundamental goal of empowering children and families to gain "a sense of mastery that will carry over into future challenging situations" (Mohl & Goldberger, 2014, p. 1).

If we intend to advocate for empowering experiences for children and families and to model empowerment practices for others, we must also be intentional in choosing language that reflects our belief in the power and agency of the children and families we serve. *Meaning* has been defined as "what is intended to be, or actually is, expressed or indicated; signification; import" ("Meaning," 2018). It has an objective component (i.e., the dictionary definitions of the words we use) and a subjective component (i.e., the information the receiver connects to the words we use). Our control of the message we intend ends with the words we choose. Once the word or phrase leaves our mouths, our pen, or our fingertips on a keyboard, it is interpreted by the listener/reader who attaches meaning to the sounds they hear or the words they see, and who infers meaning through the lens of their own experiences, knowledge, beliefs and emotions.

Words such as compliance, noncompliance, comply, distraction, and allow hold objective and subjective meanings that reinforce the traditional, paternalistic view of power in the hands of the professional as authority and expert. To move away from words that align with the professional-centered paradigm toward words that truly reflect the values and principles of patient- and family-centered care requires us to consider both the definitions and what meanings may be inferred by others from the words we choose. By choosing words that position patients and professionals in a more neutral context, such as adherence and nonadherence, and those that position patients and families in empowering contexts, such as self-management and planned alternate focus, we will communicate more clearly our own beliefs and attitudes toward the children and families we serve. 🏃

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Teddy bears are provided to all children attending the Pediatric Evening of Remembrance, generously donated by Trudi Bears

Redesigning the Pediatric Evening of Remembrance

Teresa McGinley, MA, CCLS
YALE NEW HAVEN CHILDREN'S HOSPITAL, NEW HAVEN, CT

Losing a child is surely one of the most difficult experiences a child life specialist will support a family through in the hospital environment. This intense, emotional experience does not end when the family walks out of the hospital doors. Rather, the family's grief is ongoing, and their relationship with the hospital and its staff may continue as well. After having spent significant time working with a child or family, child life specialists may find themselves wondering how the family is processing their grief or may feel emotional themselves regarding the loss.

At Yale New Haven Children's Hospital, the child life department has a special role in providing ongoing bereavement and emotional support to families through the hospital's Annual Pediatric Evening of Remembrance. The hospital's interdisciplinary Evening of Remembrance Planning Committee is led by a child life specialist and consists of staff members from the child life, social work, spiritual care, patient relations, nursing, family resource, and language services departments.

In previous years, the format of the evening included a sit-down ceremony, during which parents and staff members gave speeches, performed readings and

recited poetry, and children's names were read aloud. Siblings who attended went to a separate room outside of the auditorium and spent time engaging in play with child life specialists and hospital volunteers. The redesign of the Pediatric Evening of Remembrance event was prompted by direct feedback provided by staff and families stating that the event was somber and did not lend itself to siblings being present. In addition, it was discovered that staff members were discouraging families from bringing siblings to the event based on their experience with the old format. In discussions of redesign, one goal was paramount: ensuring that the event was appropriate for and beneficial to adults and children alike. Ideas for the new format modeled child life bereavement support interventions, which are often targeted for both caregivers and siblings. In addition, the aim was for families to remain together throughout the evening and to create a sense of community between the different families attending the event.

The event now begins with one hour of interactive, therapeutic activity stations for both adults and children to participate in together. The committee drew on the expertise of the Certified Child Life Specialists, art therapists, and music therapists employed at Yale New Haven to develop family-friendly activities simple enough for siblings to complete, with accompanying layers of meaningful, therapeutic dialogue for the adult family members in attendance to participate in. The theme for the activities and each year's event is derived from a developmentally appropriate children's book, selected by the child life specialists. Each family takes home a copy of the book with them from the event. In making adjustments to the event, the committee knew families would still be expecting some type of formal ceremony to honor their child. The ceremony was condensed to 20-30 minutes in duration. It includes a bilingual gathering and reflection of the theme presented in the year's selected book, a reading of each child's name, and presentation of a communal piece of art: a song, a video, or a written piece that has been created by all of the attendees at the event during the activity station session. Following the ceremony, families are invited to return to their activities, enjoy refresh-

Specific Activities

Activities provided at Yale New Haven Children's Hospital Evening of Remembrance are derived from the specific talent/specialty of the child life and Arts for Healing staff. A child life specialist is present at each station to facilitate. Examples include:

- **Memory/Thought Stones:** Families are encouraged to select a memory or words and phrases that represent their child. These are written on paper and affixed to a small, clear stone that families can easily carry with them.

- **Bookmarks** reflecting quotes/themes from the book *The Invisible String*. Families select passages from the book and have the opportunity to design their own bookmark.

- **String Painting Activity:** Families take a string, dip it in paint, and walk their string across a large array of canvases, making a design. Their string represents their family or child. By the end of the evening each canvas has been touched by the strings of every family, connecting them all together.

- **Heartbeat and Voice Recordings:** Music therapists assist families in recording their heartbeats and short voice recordings. These recordings are then compiled and arranged together to allow the music therapists to use them in performing an original song during the ceremony.

- **Weaving Loom:** A local artist assists families in selecting a textured material to weave into a community piece on the weaving loom.

- **Hammered Dulcimer:** Children are invited to play this instrument. The striking of the mallet is often therapeutic, while the sound produced is calming and mellow.

- **Wire Family Tree Activity:** This activity includes families constructing their own family tree out of wire. Each bend in the wire can represent a branch of their family, with the options of adding beads to represent each family member.

- **Jewelry Making:** Varieties of beads are provided for families to design jewelry. For children, there is an option of selecting the colors of beads based on the emotions they are feeling.

Redesigning the Pediatric Evening of Remembrance

ments, and spend some time interacting with other families, staff members, or community resource representatives in attendance.

Formal evaluations were provided to staff members who attended the redesigned event to gain their feedback regarding the new format. Feedback specifically asked staff to rate both the length of the activity session and the formal ceremony on a Likert scale ranging from too short, to appropriate length, to too long. Additionally, staff rated individual activities on a Likert scale measuring how meaningful the activities appeared to be for families. Finally, staff members were provided an opportunity to provide open-ended responses. Responses indicated the activity session and formal ceremony were both appropriate in length, although some suggested expanding the activity session even longer than one hour in duration.

> ### Soon enough, we were able to share our stories and discuss our beautiful children. I didn't even realize we were both crying. I never would have been able to approach her and talk about my son had we not been placed together in that setting.

Initially, the committee was unsure of how families would respond to the drastic change of format. Although there has not been a formal evaluation provided to the families attending the event, informally, these families have expressed overwhelmingly positive reactions to the change. Families have mentioned that the hour of activities allowed them the opportunity to meet and speak to other families with a shared experience in an open, welcoming and supportive environment. One attendee stated,

"The pressure of the situation was off. Me and this other woman both were working on creating a wire tree to represent our child. We started talking about how to twist the wires and which color beads we would use in our creations. Soon enough, we were able to share our stories and discuss our beautiful children. I didn't even realize we were both crying. I never would have been able to approach her and talk about my son had we not been placed together in that setting. I asked to be invited again next year."

Another parent said,

"I was so nervous to bring my 5-year-old with me to the event this year. She has struggled so much with losing her sister and I just didn't want to risk her experiencing any type of pain like that again. I had not been good with talking to her about her sister. I just didn't know what to say. Shortly after arriving, she pulls me over to a table with her. She tells me 'Look Daddy, I'm making a thought stone for Jenna so I can hold it and think of playing and laughing with her. Isn't is so pretty? I think she'd like it!' I almost collapsed right then and there. She benefitted so much from being able to talk about her sister and make something for her. I was blown away."

The committee has continued to plan the Pediatric Evening of Remembrance in this format, offering families interactive bereavement activities with a Certified Child Life Specialist present at each station to support families through this grief experience. The event continues to evolve with increasing participation from community resource organizations and various volunteers and sponsors dedicated to continuing to improve this event for families. For example, the Hole in the Wall Gang Camp Hospital Outreach Program now partners to offer a station at the event.

Representatives from community resources have a table where they offer families resources and information. A different nonprofit organization funds the purchase of a book for each family in attendance at the event. The hospital volunteer program supports the event with dedicated pediatric volunteers, as well as the presence of three dog therapy teams, to staff a "safe play space" which allows siblings and any children in attendance to take a break from the activities and engage in play and normalization. All of the child life staff members in attendance volunteer their time for this event and Arts for Healing staff members are compensated for their time and talents.

With the change of format, the committee also participated in additional staff outreach to encourage staff members to attend the event. Staff members attending the Pediatric Evening of Remembrance are participating in the event to provide support to bereaved families. The goal of their attendance is to show families that not only do they remember those children who have died, but also that they actively honor these children. Staff

members are invited to participate in certain activities throughout the event that provide healing/therapeutic intervention; for example, writing messages of hope on luminaries displayed at the event. Staff members have expressed having difficulty withholding their emotions during the formal ceremony and have reached out to child life staff for advice. Child life specialists continue to validate that it is normal and acceptable for staff to show their emotion during the event, as families truly appreciate seeing the professionals impacted by their children in that way. The pediatric chaplain is available throughout the event to assist staff members who might need support in the expression of their emotion.

There is a separate event for staff members held at the hospital, the Staff Evening of Remembrance. During this event, professionals are able to more candidly express the difficulties or address their emotions surrounding the loss of pediatric patients. This event includes moments of reflection and opportunities for staff members to lean on one another to process the loss of children throughout various units in the hospital system.

Planning this type of event can be stressful, particularly for the child life specialist. Concerns may include whether the event is too somber or whether families feel the event is not acknowledging the devastation of their loss by having portions of the event be uplifting. There was also concern about how to make it easier for families to walk through the hospital door for the first time since leaving the hospital without their child.

The committee has found that by creating a sense of community through the interactive activities at the beginning of the event, families connect with and support one another. In addition, many families arrived eager to reconnect with the staff members who accompanied them during the most difficult moments of their lives. For staff members, being able to see a family again, or to see a sibling again, and tell them "I always remember your child; your brother; your sister" is something invaluable to provide to families. The emotion of the night is sincere, often raw, and sometimes overwhelming, but no matter what, by the end of the evening it serves to unite a room full of people in the most special and significant way.

RESEARCH CORNER

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CHILD LIFE WORK AND QUALITATIVE RESEARCH:
A Perfect Match

As a graduate student in the 1990's, I fell in love with qualitative research. My first introduction was reading Barrie Thorne's *Gender Play: Boys and Girls in School* (1993), detailing her ethnographic research focusing on fourth and fifth graders in their world of the classroom and school playground, and how intersections of race, socio-economic class, and gender help shape childhood experiences. As I read on, I could see myself on those playgrounds with the kids, could remember back to my own experiences playing with friends in school, and remember who controlled the *cool* spaces, and who was ostracized from their peers and *why*. I could vividly picture the playgrounds Thorne described, feeling the dirt at my feet as I smacked the ball around the pole in the tetherball pit. The idea that I could feel so connected to people's stories was powerful, and that feeling has never left me. I did not know research as a process could be *this* fascinating. As I was assigned and read more qualitative research throughout graduate school, it brought me into the living rooms and the work and play spaces of adults, families, and children. To borrow from the movie *Jerry Maguire*, qualitative research "… had me at hello."

As I began teaching child life students and integrating qualitative research as a process into my classes, I realized the power of capturing the voices of child life specialists, patients, siblings, and parents and caregivers in my scholarship. I wanted my students to fall in love with this research methodology, and I encouraged this by discussing my experiences doing this kind of research. As I taught the key concepts and methods of qualitative research, the powerful connections between the skills of qualitative researchers and the skills, roles, and responsibilities of child life professionals began to clearly unfold. For this Research Corner article, I would like to discuss some of those research concepts and essential skills and how they connect so well to the daily work of child life.

The clinical skills of a child life specialist fit beautifully with the skills necessary for a qualitative researcher, including being able to **sharply observe your surroundings (observation)**. Daily, as child life professionals, you help patients and their families understand the world of healthcare by stimulating sensory experiences. As a qualitative researcher, you utilize all of your senses during your observation of people in their natural setting, so you can teach children to do what you know so well. In both realms, you record in detail what you are witnessing—doing so objectively—yet you are also called upon to *interpret* what you are seeing, to help others gain an understanding of what is going on in the setting you are studying. In child life work, you do this every day. You are acute observers of body language, watching for subtle aspects of non-verbal communication, as you work to interpret what a child may be thinking, worrying about, and questioning. In your work, you are called to interpret what a child could be thinking or feeling to medical and other psychosocial team members, so observation is an essential skill in your daily work and these skills mirror the work of a qualitative researcher.

Skilled observers also work to **learn the language** of the people they are studying, as you do in child life. You build on your awareness and gather details of children's and family's lives. In child life, you capture the dailiness of each patient's and family's experiences, and this is what we do as qualitative researchers. You immerse yourselves in these settings to help build trust and rapport, and work to foster an in-depth and rich understanding of their lives as patients.

My first attempt at qualitative research was for my doctoral dissertation. I was a graduate assistant in student affairs throughout my doctoral program. I began to witness the difference in the experiences of two women in our office who were trying to become parents. One was heterosexually married, very open about her path towards parenthood, sharing updates and her excitement, and she became pregnant. The other woman was in a lesbian relationship, and was not open about her own path. She had disclosed to me that she was dealing with infertility as she attempted to become a parent via

donor insemination. Observations of real-life experiences can often lead to a research study (the beauty of grounded theory), whether qualitative or quantitative. As both women shared their experiences of parenthood, it began to become glaringly obvious how different their paths to parenthood were: One was openly excited and sharing, and the other was not quite ready to "out" herself in her workplace while having to be incredibly intentional in her goal to be a mom. This led to me interviewing 10 lesbian couples who became parents together in the context of their current relationships, and who utilized donor insemination. To learn more about the parenting process for these families, I was invited to a lesbian mom's support group in my community, where I was able to introduce myself and share my research idea. What I learned from these women, and as I completed two focus groups and interviews with each couple, was that there were issues surrounding the intentionality of their path to parenthood, including legal issues and decisions about who would attempt pregnancy first, how to navigate the often complex process, and many other aspects of navigation. As a researcher viewing this topic through the privileged lens of heterosexuality and as a non-parent, I had a lot of work to do to understand the language of my participants. I carry these early experiences with me every day in my work, to remember the importance of doing my best to understand what and whom I am researching.

Interviewing skills are essential in qualitative research: asking relevant, open-ended questions that are not leading. Again, this is a skill of child life work, as you ask questions of patients and families that are created *with thought*. The questions you ask are done with great care, to ensure they are developmentally appropriate, sensitive, yet probing so you can help patients understand the healthcare experience. It is not a far leap to take these kinds of interview skills and translate them to the world of research, where carefully crafted questions are an integral part of solid research design. You probe for further information, as do qualitative researchers needing additional clarification for a question posed to participants.

Facilitating focus groups, another tool used in qualitative research, is also not a far leap from child life work. Many of you facilitate a number of groups, including sibling support groups, bereavement groups, and parent advisory teams. This is a tool already familiar in your child life profession. In order to successfully facilitate focus groups, you need to be a skilled moderator, knowing how to sensitively handle tougher topics, making sure every participant has a voice, and ensuring participants feel safe. As child life professionals, you already are skilled moderators as you advocate for children's voices to be heard, making sure they feel safe in the healthcare environment. Having a plan is important (just like you do in planning child life interventions), as is ensuring that participants understand their role in a research study (as you do every single day helping children to understand their role in their own healthcare experience).

Case studies are often done in qualitative research, providing an in-depth look at a particular family, phenomenon, community, or institution. We delve deep in case studies and you delve deep in understanding the children and families you work with in child life. You consistently ask yourselves, "What can I learn from this family?" in the same way I ask, "What can I learn from this study?" to advance and/or validate lived experiences.

Child Life Work and Qualitative Research: A Perfect Match

Ethnography, a form of qualitative research, often uses case studies to place us at the center of who/what we are research-ing. Is this not what child life workers do every single day? You place yourself at the center of your patients and their families to learn and understand their story—so critical in the daily work you do. A great example of an ethnographic study that is relevant to child life work is a book I assign in my qualitative research class, Annette Lareau's (2011) *Unequal Childhoods: Class, Race, and Family Life*. Lareau shares very detailed case studies of families she and her research team spent time with, exploring the roles that race, socio-economic class, and gender have within each family system she studies. I challenge anyone to read this book and not reflect back on your own childhoods, comparing yourself to the different families highlighted. The children and their families Laureau spends time with (often staying at their houses for days at a time) are the children you work with in your various, diverse healthcare settings, so this book resonates well with child life students, as it provides a cross-section of the diversity of family life throughout the

United States. Actress, director, and producer Sarah Polley's (2012) documentary on her own family experiences, *Stories We Tell*, is another interesting glimpse of ethnography using a case study, told through the lens of Polley's siblings and parents as they examine the history of their family and explore the question that has existed throughout the timeline of their family: Who is Sarah's biological father? Although not an actual research project, *Stories We Tell* is a fascinating introduction to the unfolding stories of families that occurs in qualitative research.

In **critical ethnography research**, we take on the role of an advocate, finding ways to empower those who are often pow-erless by telling their stories as accurately as possible, without exploitation of their participation. We work to gain entry as trusted researchers in the same way you work to gain entry to the lives of patients and their families: We are the gate-keepers of doing our work in non-exploitative ways and with integrity. Advocacy on behalf of children and families, and creating a safe, trusted environment, are at the heart of child life work—a perfect partnership of these skills.

What I have discussed here is a small piece of qualitative research and is just a glimpse of the complex work you do in child life. However, I hope it serves as a tool to get your creative juices flowing and to begin your interest in this kind of rich, fulfilling research. Reflect on the stories of your patients and their families that need to be told and put in the context of the research process (with proper institu-tional IRB approval, of course—essential in all research), so that their voices are heard. Find ways to utilize qualitative research to capture the aspects of your work that can be difficult to measure: emotions, rituals, routines, feelings, behaviors, and meaning of experience, to name a few. Child life professionals have direct access to the stories of patients and their families, and sharing these voices in the research format creates a powerful partnership that can only advance what we know about patient and family experiences.

REFERENCES

Lareau, A. (2011). *Unequal childhoods: Class, race, and family life, with an update a decade later* (2nd ed.). Berkeley, CA: University of California Press.

Polley, S. (Writer & Director). (2012). *Stories we tell* [Motion picture]. Canada: National Film Board of Canada.

Thorne, B. (1993). *Gender play: Boys and girls in school*. New Brunswick, NJ: Rutgers University Press.

Supporting the NICU Preemie Family

Meaghan Andrews, MS, CCLS

In 2017, one of every ten babies born in the U.S. was premature (under 37 weeks gestation; National Center for Health Statistics: Division of Vital Statistics, 2018). It is commonly expected that the birth of a child will be a joyous occasion, filled with tender memories, precious meetings, and moments of serene bonding following a newborn's arrival. Increasingly, however, the story of many babies and families tells of a more intense, unexpected, precarious, and emotionally strenuous beginning together—in a hospital Neonatal Intensive Care Unit. Families of premature neonates find themselves very vulnerable, faced with immense stress and inundated with medical and practical concerns that can be overwhelming and potentially debilitating. In the NICU, families are given ample information on medical issues, but may need guidance with non-medical concerns such as concrete care needs, immediate or long-term developmental needs and issues, long-term sequela, or parent and sibling support needs. Understanding the unique challenges facing these families is a necessity to provide support and help them adjust to and cope with having a baby born prematurely. Child life specialists can serve as key links to empower families by connecting them with valuable resources to aid in their coping, validate experiences, and support communication with siblings. With this in mind, the following resources can assist the child life specialist in this supportive role.

REFERENCE

National Center for Health Statistics: Division of Vital Statistics. (2018). Births: Provisional Data for 2017 (report no. 004). Retrieved from https://www.cdc.gov/nchs/data/vsrr/report004.pdf

RECOMMENDED RESOURCES

Parent/Caregiver Resources: Listed resources cover topics ranging from essential NICU terms and medical information to personal stories, guidance on emotional processing, and practical tips for parenting a preemie.

■ American Academy of Pediatrics. (2017). *NICU journal: A parent's journey*. Elk Grove Village, IL: Author.
A caregiver journal that serves as a source for tips and medical terms, a record of an infant's medical information and progress, and a keepsake for memories and milestones.

■ American Academy of Pediatrics. (2017). *Understanding the NICU: What parents of preemies and other hospitalized newborns need to know*. Elk Grove Village, IL: Author.
A guide for parents on preemie needs, parenting and bonding in the NICU,

caregivers' emotional needs, and a wealth of information to help demystify the medical setting.

■ Wechsler-Linden, D., Trenti-Paroli, E., & Wechsler-Doron, M. (2010). *Preemies: The essential guide for parents of premature babies*. New York, NY: Gallery Books.
An excellent parent/professional resource that clearly presents medical and developmental information alongside personal stories, practical suggestions, coping strategies, support resources, and bonding interventions for parents of preemies.

■ Gunter, J. (2010). *The preemie primer: A complete guide for parents of premature babies—from birth through the toddler years and beyond*. Philadelphia, PA: Da Capo/June Da Capo Press.
Written by a preemie parent and OB/GYN, this book provides medical information and parents' perspectives of their emotional journeys, along with coping and self-care strategies.

■ VandenBerg, K. & Hanson, M. (2013). *Coming home from the NICU*. Baltimore, MD: Brookes.
A book preparing caregivers for the transition home. Parents learn about their baby's needs, bonding time, supporting development, and tips for adjusting to life with a preemie.

■ Driscoll, J. (2018). *Preemie parents' tips to get you through the NICU*. Allentown, PA: Lily's Hope Foundation.
Voiced by preemie parents, this brief guide offers tips on parental coping, involvement, and advocacy in the NICU, along with packing checklists, blank calendars, and journaling pages.

■ Davis, D. & Tesler Stein, M. (2013). *Intensive parenting: Surviving the emotional journey through the NICU*. Golden, CO: Fulcrum.
Focusing on the emotional aspect of parenting in the NICU: Parental feelings, issues, and concerns are explored, and personal stories to aid in processing and coping are offered.

Sibling Resources: These storybook resources provide caregivers with tangible tools to help in discussions about a baby's early birth, describe and show the NICU setting, and support siblings' processing and coping. Content and age-ranges can be adapted to meet sibling or family needs.

■ Bracci, J. and Jones, A. (2012). *Waiting for baby: A sibling visits the NICU*. Bloomington, IN: Balboa Press.
This book describes the experience of a brother's visit to the NICU and what he sees and experiences. The rhyming story uses sensitive language and accurate child-friendly illustrations. (Ages 3 and up)

■ Vitterito, J. A. & Chuzzlewit, A. C. (2012). *My brother is a preemie: A children's guide to the NICU experience*. Saco, ME: Bryson Taylor. (Additionally, a version for those whose sibling is a girl is available: Vitterito, J. A. & Chuzzlewit, A. C. (2012). *My sister is a preemie: A children's guide to the NICU experience*. Saco, ME: Bryson Taylor.)
Simple pictures and explanations offer basic information to use in talking with a sibling about a baby's medical needs or visiting the NICU. (Ages 2-5)

Specialized Resources" Supporting the NICU Preemie Family

Pankow, V. & Connelly, G. (2011). *No bigger than my teddy bear*. Petaluma, CA: Family Books.
This book explains life in the NICU through the eyes of a young child and touches on siblings' emotional experiences and concerns. (Ages 3-12)

Leibovici, D. (2014). *Waiting for Emma: A brother's story*. Norfolk, VA: Bloom.
A school-aged boy experiences various emotions and challenges as he adjusts to having a preemie sister. Language and illustrations are fairly detailed and realistic. (Ages 5-12)

Hogue, R. (2006). *Evan early*. Bethesda, MD: Woodbine House.
The sister of a preemie brother in the NICU confronts and processes many of the emotional reactions and challenges of siblings with the help of her supportive parents. (Ages 5-12)

Medical Memories. (2018). *My sibling scrapbook - NICU*. Buffalo Grove, IL: Author.
This sibling workbook includes activities to support emotional expression, increase knowledge of the NICU and medical equipment, and encourage sibling bonding opportunities. (Ages 4-12)

Amadeo, D. and Bladholm, C. (2005). *My baby sister is a preemie*. Grand Rapids, MI: Zonderkidz.
This story explores sibling's questions, emotions, and concerns, while touching on family reactions and spiritual coping. Language and illustrations are detailed and realistic. (Ages 5-12)

Child Life/Professional Resources: The following resources, as well as those in the parent/caregiver section, are recommended to advance professionals' knowledge, understanding, and ability to support preemie babies and families.

Kenner, C. & McGrath, J. (2010). *Developmental care of newborns and infants: A guide for health professionals* (2nd ed.). Glenview, IL: National Association of Neonatal Nurses.
This comprehensive textbook details developmental care practice, interventions, and standards from neonates to infants, with inclusion of family-centered care practice. Published by the National Association of Neonatal Nurses, this extensive resource is a foundational text with evidence-based and best practice standards for all NICU staff.

Now I Lay Me Down to Sleep. (2018). Services for Families. Retrieved from https://www.nowilaymedowntosleep.org/families/services-for-families/
This non-profit organization provides complimentary professional photography sessions in the hospital for families with infants at end-of-life.

Websites/Electronic Resources: Families and professionals can find valuable information on preemie and NICU resources including medical topics, support resources, care packages, coping strategies, and personal NICU stories.

March of Dimes. (2018). NICU Family Support. Retrieved from https://www.marchofdimes.org/nicufamilysupport/index.aspx
March of Dimes offers resources on a range of topics from perinatal care and infant health to complications of prematurity and infant loss. This

website also details information on research, education, and prematurity prevention efforts.

- Peekaboo ICU. (2016). Premature baby development. Retrieved from http://www.peekabooicu.com/
  This web resource provides parent-friendly information on developmental growth, care, and bonding with preemies. Resources address understanding a baby's cues and sensory needs, and the interplay of sleep, feeding, supportive touch, and environment on a preemie's development and coping.

- Hand to Hold. (n.d.). NICU family support. Retrieved from https://handtohold.org/nicu-family-support/
  This family-centered website features a blog for NICU families, a podcast on preemie and NICU topics, peer parent mentor connections, and resources for sibling support, transitioning home, and family bereavement needs.

- Hand to Hold. (n.d.). NICU now podcast. Retrieved from https://handtohold.org/resources/podcasts/nicu-now/
  This podcast series aims to support caregivers of preemies with topics on navigating the NICU, caregiver coping/mental health, parent-child bonding, supporting preemie's emotional and developmental needs, and personal parent stories and reflections.

- Graham's Foundation. (n.d.). Parent resources. Retrieved from https://grahamsfoundation.org/resources/
  This foundation for preemie parents offers an online forum for parents, personal peer mentors, and care packages designed for NICU stays, transitioning home, and bereavement.

- National Perinatal Association. (NPA) (2018). Retrieved from http://www.nationalperinatal.org/
  NPA is an association focused on education, research, advocacy, and developing best practice standards surrounding the needs of pregnant women, infants, and their families.

- Support 4 NICU Parents. (2018). Retrieved from http://support4nicuparents.org/
  This website provides information, resources, and standards of care on infant developmental care and supporting NICU families. Subject matter includes parental well-being, stressors, mental health, and where and how to find support for caregivers.

Mobile Apps: These apps supply caregivers with information on preemie milestones, tools to track medical, developmental, and feeding progress, and allow parents to journal and document information.

- March of Dimes. (2018). My NICU baby app (1.8) [Mobile application software]. Retrieved from https://www.marchofdimes.org/nicufamilysupport/my-nicu-baby-app.aspx
  This mobile app provides information on the NICU, medical terms, and common questions and needs. Features allow families to track vitals, feeding, and medical data, document bonding moments, upload photos, and connect with other families.

- Peekaboo ICU. (2017). Peekaboo ICU preemie (0.5) [Mobile application software]. Retrieved from http://www.peekabooicu.com/app/
  This app for parents educates on infant milestones, development by gestational week, medical lingo, and navigating the NICU, with features for journaling, photo upload, and customizing growth tracking charts.

- Graham's Foundation. (2017). My preemie app (2.1.0) [Mobile application software]. Retrieved from https://grahamsfoundation.org/mypreemie-app/
  This caregiver app includes information on preemie developmental issues and parenting concerns with features for journaling, growth tracking, to-do lists, Q&As, and keepsake ideas.

Meaghan Andrews has been a child life specialist for over 11 years and has worked with a variety of populations; most recently, she started a NICU program at Lucile Packard Stanford Children's Hospital. She is also the parent of former 27-week-old twins and was a NICU parent for 3 ½ months. Her knowledge is garnered from both professional and personal experience, as well as her volunteer work as a NICU Family Advisory Board parent and NICU parent mentor. She can be reached at meaghan.andrews@gmail.com.

Child Life Focus

ABSTRACT

Chronic illnesses can affect individuals for their entire lives. With today's medical advances, many children with chronic illness reach adulthood. As children with chronic illness age, they become responsible for their own care. Transitioning to self-management of care can be difficult, and without the proper support, unsuccessful. This article examines the many challenges adolescents face while transitioning to self-management of care and proposes how child life specialists can support this process and the patients, families, and medical providers involved in the transition. Future research is needed to examine the efficacy of the purposeful integration of child life specialists into care teams for adolescents transitioning to self-management of care.

The Role of Child Life Specialists in the Successful Transition to Self-Management of Adolescent Chronic Illness

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Introduction

Many adolescents in the United States live with chronic illness. These children have the same developmental needs as other children; at the same time, they have additional hurdles in their development due to the demands or challenges associated with the chronic illness (Rollins, Bolig & Mahan, 2005). During adolescence, youth transition from child-centered care, where guardians are responsible for the monitoring and treatment of their conditions, to adult care where patients are responsible for their own needs. As a result of medical advances, 90% of all children who have a chronic illness reach adulthood; thus, about half a million adolescents undergo this transition each year (Hergenroeder, Wiemann, & Cohen, 2015). While the process of transition to self-management can be difficult and is often unsuccessful, researchers and practitioners have identified strategies and factors associated with successful transitions into adult care (Gabriel, McManus, Rogers, & White, 2018; Hepburn et al., 2015; Nakhla, Daneman, To, Paradis, & Guttmann, 2009; Northam, Lin, Finch, Werther, & Cameron, 2010). Successful transitions involve continuous and uninterrupted delivery of quality treatment and care, prevention of adverse health outcomes, and low levels of added anxiety and stress. As such, the expertise of

healthcare professionals, especially child life specialists, can ease the process and improve transition outcomes. In order to provide the best support for adolescents transitioning to self-management of care, understanding the accompanying challenges and the key components to successful transitions is critical. By better understanding youth's needs, child life specialists can support adolescents' transition to self-management by focusing on timing, planning, individual knowledge base, identity development, autonomy, guardian/child conflict, and readiness for the adult healthcare system.

Transition

Transition can be defined as adolescents' and young adults' purposeful and planned movement from the pediatric child-centered healthcare system to the adult healthcare system for the monitoring and treatment of chronic medical conditions (Lewis, 2013). It is not merely a switch from a pediatric to adult provider, but rather a complex process that must take into account the developmental course of adolescence. Therefore, child life specialists can use their backgrounds in child development to aid in the transition to self-management of chronic illnesses for adolescents.

Transition for adolescents with chronic illness has been a topic of interest and concern for years. In 1985, the U. S. Surgeon General C. Everett Koop noted that the topic was not adequately addressed, convening a conference focusing on transition titled "Growing Up and Getting Medical Care: Youth with Special Health Care Needs." In 1993, the Society of Adolescent Medicine published a discouraging paper noting little improvement in transition success, urging for increased attention and progress (Lewis, 2013). Transition of adolescents with chronic illness continued to be a hot topic, and in 2002 the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians–American Society of Internal Medicine convened and released a consensus statement promoting the recently established 2010 Healthy People national objective. This objective stated that by 2010, all physicians treating adolescents with chronic illnesses should understand the reasoning behind transitioning to self-management of care, know how to successfully facilitate the transition, and be able to identi-

fy the optimal time for this process (American Academy of Pediatrics et al., 2002).

Challenges with Transition to Self-Management of Care

The American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine (2002) state that the goal of a successful transition to self-management of care is to provide uninterrupted, quality healthcare that is developmentally appropriate for an individual as they move from adolescence to adulthood in order to maximize potential and lifelong functioning. A study by Northam et al. (2010) indicated that one in three adolescents fail to transition successfully due to interruption in care, inadequate level of quality of care received, or negative health outcomes and high stress or anxiety. Challenges such as the timing and planning of transition to self-management of care, general knowledge of the patient, decreased treatment adherence and the adoption of risk behaviors, desire for autonomy and identity development, guardian/adolescent conflict, and the readiness of the adult healthcare system have all been identified as factors affecting transition to self care (Lewis, 2013). Fortunately, healthcare professionals, including child life specialists, can help adolescents navigate the transition and ameliorate some of the challenges they face, improving the likelihood of a successful transition. By looking at each of the previously mentioned major challenges adolescents with chronic illness face, solutions can be developed to address these concerns and support individuals on their journey.

Timing. Adolescence is a time marked by biological, cognitive, social, and behavioral changes. It is important to note, however, that many of the changes that happen in adolescence do not happen at the same time. While individuals may appear mature, adult-like, and ready to take on certain responsibilities, they may still be more child-like in others respects (Steinberg, 2014). Therefore, it is important for practitioners to look at both the adolescents' development holistically as well as specific aspects of development when determining the appropriate time frame for transitioning to self-management of care. For example, Piaget's (1952) framework of cog-

nitive development identifies distinct stages of psychological development and levels of understanding. This has been shown to be useful for outlining adolescents' understanding of their illness; however, an individual's experiences with their condition can also lead to the acquisition of specific knowledge and advanced reasoning abilities related to their condition and treatment regardless of their developmental stage (Rollins, Bolig, & Mahan, 2005).

Advanced planning for transition is a necessity. Well-planned transitions to self-management of care are more likely to result in positive outcomes compared to those with little planning (Gabriel et al., 2018). Ninety percent of surveyed practitioners recommend at least one year of planning prior to beginning transition, as this results

in fewer adverse health outcomes and gaps in medical care (de Beaufort, Jarosz-Chobot, Frank, de Bart, & Deja, 2010). Practitioners advise that such preparations begin in early to mid-adolescence; however, a recent study found that 65% of surveyed parents of 15 to 17 year olds had not yet discussed transition to self-management with their child, and 47% of young adults were transitioning without a direct referral to an adult provider (Egan, Corrigan, & Shurpin, 2015). While the determination of a specific age at which a child should transfer is at present arbitrary, a timely transition is imperative as many pediatric healthcare centers and practitioners are not permitted to see patients over the age of 18 (Lewis, 2013; Rollins, Bolig, & Mahan, 2005).

Timing is important, but equally important is ensuring that too much responsibility is not placed on the adolescent before they are ready, as this may lead to anxiety, decline in care, and complications. Child life specialists' background in child development make them uniquely qualified to aid in these assessments and can help ensure that the transition plan meets the developmental needs of the adolescent, encouraging a successful transition. They can be helpful in evaluating and assessing the developmental readiness of an adolescent, their understanding of their condition, related treatments and medications, their ability to verbalize needs and concerns, their willingness to comply with their treatment regimen, and their interest in taking on the responsibility and beginning the transition to self-management (Rollins, Bolig, & Mahan, 2005). Diagnosis-specific assessments such as those developed by Got Transition/Center for Health Care Transition Improvement, can be useful tools for such evaluations (Got Transition/Center for Health Care Transition Improvement, 2014; see Figure 1). Based on the results of this or similar assessments, child life specialists can work to strengthen adolescents' preparedness by identifying areas in need of more attention.

Planning. Healthcare practitioners recommend a gradual process for an adolescent's transition to self-management of care. This enables time for adolescents to practice self-management skills and build confidence in themselves while also giving guardians time to adjust to relinquishing control (Meyer,

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2014). Kieckhefer and Trahms (2000) developed the *Leadership Model for Systematic Transition of Care*, which outlines the gradual handoff of care responsibilities (see Figure 2). This model, which has similarities to scaffolding in Vygotsky's socio-cultural theory of development (1978), highlights that individuals do not assume responsibility for their own care immediately—one day being a child receiving care and the next day being solely responsible. Rather, what occurs is a gradual handoff of responsibilities. Collaboration between the guardian and child, as well as between the pediatric practitioner and future adult provider, is important to ensure that there is not a lapse in care during an adolescent's transition to self-management. It is also beneficial to have a transition coordinator in place to provide expertise, familiarity, and continuity to the process (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians, Transitions Clinical Report Authoring Group, 2011). Having a child life specialist assume this role helps to ensure that family-centered care and developmentally appropriate education are at the forefront of the transition plan.

General knowledge base. Another challenge that adolescents face is having the necessary knowledge to be successful in their transition to self-management of care. Preparing adolescents for transitioning into adult healthcare is just as important as preparing young children for upcoming procedures (Hicks & Davitt, 2018). One of the most effective coping strategies for many children is information seeking. Education about what to expect and why it is happening reduces worry, promotes empowerment, encourages self-advocacy, and improves overall quality of life. There is evidence that individuals who understand their condition and associated treatment plans display better treatment adherence because they understand the purpose behind the

interventions (Hart & Rollins, 2011). At the same time, as more information about what is happening is provided to the child, less distress regarding their illness, diagnosis, or hospitalization is experienced (Boles, 2010).

As adolescents take on responsibility for the self-management of their chronic condition, they need to be well educated about their condition and all of the necessary elements of care. Unfortunately, adolescents may lack the education about their diagnosis required to be successful. As many individuals with a chronic illness are very young at the time of diagnosis, guardians are typically the ones who are educated about the condition and how to monitor and treat it (Meyer, 2014). This knowledge is then passed down to the child secondhand through the guardians. While many guardians stay up to date with new information and techniques and communicate this to their child, direct and proactive education by the healthcare team would also be beneficial. One-on-one education has been associated with positive illness management in adolescents and has been shown to promote both confidence and capability in self-management (Forshee et al., 1998). Most of the direct education an adolescent with a chronic illness receives is reactive (Visentin, Koch, & Kralik, 2006). Adolescents receive coaching about self-management strategies while in the hospital for emergencies such as ketoacidosis; however, instruction during an emergency is not an optimal environment for learning and being able to retain what is being taught (Meyer, 2014). Integrating child life specialists into a child's healthcare team to provide information throughout their journey with their chronic illness would be an ideal strategy to meet this need. Being able to schedule a series of diagnostic education sessions with a child life specialist as part of routine clinic visits would create a setting more conducive to learning and retention.

Sample Transition Readiness Assessment for Youth
Six Core Elements of Health Care Transition 2.0

Please fill out this form to help us see what you already know about your health and how to use health care and the areas that you need to learn more about. If you need help completing this form, please ask your parent/caregiver.

Date:

Name: Date of Birth:

Transition Importance and Confidence   *On a scale of 0 to 10, please circle the number that best describes how you feel right now.*

How important is it to you to prepare for/change to an adult doctor before age 22?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)

How confident do you feel about your ability to prepare for/change to an adult doctor?

0 (not)	1	2	3	4	5	6	7	8	9	10 (very)

My Health *Please check the box that applies to you right now.*	Yes, I know this	I need to learn	Someone needs to do this… Who?
I know my medical needs.	☐	☐	☐
I can explain my medical needs to others.	☐	☐	☐
I know my symptoms including ones that I quickly need to see a doctor for.	☐	☐	☐
I know what to do in case I have a medical emergency.	☐	☐	☐
I know my own medicines, what they are for, and when I need to take them.	☐	☐	☐
I know my allergies to medicines and medicines I should not take.	☐	☐	☐
I carry important health information with me every day (e.g. insurance card, allergies, medications, emergency contact information, medical summary).	☐	☐	☐
I understand how health care privacy changes at age 18 when legally an adult.	☐	☐	☐
I can explain to others how my customs and beliefs affect my health care decisions and medical treatment.	☐	☐	☐

Using Health Care			
I know or I can find my doctor's phone number.	☐	☐	☐
I make my own doctor appointments.	☐	☐	☐
Before a visit, I think about questions to ask.	☐	☐	☐
I have a way to get to my doctor's office.	☐	☐	☐
I know to show up 15 minutes before the visit to check in.	☐	☐	☐
I know where to go to get medical care when the doctor's office is closed.	☐	☐	☐
I have a file at home for my medical information.	☐	☐	☐
I have a copy of my current plan of care.	☐	☐	☐
I know how to fill out medical forms.	☐	☐	☐
I know how to get referrals to other providers.	☐	☐	☐
I know where my pharmacy is and how to refill my medicines.	☐	☐	☐
I know where to get blood work or x-rays if my doctor orders them.	☐	☐	☐
I have a plan so I can keep my health insurance after 18 or older.	☐	☐	☐
My family and I have discussed my ability to make my own health care decisions at age 18.	☐	☐	☐

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Figure 1. Sample Transition Readiness Assessment to evaluate the understanding of an individual and identify needs. Developed by Got Transition/Center for Health Care Transition Improvement (2014). Reproduced with permission.

An adolescent needs to know about his or her treatment plan, as well as other accompanying responsibilities such as acquiring the necessary medical supplies, scheduling appointments, and dealing with and maintaining adequate health insurance in order to successfully transition to self-management.

The daily demands of having a chronic illness "must be woven into all the normative choices regarding relationships, occupations, living arrangements, and financial management" (Weissberg-Benchell, 2007, p. 2442). Youth need to understand how risk-taking behaviors can have a negative effect on their condition, as well as how their condition may affect the outcome of participating in risk-taking behaviors. Developing skills and problem-solving strategies ensures that the adolescent is able to manage their life with their chronic condition, rather than having their condition manage their life (Lorig, 2003).

Individual assessments can be used to look at the child's knowledge base in order to determine their specific needs. Establishing the knowledge base of individuals is also helpful in tracking the preparedness of the adolescent from a timing perspective, ensuring they are "on track" for being fully self-sufficient at the projected time of completion. As previously mentioned, child life specialists' background in child development enables them to conduct these assessments as well as work with the transition team to develop a course of action ensuring the adolescent is receiving the education needed to be successful.

Identity development. Chronic illnesses can also affect an individual's identity development, especially during adolescence. Hospitalizations, time spent treating the condition, frequent medical appointments, side effects from medication, physical constraints or limitations, fears, and possible guardian overprotectiveness can all impact the adolescent's sense of self (Rollins, Bolig, & Mahan, 2005). Having a chronic condition can also affect individuals' concept of their body, leading to distorted views of their body, focusing more on the specific organ or organ system affected by their illness, and knowing less than their healthy peers about the functions of the body in general (Hart & Rollins, 2011). Chronic illness poses additional developmental challenges as well. As adolescents develop and question their identity, those with chronic illnesses have the additional consideration of their illness identity and how that fits into their overall identity. For example, one study in Belgium found that young adults with diabetes who recently completed the transition to self-management reported a more negative experience if they did not incorporate diabetes
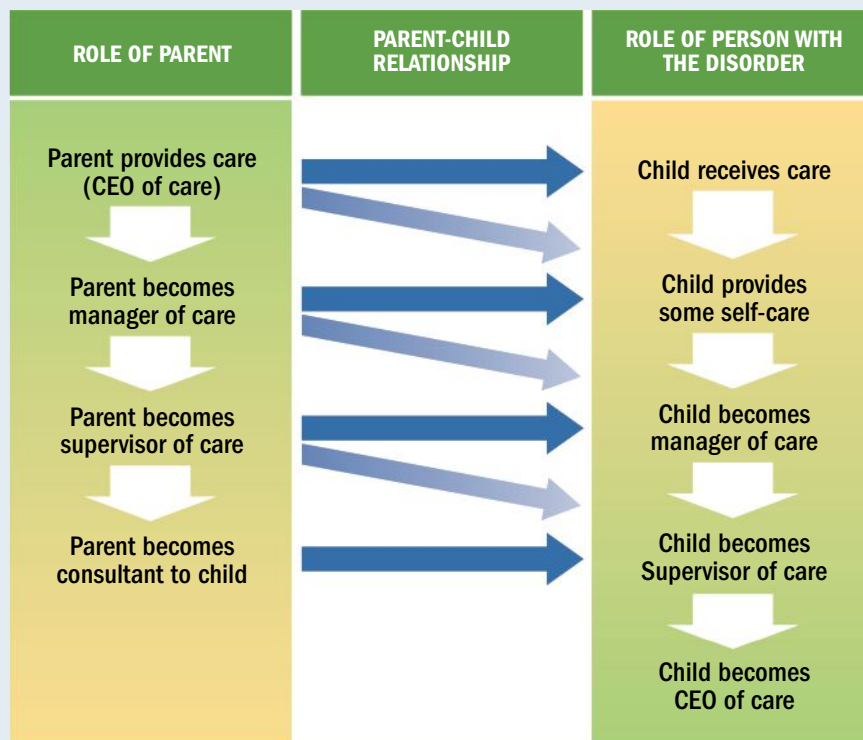

into their identity compared to those who included their illness identity into their overall sense of self (Luyckx, Moons, & Weets, 2011).

Chronic illnesses can also impact an individual's identity and self-esteem. In one study, self-esteem was correlated with positive emotional outcomes for transition to self-management (Tong et al., 2013). Adolescents with kidney disorders who have higher self-esteem experienced an increased sense of motivation and accomplishment when achieving treatment goals such as efficient dialysis, and were particularly proud of the ability to manage and "own" their dialysis treatments (Tong et al., 2013). Child life specialists can utilize developmentally appropriate self-expression activities to encourage youth to integrate their illness identity into their overall identity. They can also guide individuals to other interventions, such as diagnosis-specific camps, where they can foster relationships with peers going through similar experiences to build a sense of identity and improve self-esteem.

Desire for autonomy. Another challenge adolescents face is aligning their desire for autonomy with the care for their chronic illness. In many cases, this can be a driving force for transition to self-management to

occur. However, this can also put additional pressure on the process. Adolescents develop more sophisticated thinking, and are able to understand hypothetical situations and abstract concepts. Changes in the way teenagers think due to development impacts their ability to solve problems, plan ahead, create arguments, and address moral dilemmas. Adolescence is typically the first time that individuals logically think about politics, philosophy, religion, relationships with friends and family, the future, and what they want their life to look like (Steinberg, 2014). With more advanced cognitive ability comes a greater desire for independence and less adult supervision, and an increase in risky behaviors. While it is common for adolescents to experiment with risky behaviors, it is crucial for adolescents with chronic illnesses to understand how the effects of these behaviors relate to their health. For instance, adolescents with diabetes need to understand the impact that alcohol has on their blood sugar and how to manage these effects, as drinking increases their risk for hypoglycemia (Kakleas, Kandyla, Karayianni, & Karavanaki, 2009).

Along with the desire for autonomy often comes a decrease in treatment adherence

(Kakleas et al., 2009). Adolescents may begin to question or rebel against the rigid nature of managing their condition, be unable to understand the long-term consequences of not adhering to treatment plans, or adopt behaviors that make consistent monitoring/controlling their condition more difficult. For example, studies have shown deteriorating glycemic control in adolescents with diabetes during the transition to self-management as they begin to control certain aspects of their care without fully understanding others (Kakleas et al., 2009; Northam et al., 2010). Including adolescents in conversations surrounding their current treatment plan and any modifications to better meet their lifestyle will aid in reducing the decreased adherence, and child life specialists can assist with this process. A child life specialist can also be a "safe" person for the youth to ask questions they may not be comfortable talking about with their guardians. Similarly, child life specialists can be someone who can provide information on the impact of various risk-taking behaviors, information which may seem more intrusive or threatening coming from a guardian.

Guardian/adolescent conflict. The transition period can put stress on family relationships and possibly lead to guardian-adolescent conflict (Egan, Corrigan, & Shurpin, 2015; JDRF, 2013; Marshall, Carter, Rose, & Brotherton, 2009). Guardians and adolescents may have diverging views of transition to self-management of care. One study found that while adolescents viewed the transition as a normal part of growing up and moving on, their parents saw it as a positive step but were filled with concerns about being pushed away and unable to keep their child safe (Marshall et al., 2009). For years of their lives, guardians of children with chronic illnesses have been solely responsible for their care and treatment. Guardians' continued involvement as their children become more independent may seem like nagging, being overly strict, or questioning the child's ability to be self-sufficient. For example, in the case of diabetes management, a parent consistently checking in with questions such as "Are you low?" or "Have you checked your blood sugar?" can undermine the youth's independence (JDRF, 2013), which may lead to increased frustration in the adolescent and limit the ability to develop the skills to manage care autonomously. In another study, continued parent involvement and decreased child autonomy led to rebellion and a decrease in adherence to diabetes

care, causing deteriorating glycemic control (Kakleas et al., 2009). As a result of a teen's poor self care, guardian involvement might rise and lead to increased frustration and conflict experienced by the adolescent, creating a vicious cycle (Lewis, 2013). When child life specialists work to put the focus on strengthening the guardian-adolescent relationship during the transition period, conflict can be minimized, and this negative spiral of care can be avoided. For example, child life specialists could facilitate activities where guardian-child dyads work together to accomplish goals, or guide guardians on the use of non-accusatory language when checking in with their child about healthcare questions.

Readiness of adult healthcare system. In addition to supporting the patient and family, child life specialists can also support the pediatric and adult healthcare teams. One concern for many adolescents is that adult care facilities are not welcoming. Lowes (2008) identified that waiting rooms in adult clinics are often filled with elderly patients facing complications, such as amputations for individuals with diabetes, forcing young adults to face their potential future and poor health outcomes. Additional conversations with adolescents about treatment adherence and how close management can ameliorate complications should be included to promote these behaviors and decrease fears.

Another challenge is that adult physicians may not be prepared to meet the developmental needs of younger patients. Pediatric providers have raised concerns that their adult counterparts may not be prepared to receive the transitioning adolescent, causing delay in transition (Egan, Corrigan, & Shurpin, 2015). It is often hard to engage young adults in healthcare because their priorities lie elsewhere in their busy lives. Adult providers have also reported concerns about effectively communicating with adolescents and expressed that they wished they had more resources to use as teaching materials in their clinics for adolescents and young adults (Weissberg-Benchell, Wolpert, & Anderson, 2007). Similarly, 38% of surveyed cystic fibrosis clinics do not discuss age-appropriate health issues with their newly transitioned young adult patients (McLaughlin et al., 2008).

Child life specialists can help prepare adolescents for the experience of being a patient in an adult clinic similar to the way that they regularly prepare patients for new experiences and environments in the hospital, resulting in better outcomes and reduced anxiety (Thompson, Bennett, & Snow, 2018). Therefore, preparing adolescents for experiences and responsibilities related to adult care can reduce shock and improve comfort in these settings. Child life specialists are uniquely skilled in developmentally friendly means of communication and can help prepare the adolescents for a shift in communication style, as well as help educate adult practitioners and provide them with useful communication strategies and materials.

Conclusion

As the 2002 consensus statement reads, "Clearly, no single approach will work equally well for all young people, and the healthcare sector cannot work in isolation from the other professionals and networks that impact these young people" (American Academy of Pediatrics et al., 2002, p. 1304). However, the involvement of child life specialists in the planning and execution of transition can provide the adolescent, their guardians, and providers with support necessary for successful transition. While various interventions have been proposed, additional research needs to be conducted on the efficacy of incorporating child life specialists into adolescents' healthcare teams during transition to self-management. While this would be a sizeable endeavor, requiring substantial grants, research supports the need for such questions to be "topics of interest" as those who transition successfully have fewer adverse health outcomes and complications (Duncan et al., 2009). In turn, they should cost less to the healthcare sector in the long run as they require less interventions. A study conducted years ago found that patients who engaged in education relation to self-management of care had lower average medical costs than those who did not engage in this education (Duncan et al., 2009). Therefore, additional studies focusing on how to optimize self-management education and the involvement of child life specialists should be conducted. Optimally, such a study would be able to demonstrate the significant impact child life specialists can have on transition to self-management of care, leading to child life involvement becoming an evidence-based standard of practice. 🏃

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Edible Loose Parts: Bone Structure

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Claudia Mincemoyer (2016) says "Loose parts can be natural or synthetic." Why can't they also be edible? As we know, loose parts can be used to help prepare children for upcoming procedures and surgeries or to teach a child about a diagnosis. Before you can explain what is going wrong in the body, sometimes you first have to explain how it is *supposed* to work. Creating a larger-scale model of the structure of the bone can help facilitate conversations, invite questions, and clarify misunderstandings for children who may be receiving a bone marrow transplant. The goals behind this activity are to build rapport, to help the child learn about the structure of our bones, and have some normalizing, messy fun. This activity could be used with a patient, a sibling, or even children of an adult patient who is in need of a bone marrow transplant.

The parts of the bone that are represented in this model are the bone itself, the veins and arteries that run through the bone, and the marrow. A more complex version of this model could be made for older children and adolescents. All of the suggested materials can be substituted with other edible materials, and presenting multiple options for the child to choose from could also provide the child with an opportunity to take ownership and personalize his or her bone model.

Materials

(See Figure 1; before undertaking this activity, it is important to note any

Figure 1. Gather your supplies.

food allergies or restrictions and select materials that are safe for the child):

- Plastic spoons
- Strawberry jelly
- Twizzlers Peelers
- Loaf of bread (or other sponge-like material to represent the spongy tissue inside bones)
- Knife
- Syringe

Figure 2. Run Twizzlers through loaf to represent blood vessels.

- Photo of bone structure
- Gloves

Other Possible Materials for Substitution:

- Tortilla
- String cheese
- Hummus
- Cucumber
- String beans
- Ranch dip
- Donut
- Fruit Roll-Ups
- Gummy Worms
- Whipped cream
- Food coloring
- Frosting
- Any additional food your patient may like to use

Figure 3. Jelly represents the bone marrow.

Instructions to make an Edible Bone Model:

1. Cut the loaf of bread into thick slices. It may be helpful to do this prior to going into the room with the patient.

2. Present materials with a photo of a bone. Giving a visual representation of the actual bone structure will help the child build connections to the model they are going to create.

3. Open the loaf of bread facing up. If able, have the child hollow out the inside of the bread. This can be done using a spoon, or with your fingers.

4. Peel off strips of the Twizzlers. These will represent the veins and arteries that run throughout the bone (see Figure 2).

5. Use a spoon to spread the jelly on the sandwich. This part can be messy, so use gloves if desired (see Figure 3).

6. Close the bread.

7. Eat!
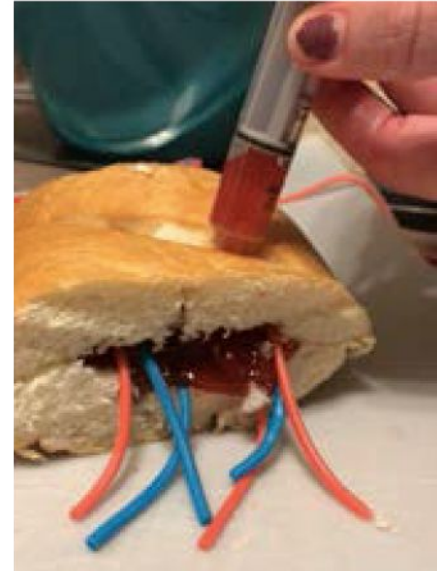
Figure 4. Demonstrating bone marrow harvest with a syringe.

Finished Product

This loose parts teaching activity can provide opportunities for enhancing a child's understanding of the bone marrow harvest and transplant processes by using a syringe to demonstrate the removal of the healthy bone marrow (see Figure 4). In this activity, allowing a child the opportunity to explore bone structure using loose parts can help a child and family create meaning out of their medical experience together, creating positive experiences and empowering the patient and family to master their environment and gain a sense of control and competence over their hospitalization (Vilas, Koch, & Passmore, 2014). 🏃

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Deep Work: Rules for Focused Success in a Distracted World

Cal Newport

"Eudaimonia" refers to the state of flourishing and fulfillment that occurs when we are achieving our full potential. As child life practitioners, we cultivate the capacity of others to realize their potential, to learn, to grow, and to cope to the best of their ability. Yet the focus required for achieving our own goals in the workplace is often under siege from an abundance of dis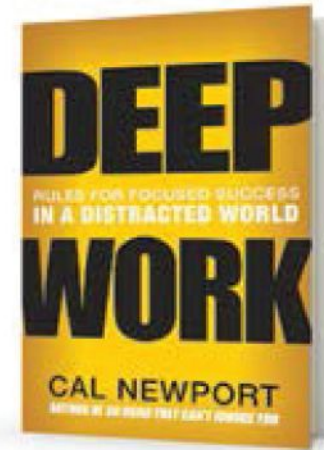tractions. In *Deep Work: Rules for Focused Success in a Distracted World*, author Cal Newport (2016) argues that the potency of distraction presents a danger of divided focus, which leads to inefficacy.

Newport's book is a nonfiction guide to cultivating a focused approach to "knowledge work" in the midst of a distraction-saturated society. The work habits discussed in the book are applicable to anyone seeking to contribute to their profession either academically (through research or education of child life students) or creatively (through devising new tools or approaches for child life interventions).

The author, a Georgetown University professor of computer science, defines "deep work" as "professional activities performed in a state of distraction-free concentration that push your cognitive capabilities to their limit" (Newport, 2016, p. 3). He explains that developing the skill of a deep work approach leads to an improved ability to master complex information and produce better results more efficiently. *Deep Work* is divided into two parts: "The Idea" (Part 1) and "The Rules" (Part 2).

The three chapters that comprise Part 1 present a mix of cultural criticism bemoaning a tendency toward "shallow work" and busyness and include examples of the work strategies of successful individuals from a wide spectrum of professions. Newport describes shallow work as tasks that are logistical in nature, not particularly demanding intellectually, conducive to being performed while distracted, and contributing little that is new or valuable to the world; the child life specialist may think of time spent organizing supplies or answering emails. Newport argues that removing all shallow work tasks completely may not be possible or even desirable, but he contends that we can change our approach to such work to reduce its impact on our productivity. For example, tracking service provision data effectively is imperative for advocating for additional child life positions, so consider if your record-keeping process could be optimized, allowing you to track data more efficiently while taking less time away from patient care.

Part 2, comprising the latter two-thirds of the book, describes four rules to follow to improve one's capacity for deep work. Each "rule," better described as a lifestyle change, is followed by examples of specific disciplines or habits to incorporate into one's adoption of the rule. Child life professionals may find Rule 2, "Embrace Boredom," particularly relevant to their practice, especially with its discussion of the importance of purposeful relaxation and productive meditation strategies. These intentional approaches to rest and rejuvenation may not only improve cognitive focus, but may help build resistance to compassion fatigue and burnout for those in caring professions.

For child life specialists whose work is largely relational in nature, perhaps the most significant gain from such work practices is an improved capacity for intentionality in our interactions.

Newport shares his personal journey of adopting a deep work mindset in the book's introduction. As a working father of two, the author is committed to keeping his evenings free for family time. By employing focused strategies to eliminate distraction and minimize the time he allocates to shallow work, Newport has been able to achieve an impressive array of professional and creative goals while maintaining a healthy work-life balance. For child life specialists whose work is largely relational in nature, perhaps the most significant gain from such work practices is an improved capacity for intentionality in our interactions. An

intimidating to-do list or a phone that constantly pings with new email alerts can rapidly detract from the efficacy of our interventions.

While research studies and articles are referenced throughout Part 1 of *Deep Work*, the practical rules section interweaves captivating stories of the personal journeys of such celebrated achievers as J.K. Rowling and Bill Gates. The arguments made in *Deep Work* are compelling, but overall, the book could be enhanced by supporting evidence for the efficacy of the suggested strategies, beyond the anecdotal. Despite its intellectual subject matter, *Deep Work* is an accessible and entertaining read. A bit repetitive in places, some of what Newport advises may strike the reader as mere common sense. Other sections leave one thinking, "Why did no one tell me this before?"

Child life teams are frequently understaffed, not only with large caseloads, but often with a wide range of additional duties beyond direct patient care. Besides what is expected of us by our coworkers, supervisors, and those we serve, we have our own goals for improving the care environment, often big-picture projects we wish we had more time to focus on. While our workday schedule may be at the mercy of clinic appointments or emergency department procedures, we can still incorporate some of the attitudes detailed in *Deep Work* to maximize our efficiency during those rare times when we find ourselves able to sit down and tackle the newsletter, presentation, or budget proposal we've been meaning to finish. One of those strategies is making use of smart tools to enhance efficiency. Are you taking advantage of the smart phrase options and other built-in shortcuts within your hospital's electronic charting software to streamline your documentation process? Another strategy has to do with cultivating the expectations of those you work with regarding your availability. Are you feeding the expectation that you will be able to respond immediately to emails, or are you communicating that your time is valuable?

Whether you are seeking increased time for learning new things, improved capacity for focus on creative projects, or enhanced energy to bring to your interpersonal work, deep work strategies will support your growth. The approaches to productivity and creativity detailed in *Deep Work* are relevant to any professional with a drive to improve their personal skill set or to contribute toward progress in their field. 🏃

REFERENCE

Newport, C. (2016). *Deep work: Rules for focused success in a distracted world*. New York, NY: Grand Central.

Correction

In the Fall 2018 issue of *ACLP Bulletin*, the article reviewing the book *Handbook of Medical Play Therapy and Child Life* incorrectly attributed the 2014 study of the state of play to the Child Life Council; it should have been attributed to Deborah Vilas, MS, CCLS, LMSW, who undertook the study for the organization. The correct citation should be:

Vilas, D. (2014). Report on findings of play practices and innovations survey: The state of play in North American hospitals. Rockville, MD: Child Life Council.

The editors of *ACLP Bulletin* regret the error and offer our apologies to Deborah Vilas.

Finding My Way: Strategies for Entry into the Child Life Profession

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Discovering the child life profession midway into my undergraduate studies, I became driven to figure out ways to pursue child life while enrolled in a program that did not have any connection to the field. Upon reflection, I have identified strategies that have allowed me to be present in the child life world– even as an undergraduate with a non-child life degree. The four strategies I have determined as guiding me to a greater understanding of the child life profession are as follows: hospital involvement, using class assignments to learn about the profession, involvement in the Association of Child Life Professionals (ACLP), and finding mentors within child life.

Getting into a Hospital

In order to logically confirm my career path, I first chose to shadow a child life specialist. This was an opportunity for me to ask questions, learn as much as possible, and engage with the child life profession. After completing multiple

An additional advantage of volunteering was that, although I was not an active participant in child life services, I still had the opportunity to indirectly observe some of the responsibilities of a traditional child life specialist

... as a member of the Leadership Scholar's Program at my university, my capstone project involved interviewing leaders in my future profession about leadership in the field.

shadowing experiences, I was able to say with confidence that I would pursue a child life career. If shadowing a child life specialist is not an option, another way to become involved is to start volunteering in a child life department, which I did as well. Doing so, I got to know my supervisor, who is a child life specialist; she served as another resource of whom I could ask questions about the child life profession. An additional advantage of volunteering was that, although I was not an active participant in child life services, I still had the opportunity to indirectly observe some of the responsibilities of a traditional child life specialist.

Classroom Opportunities

Next, as a member of the Leadership Scholar's Program at my university, my capstone project involved interviewing leaders in my future profession about leadership in the field. Reaching out to distinguished leaders was intimidating, but their extensive knowledge of the profession helped me to understand child life better than I had before. I spoke with people who have won awards in child life, who currently serve on the ACLP board, who are and were committee chairs and members, who oversee child life programs on the undergraduate and graduate levels, who are participating in up-and-coming research within child life, and who overall, do a lot of great work within their hospitals. This allowed me to determine key characteristics of successful leaders and build connections and networks within child life where I previously had none.

Involvement in the Association of Child Life Professionals

During the first of my interviews, I was encouraged to take up membership in ACLP and advised that students can be selected to serve as committee members within ACLP, which happened to be taking applications at that time. During the

second interview, I was encouraged to attend the annual child life conference, where I could learn from the various sessions and meet child life specialists and students from all over. With the encouragement of those I interviewed, I did both. Attending conference knowing no one forced me out of my comfort zone to approach people who could be inspirational and beneficial to my understanding of child life.

In applying to serve on an ACLP committee, I never expected to be selected as an undergraduate student with minimal experience. But, currently, I am serving on the Volunteer Recognition and Engagement Committee, whose purpose is to recognize volunteers for their service and encourage involvement and volunteering. Within this committee, I have taken on an active role by working to develop a manuscript for those interested in volunteering at conference. Overall, having membership in this committee, I have already become more exposed to child life and those who successfully demonstrate leadership.

> ### *Leaders are found within all levels of the child life profession: students, those in their first year of practicing, those in academia, and those who serve on the board. Any child life specialist has the potential to be a mentor to someone else.*

Recognizing Potential Mentors

The aforementioned has helped me to reach this final step: identify people that can serve as mentors. Many of the leaders with whom I have spoken increased my understanding of what is required and recommended for me to accomplish before graduate school. I have stayed in contact with many of them, asking questions and following through on their advice. Notably, I have taken on a mentee role, allowing for the identification of how I should approach writing for *ACLP Bulletin*. This has opened my eyes to opportunities for students within child life and given me the opportunity to grow my skills for future leadership.

Overall, in talking with six child life specialists who have varying roles within child life, I saw how each of these leaders demonstrated leadership, even before, or without, achieving an official leadership title or receiving an award. Their accomplishments may have set them apart at some point in their careers, but their roles as leaders began early. Leaders are found within all levels of the child life profession: students, those in their first year of practicing, those in academia, and those who serve on the board. Any child life specialist has the potential to be a mentor to someone else.

Although I still have a great deal to accomplish before becoming a child life specialist, I have begun to take necessary steps and make plans for my future in child life. My hope is that others will find these strategies to be of use and will take full advantage of every opportunity that they are given. Ultimately, I have concluded that while pursuing child life with a non-child life undergraduate degree can be overwhelming, is not impossible. I also know that coming from an interdisciplinary background will present some advantages, as well. My success, however, is reliant on what I choose to do with the resources and opportunities that I have. There is no doubt that we must work hard, but so long as we continue to actively learn about child life and be involved, success will follow.

> ### *Attending conference knowing no one forced me out of my comfort zone to approach people who could be inspirational and beneficial to my understanding of child life*

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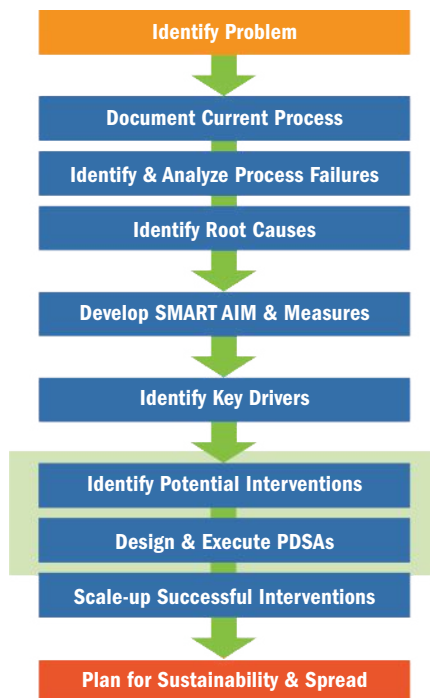
STEP 5:

Identify Potential Interventions and Plan and Execute Plan-Do-Study-Act (PDSA) Cycles

Annette Bonjour, MS, CCLS
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This article is part of the *Quality Improvement (QI), Step by Step* series on implementing evidence-based practice and evaluating change in the provision of patient care by child life professionals. Quality improvement initiatives are defined as "changes that will lead to better patient outcomes (health), better system performance (care), and better professional development (learning)" (Batalden & Davidoff, 2007, p. 2). The improvement in the delivery of patient care is a job duty that child life specialists already practice. Child life specialists can formalize these typical job duties into a QI project in order to provide supporting evidence for their interventions with patients (e.g. effectiveness of a new expressive activity).

Identify Problem

Document Current Process

Identify & Analyze Process Failures

Identify Root Causes

Develop SMART AIM & Measures

Identify Key Drivers

Identify Potential Interventions

Design & Execute PDSAs

Scale-up Successful Interventions

Plan for Sustainability & Spread

The previous four articles in this series discussed the introduction to QI and problem identification (Birkett & Froh, 2018), the analysis of process failures and root causes (Cassani & Bonjour, 2018), the development of SMART (Specific, Measurable, Assignable, Relevant, and Time Bound) aims (Calvert, 2018), and the identification of key drivers (Wittenberg & Jones, 2018). This article will address step 5 in the QI process: identify potential interventions and plan and execute Plan-Do-Study-Act (PDSA) cycles. Laying the foundation for improvement by creating a thorough improvement plan as outlined in the previous articles is crucial for a couple of reasons, including avoiding incorrect assumptions about the cause of a problem and wasting time "fixing" things that are

not actually related to your problem or goal (Luzader, 2014).

In a previous article, key drivers were described as the factors, or project activities, needed to accomplish the SMART aim. In the example used in that article, the identified SMART aim was to "increase the number of Psychosocial Risk Assessments in Pediatrics (PRAP) completed on patients seen by child life specialists each day from 0% to 50% by 7/1/2018" (Calvert, 2018, p. 49). Using the following two key drivers: 1) centralized location in the electronic health record (EHR) where PRAP score is documented, and 2) standardized assessment tool available for all staff, the next step is to identify interventions (Wittenberg & Jones, 2018).

Step 5: Identify Potential Interventions and Plan and Execute Plan-Do-Study-Act (PDSA) Cycles

Project Name: *Standardized Assessment for Child Life Specialists*   **Project Leader:** *Annette Bonjour*

SMART AIM

Child Life will increase the number of Psychological Risk Assessments in Pediatrics (PRAP) completed with initial chart note from 0% to 50% by 7/1/18.

GLOBAL AIM

Improve patient coping by stratifying child life services according to patient need.

KEY DRIVERS

Centralized location in electronic health record where PRAP score is documented

Engaged child life specialists

Standardized Assessment tool available to all staff

INTERVENTIONS

PRAP included in assessment section of child life templates in EHR

Provide small group and individual training session on using the PRAP

Provide education on how to access PRAP database on iPad and computer

Develop smart phrases for EHR documentation of PRAP

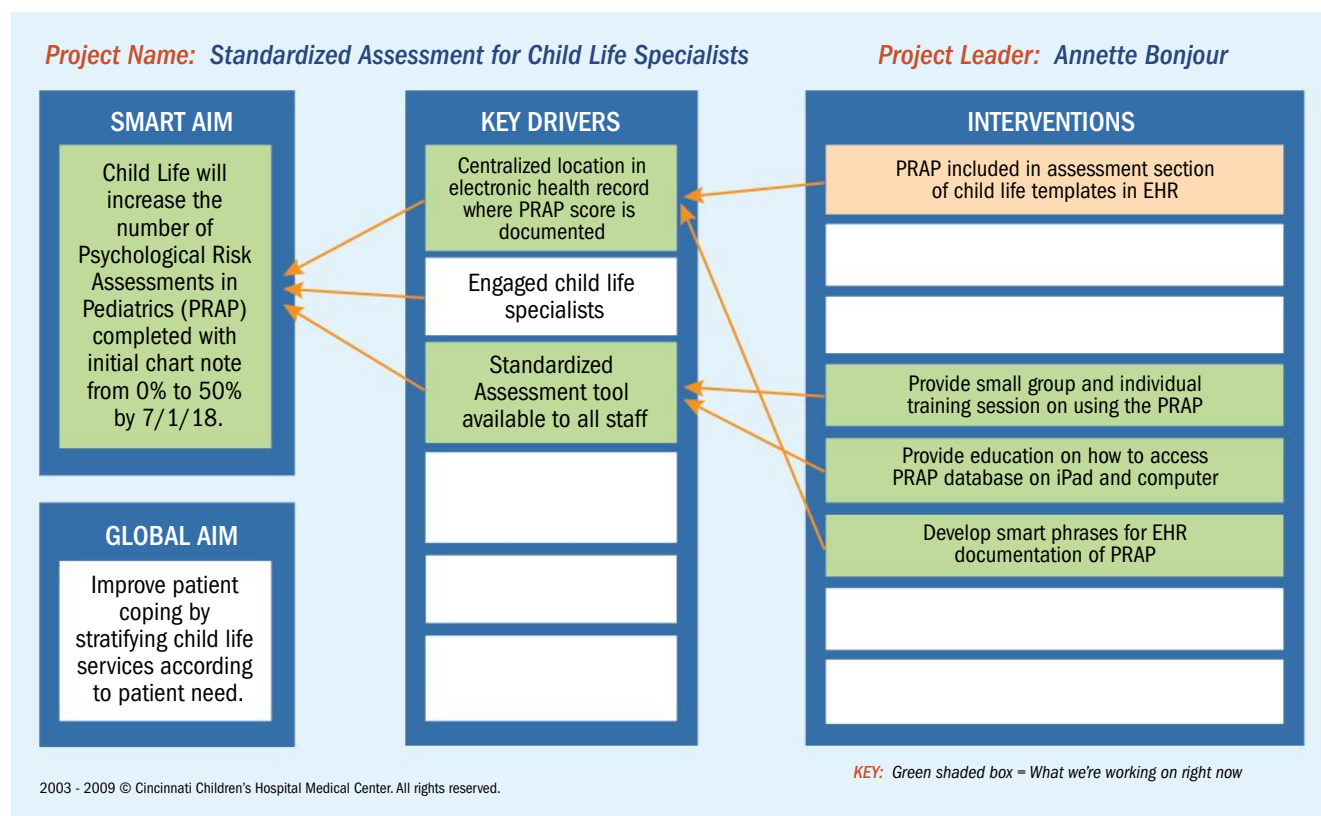*KEY: Green shaded box = What we're working on right now*

Figure 1. Key Driver Diagram

A key driver diagram demonstrates the relationship between the SMART aim, key drivers, and interventions (see Figure 1). The next step is to develop a list of interventions that will address the key drivers and aid in accomplishing your SMART aim. When following Langley et al.'s (2009) Model for Improvement, there are three key questions to drive the improvement process: 1) What are we trying to accomplish? 2) How will we know that a change is an improvement? And 3) What changes can we make that will result in an improvement?

The SMART aim on the key driver diagram in Figure 1 addresses key question #1. The interventions describe how one will make a change that will

result in an improvement. Creating smart phrases to be used when documenting the PRAP score in the EHR and building a PRAP section into the EHR child life charting templates are the interventions directly related to the first key driver listed, "centralized location in EHR where PRAP score is documented." These interventions were thought to help child life specialists when documenting the PRAP in the EHR because the PRAP section in the charting template would likely serve as a visual reminder to include the PRAP in their documentation, and the smart phrases would help by reducing the time needed to document information regarding the PRAP assessment for each patient.

The interventions in the third column of Figure 1, "provide small group and individual training sessions on using the PRAP" and "provide education on how to access PRAP database on iPad and computer," address the third key driver, "standardized assessment tool available to all staff." These interventions were thought to directly impact a clinician's ability to accurately assess a patient's risk by utilizing the PRAP tool on either a web-enabled tablet or a computer.

The next step in the QI process is to design and execute Plan-Do-Study-Act (PDSA) cycles, which address the key question #2: How will we know that a change is an improvement? After developing interventions, the next step is to trial these changes on a small

scale. These small changes are tested in a continuous cycle of testing an idea, learning from it, and then trying again. It is not a single step; instead it is an ongoing cycle that allows one to keep trying an intervention until a solution is found that achieves the SMART aim.

Using the example above, "provide small group and individual training sessions on using the PRAP" and "provide education on how to access PRAP database on iPads and computers," testing using the PDSA method may look like this:

Plan: Planning involves determining who, what, when, and where the small test will occur. It also includes deciding what to observe and how to measure what took place during the small testing cycle.

Who/Where: Child life specialists working in one specific outpatient clinic.

What: Provide small group training sessions on how to log into the PRAP database.

Measure: Project leader will observe child life specialist logging into the online PRAP database. The child life specialist will demonstrate the ability to do all functions of the database. If the child life specialist is unable to demonstrate the above items, the project leader will provide one-to-one training on how to use the PRAP database.

Do: Test the changes; record data and observations.

Observations: Child life specialist was unable to demonstrate how to access the PRAP database and was unable to document the PRAP in the correct manner.

Study: Did the results match the predictions? What was learned?

Learnings: Staff reported that they do not document the PRAP score in the EHR because they do not know how to do so.

Act: Decide whether to Adapt, Adopt, or Abandon. (Adapt: Improve the change and continue testing the plan. Adopt: Select changes to implement on a larger scale and develop an implementation plan and plan for sustainability. Abandon: Discard this change idea and try a different one; Cincinnati Children's Hospital Medical Center, n.d.).

Adapt: Before doing another PDSA in another clinical area, additional education is needed on how to access the PRAP database and document in the EHR.

The PDSA cycle will be repeated until you find the solution that meets your stated goal (SMART aim).

Review previous articles in this series in the ACLP Bulletin *archives*, and look for the final step in the QI process, *scale up successful interventions and plan for sustainability and spread*, in the Spring 2019 issue of *ACLP Bulletin*. 🏃

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The Zaadi Doll

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Child life specialists around the globe, both young and old, have historically utilized a wide array of dolls, figurines, and puppets as valuable teaching tools. In the past, dolls were viewed as play things—girls' toys for the most part—for the enactment of caring and nurturing scenarios and the elicitation of warm and fuzzy feelings. Of course, thoughts of discarded dolls, dolls in need of repair, and well-worn dolls retained for their sentimental value conjure images of dolls made of porcelain, hard plastics, or even rubber, the original color of their faces paled over time. However, those are not likely to be the type of dolls lounging in child life office chairs, resting on the top shelf of a hospital playroom, or tucked under the arms of child life specialists on their way to patient rooms. The dolls developed to use in healthcare settings as teaching tools are typically made of soft and flexible materials, with Velcro seams, extensive anatomical parts and organs, and almost cartoon-like facial features. Indeed, many variations on these teaching dolls have their origins in the earliest days of the child life profession.

The ACLP Archives, housed at Utica College's Frank R. Gannett Library, is home to some "senior" patient dolls passed on as artifacts from earlier days. One of the glass display cases holds a number of specimens including the Zaadi doll, Patient Puppet©, "Hals Pals," "Teach a Body®," and the "Buddy." Although each has a unique history worthy of exploration, the heritage of the Zaadi doll is the story featured today. Zaadi was just one of several dolls developed for teaching children and was made commercially available for purchase by healthcare institutions in 1985. The early to mid 1980's was a time when medically oriented toys were first introduced for medical education of children (and adults) of all ages. (Grissim, 2016). Medically-oriented toys and materials offer non-threatening ways to teach, prepare, and familiarize children about their condition, impending procedures, and their overall hospital experience.

The Zaadi doll has Velcro layers that could be opened, representing the skin, the ribs, and other bones, revealing 16 internal organs plus major veins and arteries.

Gail Zayke, a parent and former research chemist and medical technologist, recognized the need for preparation when her hospitalized son underwent surgery in 1981 (Taubman, 1987). Zayke's experience prompted her to design a doll that would replicate the human body and its organs. She created an anatomically correct, life-size doll to align with children's needs to provide hands-on, sensory information. Overall the Zaadi doll was created to educate, ease fears, and clear up misconceptions. The Zaadi doll was a soft-sculpture 40-inch-tall doll (yes, that is bigger than most three-year-old children). To accommodate easy handling and

visualization, these dolls had Velcro openings to allow a patient access to the various internal viscera. The large size, the removable parts, and the gender-specific features brought controversy about how to best incorporate this doll into the teaching realm; some child life specialists at that time were concerned that having organs "fall out" of the body might be frightening to some children. Of course, such attitudes have changed with the times. Expertise and training around the use of dolls and puppets in various shapes, sizes, and textures is grounded in clinical practice and supported by our internship and academic programs.

Fast forward to the 21st century: Technology is now integral in our society, and the toy industry is no exception. Children and teens now have "Wi-Fi," "wireless," "iPad," and "iPhone" as part of their lexicon and daily lives. Many child life professionals have also embraced technology, but they still recognize the importance and the power that hands-on play modalities provide. Even though the Zaadi doll may no longer stand as the teaching doll of choice in today's practice, dolls and puppets remain as fixtures in the child life tool kit for their contribution to the play and teaching approaches of child life professionals.

Many child life professionals have also embraced technology, but they still recognize the importance and the power that hands-on play modalities provide.

Many child life novices and students may notice one of these relics in their own departments, especially if the program has existed since the 1980s or earlier. Consider the value of this once-iconic child life tool. When you see these dolls simply resting on a shelf or in a closet, pose a question: Ask one of the senior child life specialists to tell you about the use of the Zaadi or other patient doll in their earlier practice. Elicit the stories that may illuminate the power of a medical teaching doll in the hands of a skilled child life specialist for improving the experience of a child in hospital. Although research supporting the use of the teaching dolls is limited, you can contribute to our body of knowledge by creating an anthology of stories or develop a project documenting the history of some of the other child life teaching and preparation tools. 🏃

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ACLP Calendar

JANUARY

1-31   Start planning your Child Life Month events and activities for March!

1   *CLPDC data entry* for 2018 Q4 begins

5   Deadline to submit *internship applications* for summer 2019

9   Deadline to apply for a *Research Recognition Award*

31   Deadline to submit 2018 *Annual Certification Maintenance Fee*

31   Deadline for Early Registration for 2019 *Child Life Annual Conference*

31   Deadline to apply to be part of the Innovators Fair at the 2019 *Child Life Annual Conference*

FEBRUARY

1-28   Continue planning your Child Life Month events and activities for March

MARCH

1-31   Celebrate Child Life Month!

10   Deadline to apply for the March 2019 administration of the *Child Life Professional Certification Exam*

15   Deadline to submit *internship applications* for Fall 2019

15-30   *Child Life Professional Certification Exam* administration testing window

24   Deadline for Online Standard Registration for 2019 *Child Life Annual Conference*

APRIL

1   *CLPDC data entry* for 2019 annual data and 2019 Q1 data begins

1   *Submission deadline* for *ACLP Bulletin* and *Focus* articles for consideration for the Summer 2019 issue

11-14   2019 *Child Life Annual Conference* in Chicago, IL

Webinars

New year, new programming! ACLP is excited to share our 2019 webinar programming with members. Visit our new *professional development page* to learn more about our offerings, and make your professional development plan for 2019.

ACLP is committed to offering our members relevant, high-quality, and accessible professional development. Our 2019 webinar lineup not only offers more webinars for members, but also provides members the opportunity to access content that aligns with their background and experience. Whether you're an emerging professional who's new to the field, or an established professional who wants to stay sharp, our updated webinar programming has something for you.

Help us kick off an exciting new year of professional development. Join us for our January webinars:

JANUARY 28TH

Giving and Receiving Feedback- Strengthening Your Skills Through Intentional Practice.

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

JANUARY 29TH

Insights and Wisdom: Global Engagement in Child Life.

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

Please be sure to visit our new *professional development page* to learn more about these webinars, view our 2019 lineup, and register for upcoming webinars. Begin making your 2019 professional development plan today!

Upcoming Events

MARCH 27-28

Virtual Medicine:
Best Practices in Medical Virtual Reality 2019
Los Angeles, CA
Visit the *Virtual Medicine website* for information.
Note: Discounted rate for ACLP members.

MARCH 7-10

National Association of Pediatric Nurse Practitioners National Conference
New Orleans, LA
Visit the *NAPNAP website* for more information.

APRIL 8-10

Annual Association of Pediatric Oncology Social Work Conference
Phoenix, AZ
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Jason A. Wolf, PhD, CPXP, is a passionate champion and recognized expert on patient experience improvement, organization culture and change, and sustaining high performance in healthcare. As President of The Beryl Institute, Jason has transformed the organization into the leading global community of practice and thought leader on improving the patient experience, engaging over 55,000 members and guests in more than 70 countries and establishing the framework for the emerging profession of patient experience.

CLOSING KEYNOTE PERFORMANCE

Funny Bones Improv shares the gifts and benefits of laughter with sick children, their families, and their caregivers, in multiple hospitals across Chicago and New Orleans through volunteer comedy improvisation performances.

The **2019 Child Life Annual Conference** will take place **April 11–14** at the **Chicago Marriott Magnificent Mile in downtown Chicago.** ACLP invites attendees to register early and take advantage of the significant discount on the standard registration price. *Early Registration ends January 31, prices increase February 1.*

WHAT'S NEW THIS YEAR?

Collaborative Sessions

ACLP's conference planning committee and staff worked diligently to solicit, review, and select abstracts for conference breakout sessions. To complement these traditional professional development sessions and to provide more time to learn through collaboration and informal conversations, we have increased the focus on peer-to-peer networking and created parallel audience-specific sessions:

- Program Leaders Collaboratives

- Academic Collaboratives

- Child Life Collaboratives

Due to the limited availability of space in the venue, we are unable to provide plenary sessions for the 2019 conference. However, we have plenty of other exciting sessions attendees can engage in!

ASSOCIATION OF
Child Life
Professionals

Register at www.childlife.org