CHILD LIFE COUNCIL Bulletin

Utica College and Kohl's Corporation Honored with 2009 *Spirit of Giving* Award

In recognition of their outstanding contributions to child life programs, the Child Life Council is pleased to announce the recipients of the 2009 *Spirit of Giving* Award: Utica College and Kohl's Corporation. The two organizations were honored during a special award presentation at the closing session of the Annual Conference in Boston.

The *Spirit of Giving* award was created in 2007 to recognize organizations with a record of exceptional generosity through the donation of funds, goods, services and volunteer hours, whose support has expanded or contributed to the value of child life services.

Utica College was selected by the CLC Executive Board in recognition of the institution's outstanding financial and in-kind contributions, which have supported the housing and mainte-nance of the Child Life Council Historical Archives over the past seven years. Since forming an agreement with CLC, Utica College has donated valuable library space, storage and other archival equipment to properly store the historical materials con-tributed by child life specialists from around the world. In addi-tion to space and materials, the college has contributed employee time and resources to support the activities of the CLC Archives Management Group.

"Utica College has been instrumental to our efforts to preserve the unique history of the child life profession," said CLC Executive Board President Janet Cross. "By promoting an active awareness of our shared history, Utica College helps us to build a stronger future – one that will continue to enrich the lives of children and families coping with stress and trauma for years to come."

The second *Spirit of Giving* Award recipient, Kohl's Corporation, was recognized for its contributions to children's

INSIDE

The Child Life Alphabet

DEVELOPMENTALLY-SUPPORTIVE CARE: CHILD LIFE IN THE NICU

Emily C. Lawton, MSEd, CCLS
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Developmentally-supportive care is based on the pioneering work of Heidelise Als and Berry Brazelton, who first demon-strated the competence of full-term newborns in using behavior to signal their needs and for their participation in the development of rela-tionships with others (Lawhon, 1984; Gorksi, 1999). For the past twenty-five years, Als and her colleagues have been studying the effects of hospitalization on premature infants and have devised care that supports the natural developmental needs of infants.

Developmentally-supportive care supports the individual infant's capacities for regulation and organization by viewing the infant as an active participant in his care (Buehler, Als, Duffy, McAnulty, Liederman, 1985). Observation is the key for child life specialists to understand an infant's behaviors and learn to tailor care to meet each infant's individual needs. The infant is an active, not a passive, participant in the care being given to him,

PRESIDENT'S PERSPECTIVE

Orchestrating a Successful Future

Janet Cross, MEd, CCLS
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"No one can whistle a symphony, it takes an orchestra."
— H.E. Luccock

As I write this, my final President's column, I can't help but reflect on the amazing orchestra I have had the honor of leading! The incredible dedication displayed by CLC leaders at all levels has been a source of pride and inspiration.

Foremost in my mind are the extraordinary efforts of the search team, led by Sheri Mosely, who were charged with the serious task of recruiting and hiring a new executive leader for CLC in the first quarter of 2009. With their hard work and expert guidance, CLC was fortunate to engage our new Executive Director, Dennis Reynolds, in early February. Dennis' leadership and skill promise to take our organization to new heights and it has been an honor to work with him thus far.

During those months that the Executive Search Committee was hard at work locating CLC's next executive director, the CLC staff rallied together under the interim direction of Chuck Rumbarger, CAE, to maintain daily operations, and to continue effective communication with the CLC Executive Board, volunteer groups, and the community-at-large. This talented, dedicated group kept the ship afloat and remained responsive to member needs, without missing a beat!

In late February, the Child Life Certifying Committee hosted an Item Bank Reclassification event in Fort Worth, Texas. With the support of our testing agency, more than 20 Certified Child Life Specialists tackled the daunting project of reviewing, reclassifying, and/or revising approximately 700 test questions to make sure the Child Life Certification Examination remains an up-to-date and effective measure of child life professional competencies. As a participant in this exercise, I was able to witness true dedication, a collaborative spirit and child life expertise orchestrated beautifully to complete this task.

Our Annual Conference on Professional Issues is one of CLC's most inspirational symphonies. The four-day event is the product of months of careful planning and collaboration by a hardworking group of staff and volunteer "players," and the attendees themselves become a part of the larger orchestra, as they enjoy the unique and powerful sense of community that comes from connecting with hundreds of other child life specialists. The recent conference in Boston provided the opportunity for CLC Committees to meet face to face and strategize for the coming year. This included the inaugural meetings of four new committees: the Program Review Service Committee, Leadership Development Committee, Web and Online Networking Advisory Task Force and Partnership Review Committee. All of these groups have begun work on charges that will help us as an organization to accomplish the goals set forth in our strategic plan.

I was also very excited about the first ever Child Life Academic Summit hosted by Wheelock College, which took place immediately following the Annual Conference. The purpose of this invitation-only event was to bring together the child life educational community to address current issues influencing education, training and scholarship. The CLC Education and Training Committee worked closely with Wheelock representatives to prepare for this historic event. The Summit laid the groundwork for establishing next steps for the work of the Education and Training Committee.

Recommendations from a governance task force assembled to examine our governance structure are on their way to implementation. Among the task force's recommended additions and changes are updates to the composition of the Board and the operating guidelines for the Nominating Committee. These modifications will help us grow and advance as an organization while maintaining safe and efficient operations.

The Board voted to implement the "Mary Barkey Clinical Excellence Award" to be presented annually to an individual child life specialist who has demonstrated exemplary child life care and a high level of clinical skill. This award is in memory of Mary Barkey and recognizes the great work she accomplished as a child life specialist. The first award will be presented at the 2010 Annual Conference in Phoenix. Additional details are available on the CLC Web site.

I will close by saying thank you for the opportunity to serve as your President. It has been such a rewarding experience. I hope that you will consider getting involved in our professional organization and joining the work of this talented, influential group of professionals. The relationships I have made are priceless both on a personal and professional level. The people of CLC are such invaluable resources! I wish each of you continued success in your work with children and families. Our orchestra is performing well and will continue to support the work of child life professionals. You really do make a difference!

CHILD LIFE
Focus

Qualitative Methodology and the Child Life Researcher: Making Connections to Support Evidence-Based Practice

Toni L. Crowell, MS, CCLS, Academic and Clinical Specialist/Manager, The Hospital for Sick Children, Toronto, Ontario

Child life specialists have shared values and responsibilities of both understanding and participating in research that helps support evidence-based practice. Just as child life specialists build skills and a comfortable repertoire of interventions utilized directly to support children and families, so too must they develop research skills. Child life specialists need an awareness of a range of research paradigms, methodologies, and designs in order to find ones that best match with their own clinical interests and styles of knowing. The intent of this article is to identify the need for child life specialists to recognize and support the transition to researcher. To this end, a brief overview of the basic assumptions, theoretical basis, and selected methodologies of the qualitative research paradigm will be presented. In addition, connections to child life practice areas will be integrated to raise awareness of the methods and enhance utilization by child life specialists.

CHILD LIFE SPECIALIST AS RESEARCHER

In establishing the *Standards of Clinical Practice* the Child Life Council (2001) outlines and defines the full scope of services which the child life specialist is responsible for maintaining. These standards set the criteria for professional expectations and responsibilities. Within this ten part outline, the areas of *Child Life Service* (section III) and *Research* (section X) are included. The intent of these documents, and subsequent integration by the child life specialist, is not to place

these standards in a hierarchical and separate framework but to create an achievable standard for practicing child life specialists. In order to be inclusive and effective one must possess, maintain, and integrate the standards and competencies of each. However, the reality is that often child life specialists see the roles of clinician and researcher as mutually exclusive. And

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indeed, this is to be somewhat expected in a profession that draws many for the clinical aspects and hands-on experiences with children and families. Although evidence for inferring this is anecdotal, it is not uncommon for one to hear some (future and current) child life specialists voicing disdain for taking research courses and confusion as to how to even begin to develop research projects.

Not all of the reasons for this stance regarding research are issues of personal

inclination, competence, and/or confidence. Other causes likely include the lack of academic professionals with clinical child life experience within institutes of higher education (and the standards requiring this to be in place) who can provide true modeling and mentoring of specific field related research. In addition, within the structure of most child life programs, research and evaluative endeavors have traditionally fallen onto the responsibility of directors or managers, which can leave the clinical child life specialist out of the research loop. Whatever the reason(s) for this divide, the imperatives remain that as a profession we need to build the evidence to guide and evaluate our clinical practice. A precursor to this goal is the need to reinforce the clinical standards of practice in regards to conducting and valuing research in its entirety, not simply from a results focus. But this participation in research will not materialize until we support child life specialists in understanding and assuming their responsibilities of being active researchers. There needs to be support for child life specialists in transitioning to roles outside of a solely clinical role. Recognizing that this is a transition and that additional education, knowledge, and mentoring are needed to support child life specialists is an integral first step.

WHAT IS QUALITATIVE RESEARCH?

To simplify, qualitative research is a type of research designed to handle non-numerical data. Examples of this data can

be text, dialogue, photographs, video, and artwork. Qualitative researchers typically study topics within their natural setting and are interested in the perspective of the subject. Qualitative research falls under a constructivist paradigm in which theory is built from the data and there is no single truth. This denotes an inductive process to research in which theory is built from the data – the end goal is to describe and develop theory specific to the phenomenon and subjects involved. This differs from the positivist paradigm, which characterizes quantitative research, and seeks to develop truths. Quantitative research requires a deductive process in which theory driven hypotheses are tested and findings can be generalized across time to apply to broader populations (Gliner & Morgan, 2000).

Many professionals may come to qualitative methods by *default* and one often hears reasons such as, "I hate statistics and numbers, so I prefer qualitative" or "qualitative research is just much easier to understand and conduct than real research." And, indeed the approach does seem to be the perceived "remedy" to the somewhat intimidating world of quantitative research. However, qualitative research is not the "easy" way out and projects often take considerably longer to complete than traditional hypothesis testing-based research. Throughout the process qualitative researchers become immersed in the data and need to develop skills that will enhance their overall productivity and ongoing results. In this sense, qualitative research is far from the easy alternative and requires knowledge of the specific methods in order to conceptualize the process from beginning to end, flexibility to adapt such plans as the data emerges, and a strong commitment and passion to carry the projects through to completion.

WHY QUALITATIVE RESEARCH?

In the realm of research within the social sciences, qualitative methods of inquiry have increasingly been utilized as both alternatives to traditional quantitative methods and in combination with (mixed-methods) quantitative methods. Leading scientific peer-reviewed journals in the health, development, and family studies fields integrate such studies in their publications and specific journals such as *Qualitative Health Research* and *Qualitative Research* (both Sage publica-

tions) exist to solely highlight this paradigm and further inform both the examined phenomena and the methodologies employed. Although the debate still exists regarding reliability, validity, and subsequent generalizability of qualitative research findings and the perceived superiority of one paradigm over the other (Creswell, 1994; Mantzoukas, 2004; Morse & Richards, 2002), qualitative research can lead to valuable insight and serve to guide clinical practice within the child life field.

Qualitative research seems a good match to the typical skill base of a child life specialist. These methodologies can provide a natural link between the *Child Life Service* and *Research* sections of the *Standards of Clinical Practice* set forth by the Child Life Council (2001). Within the inductive process of qualitative research, the researcher is an active participant who employs interviewing techniques and empathetic listening to collect data and discover the meanings one attaches to experiences (Corbin & Strauss, 2007).

Child life specialists meeting the service standard are well adept at building rapport with children and families to support the sharing process. They are skilled in asking developmentally appropriate and sensitive questions that allow optimal communication and expression. Just as these information gathering techniques lend to more informed clinical assessments, so too will they lead to rich and detailed interview data to inform future practice based on the data gathered. Also, the focus of qualitative research is on building theory from the data and at times giving voice to the participants and allowing their individual stories and experiences to come to light. Again, child life specialists meeting the service standard are strong advocates for children and families and empower them to use their own voices in self-advocacy and expression of feelings.

The qualitative format gives children, families, and healthcare workers an additional means in which to be heard as their specific experiences lend to further insight and development of future understanding and interventions. Qualitative methods have also been widely utilized within the health arena (Admi, 1996; Charmaz, 1997; Lowton & Gabe, 2004) and are often the recommended methods for researching newer or under-studied phenomena (Morse & Richards, 2002), which also applies to many child life

practice issues. Interested child life professionals are encouraged to explore these methodologies by accessing and reviewing the research examples cited below.

QUALITATIVE METHODOLOGY

Within the broad framework of qualitative research there are three primary methods of qualitative research: grounded theory, phenomenology, and ethnography. One method is not superior to another as each has a different purpose and corresponding congruence to the plan of making and analyzing data. Each method is implicitly or explicitly grounded in a theoretical framework, and this theoretical framework influences the form results take. Each also carries assumptions about social reality, and will be further explained in the sections below.

GROUNDED THEORY

Symbolic interaction provides the foundation for grounded theory. This framework is based on the assumption that we are products of our society, that interactions with others shape who we are, and that reality is comprised of processes (Strauss & Corbin, 1997). Thus, questions with a focus toward examining and understanding processes and change are explored. These are inclusive of general questions, such as *what is the process of …? What is happening here?* Grounded theory is designed also to generate and test theory (Strauss, 1987). As the name implies, the theory is derived from and grounded in the data and the researcher actively collects, analyzes, synthesizes, and integrates the data to capture the emerging theory that serves to explain the process(es) involved (Morse & Richards, 2002).

Specific studies relevant to child life practice that have utilized grounded theory methods of qualitative research include the following examples: post medical trauma growth and recovery (Chun & Lee, 2008; Salick & Auerbach, 2006); the transition of technology-dependent children to home- and community-based care (Cohen, 1999); mothering in HIV positive women (Ingram & Hutchinson, 2009); fathering a child with juvenile rheumatoid arthritis, (McNeil, 2004); processes within end-of-life care (Thulesius, Harkansson, & Petersson, 2003); and the process of hope for the family members of coma patients (Verhaeghe, van Zuuren, Defloor, Duijnstee, & Grypdonck, 2007). Morse & Richards (2002) caution that grounded theory may be one of the

most misused labels applied to qualitative research studies and that, as with all methods, researchers need to be aware of the full scope of the method and ensure congruence at each stage of the research.

PHENOMENOLOGY

Researchers using the phenomenology methodology seek to capture the lived experience of individuals and the perceptions of their own presence in the world: *What does it mean to live with a certain illness? How does the experience of having an illness or hospital experience affect my being in the world?* Phenomenology emphasizes the importance of lived experiences and has existential guides to reflection that assume all human behavior occurs within relationships to things, people, events and situations (Morse & Richards, 2002). The researcher must then take a role in understanding how people attend to and perceive the world. This is typically done through taped, unstructured conversations and later reflection on both the data obtained and the researcher's personal experiences and observations (Morse & Richards, 2002).

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Relevant research that has been conducted utilizing phenomenological methods of qualitative research has delved into the lived experiences of the following: nonvocal ventilated patients (Carroll, 2007); adolescents with spina bifida (Kinavey, 2006); burn survivors (Litlere Moi & Gjengedal, 2008); a young adult with diabetes (Tilden, Charman, Sharples, & Fosbury, 2005); long-term users of urinary catheters (Wilde, 2003); pediatric liver transplant recipients (Wise, 2002); parents of autistic children, (Woodgate, Ateah, & Secco, 2008); and nurses' experiences caring for critically burned children (Zengerle-Levy, 2004).

ETHNOGRAPHY

Ethnographic research methods are typically utilized to explore cultural groups. In the broader context, culture includes groups and subgroups that have shared values, ideals, norms, and shared patterns of beliefs, behaviors, and social interactions (Morse & Richards, 2002). Researchers conducting ethnography may be guided by the general questions: *What is currently going on within this area?* or *What are the patterns of behavior implicit within this culture?* Any specific phenomena is then explored within the relevant cultural context from the perspectives of the members of the cultural group, also called *informants* (Morse & Richards, 2002). To this end, researchers can locate broad cultural groups based on ethnicity or geographic location or smaller sub-cultural groups based on shared locations (e.g., hospitals, support groups) or shared conditions/statuses (e.g., cancer patients, teen mothers). The ethnographic researcher defines the selected setting or field and all data is collected within this natural setting. The data is always viewed within the context of the selected culture as findings and patterns are identified. Morse & Richards (2002) outline distinct steps of ethnographic research as well as various forms it may take. In addition, Pope (2005) provides guidelines and special considerations when conducting ethnography in the medical setting.

Ethnographic studies have been conducted in the following areas: palliative care team meetings (Arbor, 2007); the family and social contexts of a child with a genetic disorder (Blake, 2001); in-hospital renal technicians and the context of living donations (Crombie, 2006); the culture of a trauma team (Cole & Crichton, 2006); the role of humor within and across varied medical settings (Dee & Major, 2008); Indian children's conceptions of illness causality (Froerer, 2007); awareness among dying patients, their families, and medical personnel (Mamo, 1999); and patient and family experiences of being evaluated and treated in a cancer clinic (Peters, McAllister, & Rubenstein, 2001).

CHILD LIFE PRACTICE

Where does this leave the practicing child life specialist who has no idea of where to start? To perhaps simplify this question, one must start with ideas and general topics.

In daily practice, situations continuously abound that can provide rich opportunities for systematic inquiry, for example, the lived experiences of the children and families encountered daily balancing life while battling illness. In addition, child life specialists have stories and patterns that seem to stand out across the time of their career, including but not limited to: how children "prepare" when they know they are dying; how psychosocial needs and understanding of a chronic illness change as children enter adolescence; how medical teams come around to adopting developmentally appropriate and family-centered practices; how professional boundaries are negotiated amongst professionals and families. The shift needs to take place in which the clinician begins to view these typical occurrences through a researcher's eyes. Once this lens is in place, the stories (and perhaps frustrations) of child life practice can be placed within the context of a research question/method.

Some research questions lend themselves to a specific method more readily. Ideally, choice of method is guided by the research question/purpose. For example, questions around coping and adjusting to any given illness/treatment/procedure imply a process is involved and would seemingly benefit from grounded theory methods. Conversely, just as there is typically a match of question to method, there can also be a match of researcher to method. Specific ways of researching and knowing resonate more than others and one researcher may be drawn towards one method over another. In this regard, general topics can be formatted into questions that best fit the chosen method (see Table 1 for a hypothetical elaboration).

In their guide, *Readme first for a user's guide to research methods,* Morse & Richards (2002), set out explicit steps for potential researchers to consider when conceptualizing, planning, implementing, and writing up qualitative inquires. Throughout the text, they emphasize the need to conduct purposeful research that shows a level of fit and congruence to methods. This user friendly guide is an invaluable preliminary resource for anyone interested in learning more about how to understand and conduct qualitative research.

CONCLUSION/LIMITATIONS

The intent of this article was not to debate the merits of qualitative versus quantitative methods of research, as both are integral in building evidence-based practice in their own right and combined (mixed method research). Rather, the goal was to describe and further explore selected primary qualitative methods currently utilized in health research. Connections to child life practice were highlighted to show child life specialists the potential for engaging in meaningful research. Each method, presented briefly, also has nuances and interpretations that lend to distinct research paths of question formation and data making and analysis. Novice researchers should become well acquainted with these as well as the current relevant literature that reports utilizing such methods.

In sum, it is a *Standard of Clinical Practice* that child life specialists need the knowledge, resources, and confidence to understand and conduct relevant research to guide current and future evidence-based practice. Qualitative research methods can provide such tools. And, as elaborated upon, this paradigm can provide a natural link to research that builds upon the clinical service skills (i.e., building rapport, advocacy, and facilitating expression) of a child life specialist. In this sense, the strengths of one standard of clinical practice, *Child Life Service* can be utilized to inform and shape the attainment of another, the *Research* standard. These roles are not mutually exclusive and child life specialists need to be proficient in the full scope of standards that define the profession.

Lastly, the child life profession would benefit from the development of a process from which to attain such standards and help facilitate the connections between standards that extend beyond the typical education preparation for the clinical side of the profession. Child life specialists also achieve these standards through the related standards, *Professional Preparation and Development* (VI) and *Education of Child Life Students* (IV). In reference to these standards, as professionals, child life specialists are continuous, career-long learners, and at times, teachers. These standards encompass needs and skills that can also be utilized to provide further growth in research understanding and skills. Those current child life specialists who are well versed in research techniques can help shape and mentor those who are struggling with the concepts and implementation. Through clinical practice child life specialists support individuals in transition on a daily basis. They are well equipped and poised to help the profession transition into becoming researchers as well. Through providing support and scaffolding the learning process, new perspectives can be attained and the uncertain can become manageable (and even enjoyable). It should be recognized that clinical child life specialist colleagues might need the same support in learning how to apply a researcher's lens to issues of clinical practice and evaluation.

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TABLE 1: COMPARISON OF THREE METHODS TO CONDUCT A CHILD LIFE RELATED HYPOTHETICAL PROJECT, PARENTAL PRESENCE DURING INVASIVE PROCEDURES: PATTERNS OF PARENT-CHILD ATTACHMENT				
METHOD	**RESEARCH QUESTION(S)**	**SETTING AND PARTICIPANTS**	**DATA SOURCES AND TYPES**	**TYPES OF RESULTS**
Grounded Theory	• What is the process of supporting your child through invasive procedures? • What is the process of being supported by your parent(s) during invasive procedures?	• Interviews anywhere • Observations in the healthcare and family context	• Audio taped interviews • Participant and non participant observations • Comparative instances • New data as emerging theory directs research	• Theory about parental presence and support • Focus on the psychosocial processes involved
Phenomenology	• What is the meaning of being present for your child *and/or* having your parent present for invasive procedures?	• Interviews of parents and children at their convenience in a setting of their choice • Relevant individuals who recently or continuously experience and support through invasive procedures	• In-depth audio taped conversations • Reflection on the phenomenological literature • Memoing and reflective writing • Artwork, poetry, or expressive activities of children	• In-depth reflective description of the experience of supporting your child *and/or* being supported by your parents
Ethnography	• What are the patterns of parent-child attachment displayed during invasive procedures? • How do these patterns play out within the specific medical/family/ socio-cultural context?	• The healthcare setting and specific treatment areas • Children, parents, family members, healthcare personnel (nurse, doctors, aids, child life specialists, etc.)	• Unstructured, audio taped interviews • Participant observations in treatment rooms and on medical units • Field notes and other documents • Focus groups	• Descriptions of the patterns of attachment behaviors or styles of support

Note: Adapted from Morse & Richards (pp. 31-36, 2002).

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Transitioning Patients with Cystic Fibrosis from Pediatric to Adult Care: A Lifelong Process

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For patients and families living with chronic illness, the transition of care from a pediatric healthcare setting to an adult healthcare setting can be one of the most challenging and difficult life events that they may face. The change in healthcare providers and environment can be stressful for a patient who has grown up in one setting with one group of healthcare providers. This transition is not only difficult for the patients and families, it is also difficult for the pediatric staff, who have often known this child since diagnosis and watched the child grow up. As child life specialists, we work within a multidisciplinary team to provide support to patients and families throughout the challenges that illness provides. As such, child life specialists can be instrumental in the development and success of a transition program. This article will outline one pediatric institution's journey to develop a pathway for transitioning the care of patients with cystic fibrosis (CF) from the pediatric to adult facility. It will describe the background work that led to the development of a transition task force, the accomplishments of the task force, and the future goals that have been set by the task force. Also included is information about the involvement of the adult healthcare providers in the development of the transition plan.

Webster's dictionary defines transition as the "passage from one state, stage, subject, or place to another." On the other hand, transfer means "to move to a different place, region, or situation" (Merriam-Webster's Online Dictionary, 2009). Within the healthcare setting these words are often used interchangeably when discussing patients with chronic illnesses moving from pediatric care to adult care. However, these are two different concepts and should not be used interchangeably. A *transition* should be a gradual process that takes place over time leading to the eventual *transfer* of medical records and care from one physician and medical setting to another. It should be the responsibility of the pediatric medical staff to prepare patients and their families for this eventual transfer of care from a pediatric setting to an adult setting. Without this preparation the transition process is often met with resistance and fear. The development of a comprehensive transition pathway is an effective tool to fully prepare patients and families for this change in their healthcare routine.

THE SETTING

The transition program described here was developed within an urban hospital setting. The pediatric and adult hospitals are separate, but within close physical proximity. The pediatric Cystic Fibrosis Center has approximately 200 patients with CF, while there are 107 patients seen at the adult CF Center. It is estimated that there are five to seven patients per year who reach the designated age of transition. The maximum age for the transition of patients with CF at this hospital has been set at 21 years of age. This age was set by the pediatric pulmonologists who treat the patients with CF.

FAMILY CENTERED APPROACH TO TRANSITION

With advances in medical care, many patients with chronic illnesses are living into adulthood, thus necessitating the need for a more formal transition from pediatric to adult healthcare. For people with CF, the predicted median age of survival has risen to more than 37 years of age (The Cystic Fibrosis Foundation, 2008). With more than 40% of the CF population over the age of 18 (The Cystic Fibrosis Foundation, 2008), the need for formal transition programs becomes even greater. In 2002, the American Academy of Pediatrics, along with the American Academy of Family Physicians and the American College of Physicians-American Society of Internal Medicine, released a consensus policy statement highlighting the need for more comprehensive transition programs for patients with special healthcare needs. This statement stressed the importance of transition and provided information about the physician's role in facilitating the transition process. The group recommendations include: ensuring that young people with special healthcare needs have a health professional who is working with them regarding transitioning, including knowledge and skills that are needed to provide for developmentally appropriate transition in physician training programs, the preparation and maintenance of a portable medical summary, and ensuring health insurance coverage throughout adolescence and young adulthood for people with special healthcare needs. The Society for Adolescent Medicine, as cited in Rosen, Blum, Britto, Sawyer, & Siegel (2003), has also developed a guideline that outlines the principles and recommendations for successful transitions. These recommendations include: ongoing education for patients, families, and providers regarding the importance of a developmentally appropriate transition, the development of best practices for the management of adults with childhood diseases, eliminating policies that hamper the transition of young adults with special healthcare needs, and further research about health outcomes after transition.

The healthcare transition usually comes at a time when adolescents are faced with developmental challenges that can have an impact on how well they approach the transition. Adolescents are struggling with finding their own identity and being independent from their parents. Many adolescents with chronic illnesses experience difficulty during this stage because they have come to depend on their parents for help with managing their illness (Kaufman, 2006). Some adolescents may see the medical team as an extension of their parents and therefore resist what their current medical team is telling them. For these adolescents, transition may be seen as a positive event because the new medical staff are seen as not being as connected with their parents (Kaufman, 2006).

Patients, family members, and medical staff all have unique concerns regarding the subject of transition. Patients with CF who are facing transition are concerned about exposure to infection, inadequate understanding of their disease by the adult healthcare providers, and the loss of continuity with their CF nurse (Taylor, Tsang, & Drabble, 2006). To address these concerns, McDonald (2000) suggests providing patients with the opportunity to begin to see the doctor on their own for part of each visit

around the age of 14 years, the use of a readiness to transfer questionnaire, and providing a transfer clinic where the patient has an opportunity to meet the adult care team at the pediatric hospital. McDonald (2000) also recommends providing written information about the adult program and providing a tour of the adult CF center. Having a CF Education Day that includes both pediatric and adult patients gives teenaged patients with CF the opportunity to meet adults with CF that can serve as role models for them as they prepare to transition to adult care (McDonald, 2000).

Parents are concerned that their child's health will be compromised after the transition to an adult care center. Many families also talk about the feeling of abandonment and rejection by their previous healthcare team (Taylor et al., 2006). Instituting a family-centered approach to transitioning can make the process more successful. When families are included in the entire process, parents may find it easier to separate and allow the patient more independence (Hink & Schellhase, 2006).

Some suggestions for making transitions easier for both patients and their families are sending patients/families a transition letter at the age of 12 or 13, welcoming them to the teenage years and outlining what lies ahead, as well as the use of a transition checklist so that everybody knows where the patient is on the transition pathway. Above all else, good communication between the medical staff and the patient and family is essential (McDonald, 2000).

Recommendations for the healthcare team include: helping families to be future focused regarding their child's adult life, fostering personal and medical independence, developing a transition plan, and celebrating transitions as they occur naturally (Reiss & Gibson, 2002). In addition, McDonald (2000) does caution against transitioning patients when they are in the midst of an acute medical crisis or when they are end-stage in their disease.

SURVEY AND RESULTS

A small survey of patients and medical staff was completed within this pediatric hospital to get a better understanding of the concerns that patients and staff have regarding the transition to adult healthcare. The survey also measured patient and staff confi-

dence in the adult healthcare setting and confidence in the patient's ability to manage their care in an adult setting. Ten patients and 51 staff members (inpatient and outpatient), including physicians, nurses, respiratory therapists, dieticians, patient care assistants, health unit coordinators, and the social worker were surveyed.

The survey was qualitative, asking open-ended questions. Some of the questions asked respondents to rate their confidence level on a scale of 0-10. The ten patients who completed surveys were between the ages of 13 years and 19 years. They were asked to list their concerns regarding the transition process (see Table 1).

TABLE 1: PATIENT SURVEY QUESTIONS

1. Age
2. Name of current pulmonary doctor
3. At what age do patients with CF transition to an adult pulmonary doctor?
4. At what age do patients with CF transition to an adult CF center?
5. How confident are you that the care at the adult CF center equals the care at the pediatric CF center (0-10)?
6. How confident are you that you have the skills to manage your care in an adult healthcare setting (0-10)?
7. What concerns do you have about the current transition process?
8. Other comments

The results of this survey showed that the patients who responded were most concerned about a fear of the unknown. They were concerned about not knowing the adult healthcare providers, the quality of care they will receive at the adult CF center, and the accommodations that are provided at the adult hospital.

To gain insight into the thoughts of the hospital staff towards the transition process, 51 staff members were asked to complete surveys. They were asked to list their concerns regarding the transition process (see Table 2). The top concerns of the pediatric medical staff were the quality of care that is provided at the adult CF center, fear of the unknown, not knowing the adult healthcare providers, and the type of food that is provided at the adult hospital. Additionally,

TABLE 2: STAFF SURVEY QUESTIONS

1. Position/role
2. Work setting (outpatient, inpatient)
3. At what age do patients with CF transition to an adult pulmonary doctor?
4. At what age do patients with CF transition to an adult CF center?
5. How confident are you that the care at the adult CF center equals the care at the pediatric CF center (0-10)?
6. How confident are you that the patients with CF have the skills to manage their care in an adult healthcare setting (0-10)?
7. What concerns do you have about the current transition process?
8. Other comments

patients at the pediatric hospital have been using written daily schedules for many years so that they know when to expect treatments, medicine, and other hospital activities. Many of the staff and patients noted that they were concerned about not having schedules or knowing the schedule at the adult hospital.

THE JOURNEY TO A COMPREHENSIVE TRANSITION PLAN

The idea for developing a transition program for patients with CF first came from a Family Centered Care (FCC) Committee. The purpose of the FCC Committee is to work to ensure that the hospital unit is best meeting the needs of the patients and families that are served on that unit. This committee is made up of multidisciplinary staff and parents. Because this unit cares for patients with CF, this committee began discussing the subject of transitioning patients with CF to adult care and how the committee could best provide support.

The whole process of transition usually involves only the patient, who is now an adult, which tends to minimize the concerns of the parents. Due to privacy regulations, once a patient turns 18 their parents are no longer allowed access to medical information. For parents who have always been the medical decision-makers this can be a difficult adjustment. It can be equally as difficult for the now-adult patient to begin to make

his or her own medical decisions. Based on these facts, the FCC committee wanted to take a family-centered approach and include the entire family in the transition process. This would include parents and other family members in the transition process from the time of diagnosis so that all would be prepared for the eventual transition of care.

The committee initially set out to determine what the current transition plan looked like. To begin this process the CF Clinical Nurse Specialists from both the pediatric and adult CF Centers were invited to a meeting to share their thoughts on transition and how the medical staff could make the process easier for patients and families. For the most part it was an expectation that patients would transfer their care to the adult CF Center at the age of 21. From this meeting, it was determined that there was not a consistent transition plan in place, as much of this was dependent on which primary physician was following each patient. Typically, transition was mentioned to the parents at diagnosis and then not again until it was almost time for the transfer of care to take place. Some of the patients were offered a tour of the adult hospital and a chance to meet the adult staff prior to transferring their care. Again, it was not consistent as to who toured the adult facility and who did not. On a positive note, the pediatric and adult CF Centers share one physician. To prepare patients for the transition to the adult center, most of the patients start seeing this adult physician when they are 18 years of age.

THE FORMATION OF A MULTIDISCIPLINARY CF TRANSITION TASK FORCE

After all of the background work was completed, the team realized that in order to develop a comprehensive transition plan all of the key players would need to be involved: inpatient, outpatient, pediatric, and adult. The Family Centered Care Committee wrote a proposal that was presented to the pediatric CF Center staff at a staff meeting. This was the impetus for the creation of a multidisciplinary CF Transition Task Force. This task force was comprised of staff from the pediatric center, including physician, clinical nurse specialist, outpatient nurses, inpatient nurses, respiratory therapists, dieticians, social worker, home health care nurse, and child life

specialist. The adult CF Center staff on the task force included the clinical nurse specialist and dietician. The task force also included parents of patients who had previously received their CF care at the pediatric center who now receive care at the adult hospital and the parents of patients who are approaching young adulthood. Including the parents on the task force was of the utmost importance to keep the family-centered focus on the transition plan. Who better to speak to what has been done well and not so well than those who have been through it or who are currently experiencing it with their children? These parents have offered an invaluable perspective on transition. The parents also consistently offer appropriate suggestions, based on their experiences, when discussing the direction of the transition program. While no patients were included on the task force, patient input was gathered throughout the process, beginning with the initial surveys. The patients were always more than willing to share their views on transitioning, what they thought worked well and what did not work well. Every time the task force had new ideas to test, verbal feedback was sought from the patients and considered in the task force decision-making process.

In order to demystify the concept of the adult hospital it was necessary to give the patients, their families, and pediatric medical staff an opportunity to learn more about the adult hospital.

ACCOMPLISHMENTS OF TASK FORCE

The task force began with an initial focus on patients who are closer to the age of transition, which for this institution is 21 years of age. The task force started by looking at preparing patients 15 years of age and older for transitioning to adult care. There was much discussion about the differences between the pediatric and adult hospital, because that seemed to be the greatest concern of the patients and families. The initial thoughts were to focus on the idea "just

because it's different doesn't mean it's wrong." This was soon changed to highlight positive aspects of transitioning to adult care and the adult hospital. The patients and families already knew what was different about the hospitals and programs, and it seemed to be counterproductive to dwell on the fears of those differences, so the focus was changed to be more positive.

In order to demystify the concept of the adult hospital it was necessary to give the patients, their families, and pediatric medical staff an opportunity to learn more about the adult hospital. This is where the idea of an "Orientation to the Adult Program" began. The orientation was held at the adult hospital. All of the patients with CF who were 15 years old and older and their families were invited to attend, as well as the staff from the pediatric hospital. Physicians from both hospitals were involved and spoke at the orientation, performing a symbolic handing off of the baton. The adult program was introduced through a brief slide show. Two young adults who currently receive their CF care at the adult hospital spoke about their experiences. This proved to be a very interactive part of the orientation, as the patients and parents who were in attendance had many questions for these young adults about their transition to adult care. At the end of the orientation a tour was offered that included the CF clinic and inpatient area. In addition to the families that attended the orientation there were many staff from the pediatric hospital present. Familiarizing the pediatric staff with the adult hospital was seen as a crucial step because they are often the ones who the patients talk to about transitioning and it is beneficial for them to have a positive outlook to share with the patients.

In planning for transition, a timeline was started that includes medical information and tasks that patients should know and be able to carry out by certain ages. The current process used to teach patients about CF was examined and it was realized that much of this was missing. At diagnosis, the parents are taught about CF and all of the implications that it entails but there is no formal plan for educating the patients about CF as they get older. Some parents do share the information with their children as they get older, but many do not. To determine what areas of education were missing, a confidence survey was developed for use with the patients. The survey included basic ques-

tions about CF and the tasks that patients need to be able to do in order to manage their own healthcare. The patients were asked to rate their confidence level from 0 (not at all confident) to 5 (completely confident). This helped to determine the areas where the patients needed more information, specifically reproductive health and the importance of a healthy work environment.

To be ready to transition, it was determined that the patients should be comfortable with speaking to their healthcare providers, scheduling their own appointments, recognizing when they need to see their physician, renewing their own prescriptions, and caring for the day-to-day management of their CF. The team soon realized that many of the patients who were approaching the age of transition were not doing these tasks independently. A group of pediatric staff who were involved in the transition task force set out to learn more about the skills of self-management and how to teach the patients to manage their own healthcare, so they would be ready for transitioning to the adult healthcare world. This group took ACCEPT (Advancing Communication and Care by Engaging Patients) training, which was offered at the medical center.

Throughout the course of this training the group learned about motivational interviewing, asking open ended questions, using reflective listening, how to assess a patient's readiness to make changes to improve their health, and how to help them develop a personal action plan to achieve this change. Various members of the medical staff have since begun to use these tools with patients either in the outpatient clinic or inpatient during a hospital stay. This has been met with some success. It was found that patients who wanted to make a positive change in their healthcare were excited about making an action plan and when they were able to follow their plan they have started to change their health outcome. The group has continued to change their approach based on feedback from the patients.

A transition clinic has also been started. A few times a year, when it is needed, there will be a safe hand-off meeting held at the pediatric CF center. The Joint Commission has set a requirement that accredited institutions implement a consistent approach to hand-off communication as one of their patient safety goals. According to the Joint Commission, a successful hand-off involves the sharing of information about the patient between health care providers (Joint Commission, 2008). The transition clinic will be an opportunity for the patient, physicians from both programs, the patient's primary pediatric clinic nurse, and the clinical nurse specialists from both programs to come together and discuss the patient's previous and future medical care needs. There has also been discussion about including a primary inpatient nurse from the pediatric center, if the patient is frequently an inpatient. During this appointment, information is shared between the patient and the staff of both hospitals to make for an easier, more comprehensive transition. After this meeting, the patient's next appointment takes place at the adult CF center, with only the adult staff.

FUTURE DIRECTION

While there have already been significant steps towards a comprehensive transition program for patients with CF at this medical center there is still much to accomplish. Planning is already underway for the second annual "Orientation to the Adult Program." The goal is to make this a yearly event and continue to increase the attendance. There is also the need to continue to work with the staff at the adult hospital and encourage opportunities for shadowing and the sharing of experiences between the pediatric and adult staff. The ultimate goal is to develop a timeline beginning at diagnosis and continuing through transition that outlines the information and skills that patients should develop over time.

IMPLICATIONS FOR OTHER PROGRAMS

While this transition program focuses on patients with CF, similar programs can be put in place when working with patients with other long-term chronic illnesses, including diabetes, sickle cell anemia, Crohn's disease, and many other pediatric illnesses. Despite the different implications for these pediatric illnesses, there are common variables that make the patients affected by them susceptible to a difficult transition to the adult healthcare world. Many young people with chronic illnesses spend a considerable amount of time in the hospital while they are growing up, they often rely on their parents for help managing their illness, and they often resist the idea of moving on to adult healthcare providers. Child life special-ists are in a unique position to champion the importance of transitioning patients to adult healthcare. As advocates for developmentally appropriate healthcare, child life specialists should not forget about what is most appropriate for young adults and work with the multidisciplinary team to prepare them for this change in their healthcare. Healthcare providers owe it to these young people to make a commitment to help them enter the adult healthcare world fully prepared to manage their illness within the context of their adult lives.

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Research in Brief

Child Life Research Outcome Expectations, Interests and Self-Efficacy

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This Research in Brief is included in Focus due to its clinical nature, however it has not been peer reviewed by the Focus Review Board.

Thayer (2007) articulated a vision of child life as a leader in research about pediatric psychosocial healthcare. He suggested that professionals can benefit from a variety of research experiences, whether opportunities for research are afforded at the undergraduate or graduate level or in the professional context. Typical undergraduate students in the social sciences are exposed to research methods and statistics courses in their program of study, but it is often not until graduate school that opportunities for thesis (research-based) are offered. Many students apply for the non-thesis program at the Masters level and even fewer pursue doctoral degrees. While some child life specialists do catch the research bug subsequent to entering the professional field, the level of research training, experience, interest and skills that may exist in the CLC membership is unknown.

A body of research related to research interest in students aspiring to helping professions (undergraduate and graduate level psychology and counseling) has examined relationships among variables such as research interest, expectations, and self-efficacy. Interest in research activities of undergraduate (Vittengl et al., 2004) and graduate psychology students (Bishop & Bieschke, 1998; Love, Bahner, Jones, & Nilsson, 2007) entering helping professions was found to be low. An association between research outcome expectations and research interest has been consistent across a number of studies (Bard et al., 2000; Bishop & Bieschke, 1998; Dremer, Martens & Podchaski, 2007; Kahn, 2001). Interested in predicting scholarly activity in graduate students, Kahn (2001) tested a model that included factors known to influence involvement in research. Students with an interest in working with data and ideas were found to be both excited by research and had positive research out-

come expectations about involvement in scholarly activity. The interest and positive expectations were promoted as students experienced desirable consequences from associations in a positive research training environment.

Research training in child life has not been emphasized in the past beyond the curriculum recommendations of the Child Life Council. However, greater attention to evidence-based practice is now emerging resulting in a heightened understanding of the role that research can play for the future of the profession. The Child Life Council's New Strategic Plan (2008) has an emphasis on supporting and generating research by and for the professional community. Recent articles in the *Child Life Bulletin/Focus* do indicate an increase in reported activity in research related topics but do not allow for the assessment of activity in the child life community as a whole. Thus, the purpose of this research was to survey the Child Life Council membership on research interest, expectations and self-efficacy to allow for a snapshot of the status of research in the eyes of the child life community.

Method

Members of the Child Life Council were contacted and invited to participate in an online survey through the monthly e-newsletter, *CLC Notes*. The invitation and link to the on-line survey were published twice over a 4-week period with a resulting

response rate of 175 (approximately 5% of the CLC membership). The survey results reported here consist of demographic information as well as responses related to current research related activity, and scores from the *Interest in Research Questionnaire* (IRQ, Bishop & Bieschke, 1998), the *Research Outcome Expectations Questionnaire* (Bishop & Bieschke, 1994), and the *Research Self-Efficacy Scale* (RSES, Greeley et al., 1989). As well, a brief summary of responses from one open-ended question is included. *Participants.* The majority of respondents were female (93.1%), Certified Child Life Specialists (73.5%), and working full-time (67.1%). Most of the respondents had completed bachelor degrees (73.5%) and 67.1% had completed graduate degrees in a range of disciplines (child life, arts & sciences, human development, family studies, recreation, music or art therapy, and counseling). Almost 20% identified themselves as students and 12% academics.

Results

Due to the small sample size and potential positive bias of the respondents toward research related topics, statistical analysis of the data was restricted to descriptive rather than inferential procedures.

Table 1 presents the reported research related activity. Some respondents had participated in undergraduate (45.7%) or graduate (35.4%) related research activity. Fewer reported research related professional activity (27.4%) or participation in a journal club (13.1%). Conference presentations (39.4%) and author/coauthor of an article (16.9%) were also reported.

Total scores were calculated for the three questionnaires. Out of a possible score of 40, the mean score for Research Outcome

Table 1. Participation in Research related activity

Participation in Research Related Activity	Yes	No
Journal club	13.1% (23)	86.9% (152)
Presented at conference	39.4% (69)	58.9% (103)
Undergraduate research	45.7% (80)	53.7% (94)
Graduate research	35.4% (62)	64.0% (112)
Professional experience with research	27.4% (48)	72.6% (147)
Author/Co-author article	16.6% (29)	83.4% (146)

* percentages and n do not always add up to 100% (n = 175) due to skipped responses

Expectations (ROE) was 33.29 (SD = 7.51). Out of a possible score of 80, the mean score for Interest in Research (IRS) was 58.03 (SD = 12.04). The mean Research Self-Efficacy (RSES) score, out of a possible 100, was relatively low at 64.33 (SD = 18.9).

Table 2 presents the mean score and standard deviation for the eight items that make up the ROE scale. Overall, respondents indicated agreement that research activity has benefits for themselves and the profession. However, 7.5% (12) did not agree that research activity has benefits for themselves or the profession. Individual item scores indicate that the respondents more strongly agreed that research would benefit the profession compared to items reflective of individual career benefits.

Largely, the mean scores for the IRS scale fell within the interested range. For example, respondents rated *reading a research journal article and being a member of a research team* as more interesting than activities related to the management of data, such as *taking a statistics course or developing a data analysis.* Approximately 17% (30) of the respondents reported that they were either disinterested or very disinterested in research activities.

The RSES included 50 items related to respondents' self-reported competence in their research skills and abilities. Items such as, *follow ethical principles of research, brainstorm areas in the literature to read about, conduct a computer search of the literature in a particular area* and *discuss research interest with peers* were most often rated in the category complete confidence. Items related to data analysis, such as *choose appropriate data analysis techniques,* were consistently rated in the low to moderate confidence range.

Forty-four individuals responded to the open-ended question posed at the end of the survey asking for comments. Overall, the responses were positive, often specifically noting the importance of research for the child life profession, "*I think research on subjects that are pertinent to child life could be very beneficial in continuing to establish the credibility and professionalism of child life specialists.*" Several individuals described their current or past research development, or lack of it, for example, "*I am currently a student in the process of learning statistical procedures and data collection analysis in order to conduct

TABLE 2. RESEARCH OUTCOME EXPECTATIONS MEAN AND STANDARD DEVIATION	
RESEARCH OUTCOME EXPECTATIONS	**MEAN (SD)**
Involvement in research will strongly enhance my child life career opportunities	4.01 (1.1)
People I respect will approve of my involvement in research	4.17 (1.06)
My involvement in research will allow me to contribute to the child life knowledge base	4.43 (1.0)
Research involvement will lead to a sense of satisfaction	4.06 (1.07)
Being involved in research will contribute to my development as a professional	4.30 (1.1)
I believe research skills will be fruitful to my career	3.99 (1.1)
My involvement in research will lead to meaningful contributions to the child life field	4.23 (1.1)
My analytical skills will become more developed if I am involved in research activities	4.12 (1.0)

Scale: 1 = strongly disagree; 5 = strongly agree

research"; "*I have not had any training in research, and therefore, have little confidence in this area.*" Several respondents noted time as a limiting factor for doing research as a child life professional, for example, "*I have the desire and the ideas to complete research just no time permitted or supported in my daily work hours. We are already stretched to cover what we cover and I feel I have no room for additional projects.*"

DISCUSSION

The purpose of this survey was to explore the level of research interest, expectations and self-efficacy of research in the child life community. Because the results of the study are based on a small percentage of the overall Child Life Council membership, an assumed respondent bias toward participation or interest in research is assumed limiting the external validity of the study. The low response rate can be due to a number of factors; the main factor that comes to mind is a lack of interest in the topic of research. Although disappointing, as an optimistic group of professionals, we may be inclined to view this result as evidence of the glass half-full. That is, the study does indicate that there may be a core body of approximately 50 individuals in the profession who may be inclined to pursue research now or in the future.

Research activity reported by the respondents was low. One basic activity, journal club for example, had only 13.1% indicating current participation. Undergraduate and graduate level and professional research activity was more promising as results indicate a core group with at least basic knowledge of the research process. Overall the summary

scores do indicate a moderate level of interest and self-efficacy related to some aspects of the research process. Although the research reviewed here addresses students rather than professionals in the field, there is perhaps a lesson to be applied to the child life profession. Indeed, because the profession is interested in promoting increased research and scholarship, the development of a positive research milieu must include attention to the identification of specific outcomes for both the individual and profession and increased opportunities for training.

FUTURE DIRECTIONS

Strategies promoting the involvement of child life professionals in research related activities can be shared across the professional community through networking, publications (such as the *Child Life Bulletin/Focus*) and conference activities. Suggestions include:

1. The identification of individuals who are currently actively engaged in research and those interested in becoming involved in research activities.

2. The establishment of a network for the communication of research activities and interests (e.g., online journal club, online forum; conference networking round table).

3. The introduction of basic research training workshops at conference or continuing education opportunities online (e.g., reviewing a research article, basic concepts of research, generating research ideas).

4. The communication of expectations to the Child Life Council membership and partners that research-based information is a required foundation for the development of new programs, materials and publications.

5. Advocacy for the inclusion of research training, development and participation as a component for at least one staff position in a department.

6. A focused effort to establish the credibility of research activity as it serves to benefit individual career paths and the profession through recognition and reward.

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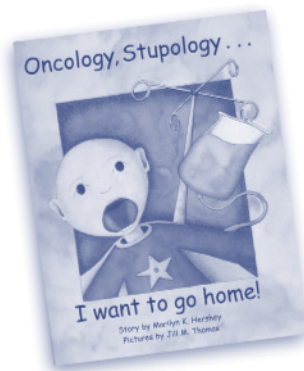
MILESTONES

Hired: Cathie Marshall, CCLS, was recently promoted to Child Life Manager at Cincinnati Children's Hospital Medical Center.   Cathie has been serving children and families within the child life profession for over 22 years.   She joins the leadership team that includes a senior clinical director and two other clinical managers.   Previously, Cathie was a child life specialist in the Emergency Department at Cincinnati Children's.

Published: Joan Turner, PhD, CCLS, and Jessica Fralic, CCLS, were recently published in the journal, *Child and Youth Care Forum*, for their article "Making Explicit the Implicit: Child Life Specialists Talk About Their Assessment Process." *Child and Youth Care Forum (2009) 38:39–54.*

Research in Brief

EXAMINING CHILD LIFE SUPPORT FOR INFANTS UNDERGOING RETINOPATHY OF PREMATURITY EYE EXAMS: A PILOT STUDY

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Private Practice Child Life Consulting and Therapeutic Services;
Child Life Officer, Daisy's Eye Cancer Fund, Registered Kenyan NGO, Registered UK, and Sick Kids Charity

This Research in Brief is included in Focus due to its clinical nature, however it has not been peer reviewed by the Focus Review Board.

In any ecological system, illness creates stress (Ambuel, Hamlet, Marx & Blumer, 1992). The ability to cope with the stresses caused by illness is important to survival and is also a foundation for growth and change in human development (Gardiner & Kozmitzki, 2008). Studies of infant distress have concluded that infants undergo significant distress during procedures and events, such as retinopathy of prematurity (ROP) eye exams (Halliday, 2006). Numerous studies suggest a mix of support techniques can assist infants in coping with pain during medical procedures (Mitchell & Brooks, 2000). Because child life specialists have been identified as an important addition to the interdisciplinary pediatric healthcare team in the management of medically fragile infants (Ueda & Caulfield, 2001), the evaluation of the efficacy of child life interventions is key to the development of nonpharmacologic interventions for infants. Therefore, the following pilot study was developed in order to begin the process of evaluation of child life interventions developed to support infant coping during ROP eye exams. The goal of this presentation of two cases is to report the measurement of change in infant behavior following specific child life interventions developed to assist infants' coping during an ROP eye exam.

Child life specialists provide supportive interventions using techniques that assist and promote coping in children of all ages. However, at present there is no best practice standard of child life interventions and supportive care focused on the specific needs of infants during hospitalization and medical procedures. Ueda and Caulfield (2001) found hospitalized infants receiving child life support showed significantly less emotional distress, more effective coping and better post-hospital adjustment than those who did not receive child life care. The specific child life interventions presented in this study consisted of three 30-minute support sessions that included the introduction and practice of comfort positioning, infant massage and caregiver education/information regarding the ROP exam, the benefits of parental presence and support, as well as developmental information, all followed by a review (contact the author for details). A change in infant distress scores following child life interventions and support was the expected outcome of the study.

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METHOD

The study took place over a 4-week period. A purposive, convenient sample of infants and caregivers was recruited from the clinic population resulting in two cases that met the study criteria and for which consent was obtained. A pre-post test design was used. Descriptive analysis of change in infant behavior between the pre and posttest, as measured using the COMFORT SCALE (Ambuel et al., 1992), will be presented here.

The COMFORT SCALE is a valid and reliable standardized assessment tool used to assess pediatric patients receiving routine nursing care. The scale consists of six behavioral and two physiologic items. Trained observers used the tool during a 2-minute observation of the infant. Inter-rater reliability has been reported as .84 (p < .01) and internal consistency as 0.90 (Ambuel et al., 1992). Higher scores on the scale indicate greater distress and less comfort, with a target range of total scores of 17 to 26 out of a possible score of 40. Two independent observers (a clinic nurse and an Opthamology fellow) rated the infants on alertness, calmness/agitation, crying, physical movement, muscle tone, facial tension, and a VAS pain scale during a ROP eye exam.

RESULTS

Descriptive analysis of the obtained scores of each observer allows for the observation of change between the pre and posttest measurement. Table 1 presents the raw data obtained for each observer at the pre and the posttest. A comparison of the ratings for cases 1 and 2 show that the total COMFORT scores decreased from the pretest to the posttest. The greatest change in scores is observed in the case 1 ratings by the Opthamology fellow. The least change in scores is observed in the case 2 ratings by the Opthamology fellow. The observed change in scores in ratings by the clinic nurse is consistent across the two cases.

DISCUSSION

The goal of this pilot study was to report on the measurement of change in infant behavior following specific child life interventions developed to assist infants' coping during an ROP eye exam. Two independent observers used the COMFORT SCALE to record infant behavior at the pretest and posttest stages of the study. Descriptive results indicate that the ratings of infant behavior fell near the expected range of scores at both the pre and posttest.

Although good inter-rater reliability was observed, it appears that the ratings of one observer were more consistent than the other observer. One purpose of conducting a pilot study is to prepare study technicians for data collection by allowing them to practice and

TABLE 1. PRE AND POSTTEST COMFORT SCALE SCORES

COMFORT SCORE INFANT CASE 1	Pretest	Posttest	Pretest	Posttest
Item	Nurse	Nurse	Fellow	Fellow
Alertness	4	4	4	4
Calmness/agitation	3	2	2	2
Crying	2	2	2	2
Physical movement	3	2	4	2
Muscle tone	3	2	4	2
Facial tension	4	2	4	2
VAS	3	1	7	2
Total (out of 40)	22	15	27	16
COMFORT SCORE INFANT CASE 2	**Pretest**	**Posttest**	**Pretest**	**Posttest**
Item	Nurse	Nurse	Fellow	Fellow
Alertness	4	3	2	3
Calmness/agitation	3	2	2	2
Crying	3	2	2	2
Physical movement	2	2	3	2
Muscle tone	4	2	4	2
Facial tension	3	2	3	2
VAS	2	2	3	1
Total (out of 40)	21	15	19	14

refine their observational skills and follow protocol. Examination of raw data, therefore, allows the researcher to watch for subtle discrepancies and address issues early in the study timeline. These data indicate that further practice observing and rating infant behavior may lead to greater consistency in ratings across cases.

Consistent with the findings of Ueda and Caulfield (2001), the supportive child life interventions appear to have influenced a positive change in the level of distress observed during the ROP eye examination. However, caution must be taken when examining data obtained from the two cases as issues of internal validity must be considered; for example, as a non-intervention control group was not included, the comparison of scores between groups was not available. Further, the observers were not blinded as to the intervention status of the infants and may have inadvertently been biased. Although the study framework of 4-weeks provides some control over the influence of normal growth and development of infants over time (maturation), the potential effects of familiarization of the ROP eye exam at the posttest should be recognized.

The benefits of reporting the results of a pilot study include allowing for reflection on the research design and protocol with an eye towards strengthening subsequent data collection. First, it is anticipated that a larger sample size will be obtained for the next stage of the study. This will allow for the application of inferential statistics and a comparison across groups, resulting in the ability to test hypotheses and apply statistical control. Second, as the project progresses, attention paid to the experience and practice of the trained observer-raters will allow for the calculation of inter-rater reliability on a larger sample with an assumed greater variability of scores. Subsequent reporting of the study procedures and results will include greater attention to the description of the child life intervention. Full description and documentation of the child life intervention process allows colleagues to consider the results of the evaluation relative to their own programs and interventions.

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CERTIFICATION CORNER

RECERTIFICATION

For Certified Child Life Specialists whose certification cycle will expire on December 31, 2009, applications to recertify through Professional Development Hours (PDHs) are due on June 30, 2009. Applicants will be notified if more information is needed or if their application has been randomly selected for audit. After the applications have been reviewed and the audit process is complete, individuals whose applications have been accepted will receive new certificates by mail late in the summer.

If you have not submitted an application to recertify by PDH and your 5-year certification cycle will expire on December 31, 2009, you can still recertify through PDHs. CLC will accept late submissions through the end of October. Candidates who apply for recertification between June 30 and October 31 are required to pay a $50 late fee and submit all supporting documentation (e.g. certificates of attendance) of the PDHs submitted. Late applications must be submitted by mail.

Recertification candidates may also recertify by taking and passing the November 7, 2009 Certification Exam.

FALL 2009 EXAM ADMINISTRATION

The following cities have been designated as sites for the November 7, 2009 Child Life Professional Certification Exam:

- Chicago, Illinois
- Columbus, Ohio
- New York, New York
- San Antonio, Texas
- Seattle, Washington

Applications for this exam are due by August 31, 2009 for anyone educated within the US or Canada, and by June 30, 2009 for those educated outside the US and Canada.

For more information on recertification options, please visit http://www.childlife.org/Certification/Recertification.

Please contact Ame Enright, Manager of Certification, at certification@childlife.org with questions about the certification program.

UPCOMING CHILD LIFE EVENTS

AUGUST 17-19, 2009

The 4th International Conference on Patient- and Family-Centered Care: Partnerships for Quality and Safety
Philadelphia, PA
Contact: 301-652-0281 or www.familycenteredcare.org

SEPTEMBER 3-4, 2009

Child Life on the Team: Supporting the Child From Primary Care to Intensive Care
Johns Hopkins Children's Center, Child Life Department
Contact: Patrice Brylske, 410-955-6276 or pbrylsk1@jhmi.edu

SEPTEMBER 11-13, 2009

Where the Stars of Child Life Come to Play
Florida Association of Child Life Professionals. The Crowne Plaza Hollywood Beach, Hollywood, FL
Contact: Rebecca Hahessy, rebecca.hahessy@deliverthedream.org or 954-564-3512; www.faclp.org

SEPTEMBER 12, 2009

Great Lakes Association of Child Life Professionals Conference
Nationwide Children's Hospital
Contact: Donna Trentel, donna.trentel@nationwidechildrens.org or 614-722-4287

NOVEMBER 5, 2009

Child Life of Greater New York 16th Annual Professional Development Conference
New York City, NY
Contact: Sharon Granville, sharon.granville@mountsinai.org or 212-241-8639

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Child Life Council

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Article Review:
Reflective Journaling for Self-Assessment and Writing Initiatives

Joan C. Turner, CCLS, PhD, Mount Saint Vincent University, Halifax, NS, Canada

This Article Review is included in Focus due to its clinical nature, however it has not been peer reviewed by the Focus Review Board.

My recent participation in a journaling workshop at the 27th Annual Conference on Professional Issues has motivated me to take a look at some of the literature related to the application of journaling as a reflective technique for professionals working with children and families. Susan "Boon" Murray inspired my interest through her discussion of journaling techniques to help children and families coping with medical events. As a professor and Executive Editor of the *Bulletin/Focus*, I have an interest in finding ways to motivate others to engage in writing activities. The article by Kremenitzer (2005) reminds us of the influence of early childhood educators on the social emotional development of young children and challenges practitioners to apply reflective practice as a way to monitor and reassess our own social and emotional skills. Similarly, child life specialists can apply these practical approaches grounded on ideas from the field of Emotional Intelligence (EI).

Kreminitzer (2005) reviews three variations on self-reflective journaling. First, four branches of EI abilities are highlighted related to: 1) perception, appraisal and expression of emotion; 2) emotional facilitation of thinking; 3) understanding and analyzing emotions; and 4) reflective regulation of emotions. Through the presentation of a series of focused questions, individuals are encouraged to write down their personal appraisal and generate ideas for increasing their abilities relative to each category. This activity raises awareness of the place of EI in our daily practice and can be used for repeated self-assessment over time.

The term, *hyper-awareness scripting,* is used to explain the notion of practices to facilitate an increased awareness or sensitivity for details of *what we do* as we move through our planned and, more often than not, spontaneous encounters over the course of each day. The second variation on reflective journaling involves the initiation of a "Focused Daily EI Journal." Whether conducted upon the initiation of an individual, peer group, or a method for meeting a professional development requirement, daily journal entries allow practitioners to stop and consider components of their busy days in light of the need to regulate and manage emotions in response to, in particular, unanticipated and difficult spontaneous situations that may arise requiring the suspension of judgment and quick emotional adjustments.

The final self-training exercise is used to facilitate the heightened awareness required to make a quick emotional transition when faced with unanticipated challenges in the moment. Brief daily notations reflecting on these challenges include a definition of emotional state using a five-point scale, as well as notes on ways in which you were able to move through the situation and reach a neutral state of emotion through the adaptation of your initial response. The final step of this process engages the professional in an extended reflection entry. Documentation of evidence over time of EI in practice (the author suggests a three-week minimum) allows for the observation of patterns of success or need for modification – ultimately a self-check.

Although reflective journaling in general is often encouraged during practicum and internship experiences, I offer this review for consideration of reflective journaling beyond the novice years as a mode for the promotion of self-improvement and the launch of writing activity into daily practice. Some professionals may have the inclination and discipline required for the maintenance of a reflective journal, others may need to find the motivation to initiate both the self-appraisal and the writing aspect of the practice. Interested professionals may see examples in the early childhood education literature of activities similar to those used in their professional practice. Consider starting to journal your activities to develop and share in *Bulletin/Focus.*

Child Life Alphabet

becoming your partner as you watch and listen to what the infant is 'saying' about what makes him feel good or what is upsetting to him (Raeburn, 2005).

Developmentally supportive care can be implemented by child life specialists minimizing noxious stimuli (loud noises, unnecessary interruptions from sleep, bright lights) while individualizing infant care and stimulation based on an infant's observable physiologic responses (heart rate and breathing) and behavioral cues based on the Synactive Theory of Development (Als, 1982). The Synactive Theory describes five systems that are in constant interaction as the autonomic (heart rate and breathing), motor control (movement and posture), state regulation (level of sleepiness and wakefulness), attention and interaction, and self-regulation. The goal for child life specialists is to provide premature infants with appropriate amounts and kinds of stimulation, similar to the kind they would have received in the womb, while protecting them from things that make them feel overloaded or stressed (Als, 2003).

There are numerous ways child life specialists can include developmental care in the NICU:

- **Adjust the Environment:** Reducing light and noise decreases the stress level of premature infants.

- **Reduce Pain:** Swaddling infants, positioning them to encourage self-regulation (including midline orientation, hand-to-mouth activity and proper flexion) and providing pacifiers and sucrose can help in pain reduction.

- **Position with Support:** Positioning infants with supportive bedding can help to prevent deformities due to being on their backs for so long and reduce behavioral disorganization and long-term disabilities. Proper positioning will provide infants with opportunities for self soothing if their hands and fingers are placed near their mouths. Position infants in flexed or tucked position which increases feelings of security and containment. Swaddling or body containment is also important as it increases an infant's feelings of security and self-control and decreases stress.

- **Observe Behaviors:** Pay close attention to an infant's behavior to learn when his natural sleep and wake cycles are and plan procedures around an infant's natural wakefulness (clustering). Provide 'time-outs' as needed with hand swaddling and containment.

- **Involve the Family:** Including family members in their infant's care is a crucial aspect of developmental care. Helping parents learn how to read their baby's cues will help them gain confidence in their parenting and promote healthy attachment. Encouraging parents to provide their baby with skin-to-skin (kangaroo) care will benefit both mother and baby and father and baby.

RESOURCES

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The Brazelton Institute — www.brazeltoninstitute@childrens.harvard.com

Contemporary Forums conferences — www.contemporaryforums.com

Bank Street College of Education, NY, NY course — The Neonatal Intensive Care Unit: Introduction to Supporting Infants and Their Families and Working with the Healthcare Team; www.bnkst.edu

Neonatal Individualized Developmental Care and Assessment Program (NIDCAP)

National Association of Neonatal Nurses — www.nann.org

Institute for Family-Centered Care — www.familycenteredcare.org

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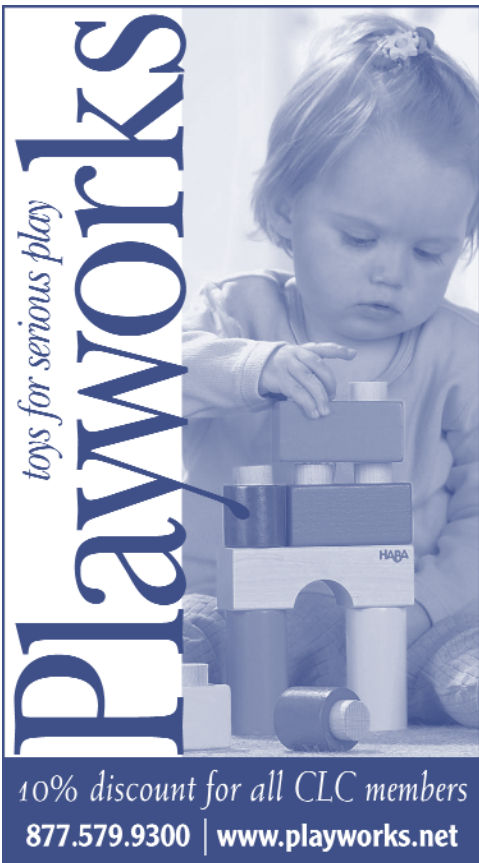
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30 Deadline for recertifying by Professional Development Hours (PDHs)

30 Deadline for applications for the November administration of the Child Life Professional Certification Exam for those educated outside the U.S. or Canada

JULY

15 Deadline for *Bulletin* and *Focus* articles for Fall 09 issue

30 Deadline for abstract proposals for the 28th Annual Conference on Professional Issues

AUGUST

31 Deadline for applications for the November administration of the Child Life Professional Certification Exam for those educated within the U.S. or Canada

SEPTEMBER

17-20 CLC Conference Planning Meeting

OCTOBER

15 Deadline for written requests to withdraw from November Administration of the Child Life Professional Certification Exam

NOVEMBER

7 Child Life Professional Certification Exam Administration

13-14 CLC Executive Board of Directors Meeting

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