Child Life in Guatemala, a Paradigm Shift in Pediatric Healthcare

by Kurt Ludwig Jenatz, CCLS, MD, Child Life Coordinator, National Pediatric Oncology Unit, Guatemala

In October 1996 I was invited to participate in a continuing medical education course in dermatology at Texas Children’s Hospital. As a newcomer to such an immense medical center I was thrilled to experience my first academic visit to a pediatric facility in the United States. Little did I know of the fascinating events that would take place during the next couple of weeks. Upon arrival, my friend Dr. Fernando Stein welcomed me and later introduced me to the dermatologist, Dr. Moise Levy.

My first rotation would be the outpatient clinic at the Clinical Care Center. One day a 10-year-old child came into the clinic. His hands and arms were covered with warts, which had to be frozen with liquid nitrogen. Dr. Levy introduced the boy to a child life specialist who worked with him for about 15 minutes and then escorted him to the procedure room. I had never heard of a child life specialist before; nor did I know what had taken place during the “preparation” session. The doctor explained the procedure to the boy and started freezing the warts one after the other.

From personal experience, I knew how painful such a procedure could be. (See GUATEMALA, p. 5)

Kuttner Featured

Leora Kuttner Ph.D. will present a half-day intensive session and the closing plenary session at the Child Life Council’s 21st Annual Conference on Professional Issue in Montréal May 23-25. Dr. Kuttner is a Clinical Psychologist internationally recognized for her work in pediatric pain management, and is Clinical Professor, in the Department of Pediatrics, UBC at BC Children’s Hospital, Vancouver, BC, has published 22 articles, the book “A Child in Pain: How to Help, What to Do” and produced and directed three documentaries on pediatric pain management. Her closing plenary session, “The Changing Face of Pediatric Pain & the Role of Child Life in the Last 20 Years” will examine the past, the present and take a glimpse into the future of the management of children’s pain. The intensive session, “Helping Ease Children’s Pain,” will be an exploration of “hands on” techniques for engaging anxious children in the process of getting through painful medical procedures.
FROM THE PRESIDENT

CLC Strategic Planning Begins; Input Encouraged

by Melissa Hicks, MS, CCLS, LPC, NCC, RPT

Spring is such a wonderful time of year. It helps to remind us of growth and renewal. As I write this article we are in the middle of Child Life Month. I hope you all are celebrating the value of our profession and the richness it provides in our own lives and the lives of those impacted by child life specialists. Additionally, it is one further opportunity to highlight needs of children and families impacted by challenging situations in a variety of settings.

The strategic planning initiative for the Child Life Council is underway, with the first meeting to be held early in April. Through questionnaires the entire membership will have the opportunity to provide input regarding the growth and priorities for our organization. I strongly encourage each of you to participate in this important information-gathering phase of the strategic planning process. The CLC Board’s goal is that the plan be reflective of membership needs, as this is a process aimed at planning for the organization, not the profession.

This time of year is always exciting as we prepare for our annual conference. I hope you will join us in beautiful Montréal for the Child Life Council’s 21st Annual Conference on Professional Issues. The conference is always such a wonderful time to network with colleagues, learn new ideas and revalidate some old ones. It is a time to recharge your professional batteries. Another important aspect of the conference is meeting other professionals and mentoring newer professionals. I encourage each of you to meet at least one person you did not know before at this conference.

In addition to the high quality program the conference planning committee has put together, there are many additional highlights at this conference. The Child Life Council and Toys ‘R Us will be awarding the first B.J. Seabury Scholarship. This year’s recipient will receive the scholarship funds for each of his/her final two years of study.

The Distinguished Service Award will be bittersweet this year. The recipient is Kathie Moffat. Kathie truly was a pioneer in the child life profession and her absence is felt. The Board felt that it would be particularly meaningful for Kathie to receive the award in her hometown and was thrilled when the conference was to be held in Montréal. We would have never thought that Kathie would not be with us; although I am sure she will be “with” us at conference. We are hopeful that her son, Brady, will be at the conference to receive the award on Kathie’s behalf.
FROM THE EXECUTIVE DIRECTOR

Still Time to Register for Montréal!

by Susan Krug, CMP, CAE

The Child Life Council staff and leadership are energized for the Annual Conference in Montréal May 23-25. The enthusiastic involvement and outstanding input of our volunteer members and the staff will surely culminate in a program that exceeds expectations. The CLC’s goals for lifelong learning, building relationships, and professional advancement are clearly evident from the tremendous program that is in place. Please join us to deepen your skills, strengthen your involvement in the CLC, and share ideas with colleagues from across the globe. To register visit our website www.childlife.org.

I continue to work with staff and volunteers to strengthen the organization’s structure, operations, programs, and initiatives. All of these actions and developments are designed to meet the changing needs of child life professionals. We now have a new phone system that provides each staff member with voicemail, so you can leave us messages directly. We continue to add new information to our website. We have implemented new and updated programs like the B.J. Seabury Scholarship, Research Competition and the re-vamped Program Review Service.

The most exciting recent update is the upgraded listserv software. The CLC staff and leadership are pleased to offer this new and improved service in response to member requests. The new CLC Forum allows members to manage their own subscriptions via the web! The new software features a web interface that will allow you to change your email address, view archived messages, stop service for a specified amount of time, or unsubscribe yourself. If you are not currently on this members-only listserv, and would like to try it out, email Stacy Berkowitz sberkowitz@childlife.org.

Thank you for participating in our programs that are designed for your advancement. I look forward to meeting you in Montréal!

RESEARCH REVIEW

Children’s psychological responses after critical illness and exposure to invasive technology.

Reviewer: Kellie Morehouse, MA, PC, CCLS, Child Life Specialist, Columbus Children’s Hospital, Columbus, OH


Introduction

This study compared the psychological responses of children hospitalized in a pediatric intensive care unit (PICU) with those on a general ward. The relationship between age, number and type of invasive procedures, severity of illness, and length of stay on a child’s psychological responses post-discharge was examined.

Method

The study sites were two Canadian, university-affiliated children’s hospitals. Sixty children were recruited from the PICUs, and 60 children from the medical and surgical wards and were matched according to age and illness categories. Eligibility criteria included: 6 to 17 years old; understood and spoke English or French; had at least one parent who read, wrote, and spoke English or French; was ready for discharge; and had either been in the PICU at least 24 hours or had been on the medical/surgical ward for at least 24 hours without previous admission to the PICU.

CORRECTION

All nominees for Executive Board and CLCC positions hold the CCLS credential. The 2003 slate of nominees should have read as follows:

Treasurer
Kelly Gleason, CCLS
Cincinnati, OH
Jane Jarboe, CCLS
Columbus, OH

CLCC Chair #1
Cynthia Huffman, CCLS
New York, NY
Amanda Littlejohn English, CCLS
Toronto, ON

Member-at-Large
AnnMarie DiFrancesca, CCLS
Mineola, NY
Linda Skinner, CCLS
Halifax, NS
Michael Towne, CCLS
San Francisco, CA

(See RESEARCH, p. 4)
RESEARCH  
(continued from p. 3)

Length of hospital stay, severity of illness, and number and types of invasive procedures were measured at the time of discharge. Three child questionnaires and one parent questionnaire were mailed to families at six weeks and six months post-discharge to assess medical fears, locus of control, and post-hospital behaviors.

Results

There were no significant group differences found between children hospitalized in a PICU versus those hospitalized on a general ward at six weeks or six months post-discharge. When data from the three child measures were analyzed using the multivariate analysis of covariance with repeated measures, it showed no significance for group, but showed a significant relationship with age.

The Children’s Health Locus of Control showed that younger children and children who were more severely ill tended to exhibit a lower sense of control over their health. At six weeks post-discharge, 8.5% of all hospitalized children had internal locus of control scores that were at least 20% below those seen in a well population. At six months post-discharge, 7.5% continued to show a lower sense of control over their health.

The Children's Impact of Events Scale determined that the number of invasive procedures a child is exposed to as well as the absence of a family member predicted higher scores, meaning more intrusive thoughts and avoidance behaviors. This scale also indicated that psychological responses are not resolved in six months post-discharge.

Children's Medical Fears Scale indicated that younger children, those exposed to a higher number of invasive procedures, and females tended to have more medical fears. Of all hospitalized children, 17.5% had significant medical fear scores at six weeks post-discharge and 14% at six months post-discharge.

Discussion

This study concluded that it is not the location of a child’s hospital stay but rather the perception of their hospital experience that affects the child’s psychological responses. The factors surrounding the hospitalization experience that were most closely associated with psychological outcome were age and number of invasive procedures. Length of stay showed minimal effects on psychological responses; which the authors attributed to the possibility that some children adapt to hospitalization over time.

The authors addressed limitations of the study. The Post-hospital Behavior Questionnaire contained question items deemed inappropriate for older children and this questionnaire may have lacked sensitivity to measure behavior change over time. The Children’s Health Locus of Control and the Pediatric Risk of Mortality Scale likely underestimated scores. The content validity of the Children’s Impact of Events Scale was in question due to its modification from an adult scale. Other study limitations were associated with the mailing of the questionnaires, which created the potential for biases since parents and siblings could influence the child’s answers.

The findings in this study showed invasiveness and severity of illness in young children may cause adverse long term effects, which according to the authors, “...indicated that hospital programs geared toward providing psychological support to these children are particularly important.” (141) Both hospitals in the study provided psychological support services, of which

A Publication of the Child Life Council
RESEARCH
(continued from p. 4)

child life programs were listed first. There are several implications for child life specialists. It is critical to accurately assess a child’s coping during hospitalization, taking into account age, severity of illness, and number of invasive procedures. Interventions to decrease the negative impact of invasive procedures, such as preparation, medical play, and distraction, are crucial. This study indicates that some children are adversely affected weeks and sometimes months post-discharge, so the question arises: should child life specialists provide follow-up services post-discharge? At the very minimum, child life specialists should be providing information to families prior to discharge on what behavioral changes to look for at home and when to seek additional help. The findings of this article indicate the need not only for further investigation of the psychological impact on hospitalized children, but how child life specialists and other multidisciplinary professionals are addressing these issues.

GUATEMALA
(continued from p. 1)

be and I was ready to restrain the child if he didn’t cooperate with the treatment. However, something was happening, the child was reacting quite differently from what I had imagined. Although he was whining, sobbing, making grimaces and fidgeting with his feet, he never even attempted to pull his arms away from the doctor. After a while, which must have seemed like an eternity to the young patient, the doctor joyfully announced that he had finished with the procedure. The boy disagreed and with tears rolling down his face told Dr. Levy in a fragile voice: “You missed one!”

I could not hold back my astonishment at the prospect of this brave boy who had courageously endured the painful procedure, and dared to point his finger at an overseen wart. Something must have influenced the kid to “behave bravely” during his ordeal. What had made the difference in this case? Had the child only feigned stoicism to avoid being punished?

Some time later I did find out that the child life intervention, through play and the use of a teaching doll, had had a decisive effect in preparing the boy for the procedure. As incredible as it may sound, this and countless similar experiences at the dermatology clinic changed my whole way of thinking about traditional medical care for children. From that day on, my attitude and expectations regarding pediatric healthcare delivery were overturned. I also became acquainted with the foremost importance and effectiveness of psychosocial support and medical play during anticipatory interventions.

Before I learned about child life, I was completely “doctor oriented.” My thoughts were on what I had learned in my student years and pediatric residency – the way it’s written in the books, the way it’s been done for centuries. I had finally been taught a quintessential lesson, one that urged me to reconsider my course of action.

A few years later, my admiration for child life had grown tremendously. I decided to drop my private practice and become an advocate in my country. Child life is a totally new concept in Guatemala and introducing its philosophy has been an extraordinary and challenging mission.

In the fall of 2000 I felt it was time to have a hands-on experience in child life theory and practice. I applied to Miami Children’s Hospital and was accepted to do the internship. Joneen Corrao, the department’s director and her wonderful staff made me feel right at home and gave me the very best options in child life training.

In April 2001 the first child life program of Guatemala opened at the National Pediatric Oncology Unit. The hospital is a 28-bed reference facility for the whole country. Approximately 600 children with cancer are being treated and 12 to 17 new patients are diagnosed monthly. As program coordinator, my vision is to change the face of pediatric healthcare. To bring the respect for children up-front, where they have options and their opinions and feelings are acknowledged. The child life program has constituted a valuable resource to allow little patients to master the experience in a positive way and promote appropriate coping skills. Psychosocial interventions, healthcare play including medical play; recreation and education are core subjects of the daily programming. We strive towards a more humane and compassionate care of the patient; thus, enhancing the emotional wellbeing and the quality of life of the child and the family.

Today, I have the emotional reward that I’m actually doing something. Change is hard to go through in the healthcare field; but this “paradigm shift” has impacted medical care in Guatemala beyond my expectations. I agree enthusiastically with the following thought written by Dr. Hunter “Patch” Adams in his inspiring book Gesundheit:

“When a dream takes hold of you, what can you do? You can run with it, let it run your life, or let it go and think for the rest of your life about what might have been.”
The Child Life Council (CLC), established in 1982, offers its annual conference as an educational opportunity for individuals to come together and focus on issues that relate to the profession. Authors are requested to read this Call for Papers very carefully before writing their proposals. Adherence to the following submission guidelines is required for consideration.

**CONTENT AREAS:**
CLC seeks abstracts on current topics including, but not limited to:

- Administrative Issues
- Adolescents
- Assessment
- Bereavement
- Child Abuse and Neglect
- Chronic Illness
- Clinical Skills
- Completed Research
- Complex Practice Issues
- Cultural Diversity
- Documentation
- Emergency Care
- Environment
- Ethics
- Families
- Holistic Health
- Infants
- Non-Traditional Settings
- One-Person Programs
- Pain Management
- Practice Standards and Protocols
- Preparation
- Program Development
- School Issues
- Siblings
- Special Populations
- Staff Development
- Student Issues
- Technology
- Trauma

**SUBMISSION GUIDELINES:**
1. Abstracts are reviewed in conjunction with the *Child Life Council Standards of Clinical Practice*. Abstracts must reflect child life issues and be presented by child life specialists or other qualified professionals.

2. Authors are limited to two abstract submissions per conference.

3. The CLC uses a **blind review process** for the first two of three committee reviews. **Authors and institutions must NOT be identified by name or description in the cover sheet, abstract, outline, or summary. The use of institution letterhead is not permitted.**

4. For abstracts reporting research activities, **research must be completed at the time of submission.**

5. Authors whose abstracts are accepted are expected to present and must register for the conference. If an author is listed on your abstract submission, s/he will be expected to present. Authors are responsible for all travel, hotel, and related costs. CLC will cover a portion of the AV expenses, which usually equals the cost of a slide or overhead projector (approx. $85). AV costs could be $350 or higher per session for an LCD projector.

**INFORMATION TO BE SUBMITTED**
*(please note changes from previous years):*
Collate items (one copy of II-VI in each set) into sets using paper clips only *(no staples, please).* Include the title of the abstract on each page of the submission. In addition, please e-mail your abstract (Items I – VII) in **Word or Word Perfect format** to clcstaff@childlife.org. If you prefer, you may include a copy of your abstract on disc with your hard copies.

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**I. Author Information Sheet**
(2 copies)
For each author, list full name, academic and professional credentials, position title, affiliation, mailing address, telephone and fax numbers, email address, and author’s expertise which qualifies him/her to present this topic. One author should be designated as the contact person. All correspondence pertaining to abstract submission will be sent to the contact person. Author information will be listed in the conference program as submitted on the cover sheet.

**II. Cover Sheet** (8 copies)
One page, with the following information:
- **Title** - make it descriptive and engaging.
- **Content Area**
- **CLC Standard(s) of Clinical Practice Reflected in Abstract**
- **Exact Word Count of Abstract** (300 word minimum and 1 page maximum)
- **Exact Word Count of Summary** (50 word maximum)
- **Audience Level** - Choose one: Entry Level, Intermediate Level or Advanced Level. NOTE: “All levels” is not an option.
- **Presentation Format and Length of Session** – Choose one format:
  - **Clinical Case Discussion**: 1- or 2-hour clinical description of issues through case presentation (limit: three panel members and one facilitator).
  - **Intensive Seminar**: 2-hour or ½-day in-depth session addressing a single topic (limit: three authors).
  - **Workshop**: 1-hour or ½-hour presentation including discussion (limit: three authors).
Panel Discussion: 1-hour, 1½-hour or 2-hour examination of specific topic/issue (limit: three panel members and one facilitator).

Poster Session: Visual display of project or innovative program relevant to child life. All content must be displayed on the board provided. Audiovisual equipment may not be used. Poster sessions will be staffed for a designated time slot and will be limited to two authors due to limited space.

III. Abstract (8 copies)
Each abstract must be written in narrative form. The abstract must be a minimum of 300 words, a maximum of one typed page, and font size 10point or larger. The abstract must include all of the following: the purpose of the presentation; a description of the originality, innovation and/or timeliness of the topic; application of the information to other child life programs and benefits it will offer; cultural implications; and reference to the theoretical base or research that supports your position. Information presented should be relevant to attendees from institutions of varying sizes (e.g., large pediatric centers to one-person programs to community setting).

IV. Organization of Presentation
(8 copies)
Outline of presentation. This is a general “walk-through” of your key points. Specific details are not needed.

V. Objectives (8 copies)
List at least three behavioral learning objectives (i.e., “The participants will...”).

VI. Summary (8 copies)
A 50-word (maximum) summary of the presentation. (Include summary word count on the cover sheet.) This summary will be used for the conference program.

VII. Curriculum Vitae
(1 copy for each author)

VIII. Self-Addressed Stamped Envelope (if you wish to confirm that the proposal was received) (optional) ABSTRACT REVIEW:

ABSTRACT REVIEW:
This Call for Papers is designed to elicit information necessary to review content and organization of proposed presentations. Authors are required to follow these directions precisely; submissions which do not adhere to all guidelines may not be considered by the Conference Planning Committee.

Abstracts are reviewed three times by members of the Conference Planning Committee. Each abstract is rated according to:

- Quality of Content: Evaluation of the
  - statement of purpose
  - originality and innovation of topic or approach
  - application of concepts or skills in a variety of settings or with various populations
  - theoretical foundation/research citations
  - strength of authors’ background to present topic
- Quality of Abstract Organization: Evaluation of how clearly, logically, and professionally the information in the abstract is presented as well as adherence to abstract format as described above.

Contact persons will be notified in writing of the Conference Planning Committee’s acceptance or declination of each abstract submission. Contact persons for accepted abstracts will sign a contractual agreement with the Child Life Council that indicates each author’s commitment to speak and present the content of the session as accepted by the Conference Planning Committee. In order to create a balanced overall conference program, the Conference Planning Committee may request changes to presentation format or length in accepted abstracts; the contractual agreement would indicate any such changes.

Submissions must be postmarked by August 15, 2003
Address all submissions exactly as follows:
2004 Call for Papers
Child Life Council
11820 Parklawn Drive, Suite 202
Rockville, MD 20852-2529
clcstaff@childlife.org

NOTE: TO BE CONSIDERED, ABSTRACT SUBMISSIONS MUST MEET ALL THE ABOVE CRITERIA.

To see an example of an abstract that meets the criteria as outlined in the Call for Papers, visit the Child Life Council web site www.childlife.org
Name or Address Changes Requested

Please send name or address changes to CLC (see address at right) to make sure you receive future mailings of certification and/or membership materials. Certified individuals: Please send changes for both work and home addresses. Include the following information: Account number (1st number on your mailing label), full name, title, institution, complete preferred address (note if home or work), day & evening phone numbers, email address.

Annual Giving Thanks

It is with much gratitude that we acknowledge those who contributed to our third Annual Giving Campaign. This additional support allows us continue moving forward with the many new initiatives of the Council.

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