



# Net News

## An Exciting Issue

Thanks to everyone who provided information for this issue. It is great when folks from across the country send their latest research findings, resources, conference information and provide posters for current research projects seeking participants.

Palliative care week has come and gone, and it is amazing to watch the growth within pediatric palliative care each year. Let's continue to celebrate our many successes!

*Written by Simone Stenekes—Newsletter Editor*

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### Special points of interest:

- *Conferences and research symposiums!*

## UNDERSTANDING CULTURAL COMPETENCE IN PEDIATRIC PALLIATIVE CARE

The immigration of people from non-traditional source countries (Asian, Middle Eastern, Caribbean, and African countries) with different cultural and religious values, beliefs, and traditions has resulted in an increased and growing demand for culturally sensitive end-of-life care services in Canada. Health care professionals and services are challenged by the tasks of providing palliative care and grief support to newcomers, often without formal training in cultural sensitivity. When there are cultural gaps between families and health care providers and these gaps are accentuated by barriers of language, faith, and cultural values and beliefs, it becomes all the more difficult to negotiate transitions on the path of a child's death.

The experience of families who are caring for a child who is dying or has died is largely influenced by cultural and religious beliefs. One of the significant factors that impacts an individual's response to death and grief are the social, cultural, ethnic and religious/philosophical values and beliefs. Misunderstandings and a lack of knowledge regarding the significance of these contributing factors can undermine the sensitive and competent care that is critical when a child is dying, has died or in times of grief.

The Diversity Program and the Pediatric Palliative Care and Grief Support Service at the Alberta Children's Hospital, Calgary in collaboration with Dr. Daniel Lai, Professor Faculty of Social Work, University of Calgary, have conducted a qualitative research study to address the needs and challenges that families from the ethno-cultural community and healthcare professionals meet when caring for children who are dying, or have died.

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To submit information, email Simone Stenekes, the CNPCC newsletter editor at:

[newsletter@cnpsc.ca](mailto:newsletter@cnpsc.ca)

The purpose of this research was to explore the *challenges* and *needs* experienced by families and health care professionals when receiving or providing pediatric palliative care and grief support. The findings of this research provides for the following: (a) increased knowledge and understanding of the values and beliefs of various ethno-cultural communities as a child is dying and after a child has died; (b) an examination of the level and quality of palliative care received when a child is dying as perceived by bereaved parents from the ethno-cultural community; (c) an understanding of the roles and functions of ethno-cultural community organizations and the social support provided to families; (d) an exploration of the level of health care professionals' understanding of diverse backgrounds and cultures when providing pediatric palliative care to families; and (e) a determination of the learning needs of health care professionals in order to provide culturally competent pediatric palliative care.

A grounded theory approach was used with individual interviews and focus groups were used to gather data. The participants were divided into the following categories: bereaved parents (n=19), ethno-cultural focus groups (n=7), key cultural informants (n=6), religious leaders (n=8) and health care professionals (n=13). The cultural groups included in this research were as follows: Sudanese, Hutterite, South -Asian, Chinese and Filipino. Findings from this research supports to overall conceptual understandings that ethno-cultural background impacts community responses and the appropriateness of health professionals' conduct. Some participants mentioned that in a close-knit culture, the community response is quite large when someone is sick and many people come to the hospital to visit and show their support for the family. An example that relates to the proper conduct of staff is the manner in which bad news is conveyed to families. Muslim participants, in particular, appeared to prefer that a terminal prognosis not be shared with the families, especially with mothers. According to health care professionals, staff often assume that all members of an ethno-cultural group have the same beliefs and family members similarly described a tendency among staff to generalize by community rather than recognizing a person as a unique individual. Prejudices, which are intimately linked to stereotypes, were additionally identified as being held by some professionals. This study suggests that it is essential that health care professionals not only educate themselves about the values, beliefs, and cultural practices around paediatric death and dying but that they acquire skills to care for families from diverse cultural backgrounds.

The objectives for education based on this study are:

- For Health Care Professionals to have increased knowledge and awareness around cultural competent pediatric palliative care.
- Improved access to key ethno-cultural informants and religious leaders to guide us in providing culturally sensitive pediatric palliative care.
- To develop a practice guideline tool that health care professionals could use when caring for a child from a diverse background, who is dying and the child's family.

The findings of the research were disseminated with the participants, ethnic community groups and health care providers in June 2009 at an interactive presentation whereby care providers heard varying presentations from families and key informants regarding cultural and religious needs and practices for end of life and bereavement care when a child dies.

A Literature review, research report, a tool consisting of booklets to guide care and a workshop module for health care providers has been developed as a result of this research study. Copies of the report and tool can be found and downloaded at <http://fcrc.sacyhn.ca/publications.php#training>. Anyone who wishes to purchase the printed version of the tool can contact Linda Kongnetiman.

*For more information please contact:*

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## Canadian Hospice Palliative Care Conference

## Congrès canadien de soins palliatifs

Changing the National Perspective on Hospice Palliative Care  
The Westin Ottawa • Ottawa, Ontario Canada • October 27 - 31, 2010

For more information: <http://conference.chpca.net/>



# 18<sup>th</sup> International Congress on Palliative Care

October 5 - 8, 2010

Montréal, Canada

Palais des Congrès

## Two-Day Seminar

Tuesday, Oct. 5, 9:00 - 17:30 & Wednesday, Oct. 6, 11:00 - 17:30

### **PEDIATRIC PALLIATIVE CARE**

Organizers and Chairs: STEPHEN LIBEN, *The Montreal Children's Hospital, Montréal, QC, Canada;*

JOANNE WOLFE, *Dana-Farber Cancer Institute, Children's Hospital Boston, Boston, MA, United States*

**Day 1:** The theme for Day 1 will be "**Easing Suffering in Pediatric Palliative Care**" with a specific focus on therapeutic modalities aimed at reducing pain and suffering of the body (both allopathic and complementary approaches) and of the mind, soul and spirit. The day will include a combination of internationally renowned plenary speakers and those selected through abstract submission, with an emphasis on encouraging interactive presentations.

**Day 2:** The second day will focus on **Research in Pediatric Palliative Care**. The day will include oral and poster paper presentations selected through abstract submission, with an emphasis on state of the art pediatric palliative care research initiatives, and will conclude with two internationally distinguished plenary speakers.

[www.palliativecare.ca](http://www.palliativecare.ca)



# TRAC PG

Team for Research in Adolescent and  
Childhood Palliation and Grief

## HOLD THE DATE!

TRAC-PG will be hosting the Second Annual  
Pediatric Palliative Care Research Symposium at  
SickKids on Wednesday September 29th, 2010.

### **Special Grand Rounds Guest Speaker:**

**Myra Bluebond-Langner, PhD, Distinguished Professor of Anthropology,  
Rutgers University , Camden, NJ**

Myra has recently been appointed, Professor and True Colours Chair in  
Palliative Care for Children and Young People at the UCL Institute of Child  
Health and Great Ormond Street Hospital.

The day will focus on the importance of listening to the voices of  
dying children. Concurrent oral and poster presentations will  
highlight the research work of TRAC-PG, and we will feature an  
expert panel, breakout sessions and an evening town hall event.

Stay tuned for more information about the symposium at  
[www.tracpg.ca](http://www.tracpg.ca)



**STRESS AND GROWTH OVER TIME:  
CAREGIVING AND BEREAVED PARENTS OF CHILDREN  
WITH LIFE-LIMITING ILLNESSES**

**Principal Investigator: Dr. Susan Cadell  
Assistant Professor & Director of the Centre for Healthy Living  
Wilfrid Laurier University**

**Are you a parent/guardian whose  
child has died  
from a life-limiting illness?**

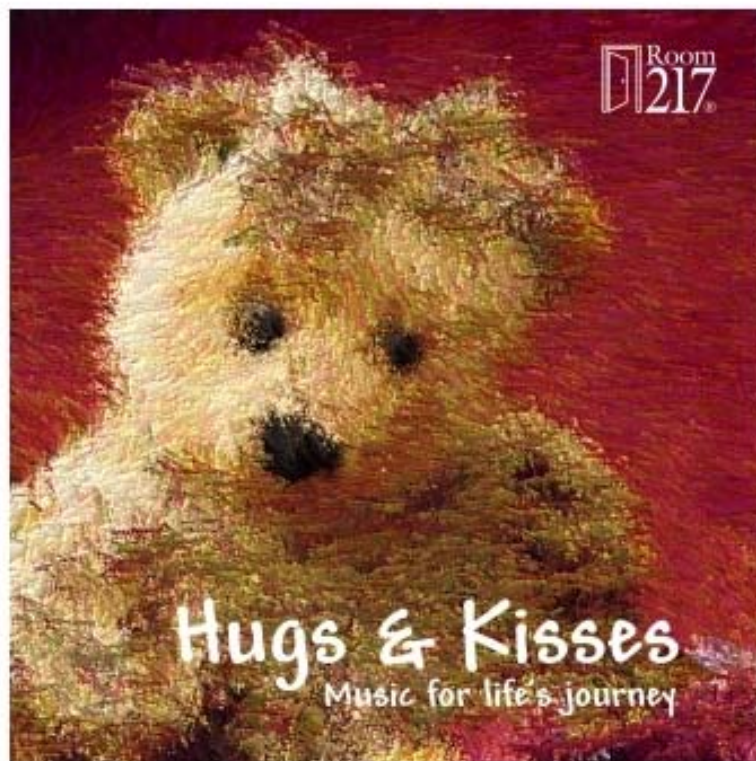
**If so, we require parents/guardians who are willing to participate in a study of how the experience of having cared for a child with a life-limiting illness changes parents' lives.**

**For this study, you will be asked to complete a set of questionnaires at two separate times. The questionnaires will be sent to you by mail and will take 1 to 1.5 hours to complete.**

**Questionnaires are available in either English or French.**

**For more information, or if you are interested in participating in this study, please contact the  
Research Coordinator at 1-800-810-0721.**

**An album of soothing music for children, their  
siblings, parents and other caregivers**



Hugs & Kisses threads together timeless children's classics with popular favourites, original tunes and lullabies chosen to convey to children that they are loved, that it's okay to express fear and sadness and that they have friends who support them. And most of all, that they are treasured.

Hugs & Kisses is part of the Room 217 Collection, a series of distinctive therapeutic music resources designed to bring comfort and peace when the stress of daily living can be overwhelming, especially when illness strikes, or it comes time to say goodbye to a loved one.