



# Net News

## Pediatric Palliative Care Research Updates

This issue of the CNPCC newsletter contains exciting information on a variety of pediatric palliative care research studies.

You will find information on a video that can be used

for educational purposes. "Ed's Story" was presented at the International Congress on Palliative Care in Montreal in October.

As always, I am looking for content to include in future

issues, so send things my way to:

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

I hope you enjoy this issue!

*Written by Simone Stenekes*

CNPCC Net News

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### Special points of interest:

- *Research—updates on what's happening in Canada*
- *Conferences and Educational Resources*

## Quality of Children's End-of-Life Care Study

Quality end-of-life care is the right of every Canadian according to the Senate of Canada. Quality end-of-life care is important to the dying child and to both short and long-term health outcomes for parents, siblings, and extended family members. Unfortunately, we do not currently have good ways of measuring the quality of the care that is provided to dying children and their families.

The comprehensive assessment of children's end-of-life care quality will require multiple methods and perspectives. As a first step in this assessment, the purpose of the Quality of Children's End-of-Life Care Study is to develop and test an instrument to measure parents' perspectives of the quality of children's end-of-life care. This study is the PhD work of Kimberley Widger in the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto under the guidance of her thesis committee: Dr. Ann Tourangeau (supervisor), Dr. Rose Steele, and Dr. David Streiner. The study is funded through a grant from The Innovation Fund in Children's Palliative Care Research, The Hospital for Sick Children, a Canadian Institutes for Health Research Doctoral Fellowship, and the Canadian Child Health Clinician Scientist Program, Career Enhancement Program.

The study is being conducted in three phases. The purpose and progress to date for each of the phases is described below.

The purpose of Phase 1 was to identify the key components of quality children's end of life care through a literature review and focus groups. Three focus groups were held with 10 bereaved parents in the Toronto and Hamilton area between April and June 2009.

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

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

## Quality of Children's End-of-Life Care Study *(continued from page 1)*

Results from the literature review and focus groups were used to identify five domains of quality care (connect with families, involve parents, alleviate suffering, share information, and provide bereavement care) as well as a number of indicators within each domain. The full results of this phase of the study are posted on the study website: <http://www.atourangeau.nursing.utoronto.ca/studentresearch/widger.htm>

The purpose of Phase 2 was to develop instrument items and conduct initial testing of the instrument. Instrument items were developed from September to November 2009. The items were reviewed by eight health professionals from across Canada early in 2010 to assess content validity. The content validity index for the instrument was 0.84, meaning that the instrument items are representative of quality children's end of life care and that the instrument as a whole was comprehensive. Instrument items were revised based on feedback from health professionals and tested with bereaved parents. There were six parents who assessed the content and face validity of the instrument as well as their cognitive understanding of the items. Final revisions were made to the instrument based on parent feedback and the instrument was approved by the thesis committee on May 26, 2010.

The purpose of Phase 3 is to assess the reliability and validity of the instrument. A minimum of 150 mothers are needed from across Canada to complete the instrument for this phase of the study. Mothers are eligible for the study if their child died in a hospital or hospice between 6 and 36 months prior to the study. There are 11 sites across Canada involved in recruiting mothers to take part in the study: Canuck Place Children's Hospice and BC Children's Hospital in Vancouver, Stollery Children's Hospital in Edmonton, Winnipeg Children's Hospital in Winnipeg, Children's Hospital of Eastern Ontario and Roger's House Children's Hospice in Ottawa, McMaster Children's Hospital in Hamilton, Children's Hospital London Health Sciences Centre in London, The Hospital for Sick Children and Sunnybrook Health Sciences Centre in Toronto, and the IWK Health Centre in Halifax. Much of 2010 has been spent obtaining ethics and administrative approval for the study at all of these sites. The approval process is now complete at all but one site. The procedures for recruitment vary somewhat across sites due to local requirements. At all sites the contact information (name and address) for eligible mothers is obtained through review of health records or other database. Once eligible mothers are identified, a letter about the study is sent to the mother from someone who provided care to the family prior to the child's death or who provided bereavement follow-up care to the family. At one site the letter is sent by someone who may have provided care before the death but who is not involved in providing bereavement follow-up. At another site the letter is mailed from the manager of the health records department. The letter includes a brief description of the study. At most sites the letter includes instructions to return an enclosed card in a self-addressed and stamped envelope if the mother does NOT wish to take part in the study. If the card is not received at the originating site within three weeks, the survey booklet is mailed. At four sites, an opt-in method of recruitment is used. At these sites the letter is mailed to the mother with instructions to contact the investigator at the University of Toronto by return card, telephone or email if she wishes to take part in the study. In the survey booklet mothers are also invited to provide their contact information if they are willing to complete the same survey again in two weeks time to be able to assess the test-retest reliability of the instrument. The first surveys were sent out in the summer of 2010. Currently, the response rate is about 20% which is typical for a mailed survey that does not include any reminders to complete the survey. Recruitment and data collection will continue until the end of January 2011. Data analysis will be conducted in the spring of 2011 with final study results available in the fall of 2011.

This study is a first step in the development of a comprehensive instrument to measure the quality of children's end-of-life care. Once developed, the instrument will provide a mechanism for feedback to health professionals, health systems, and policy makers to improve care provided to families facing the death of a child. The instrument may also be used to explore best models of care and the long term impact of care quality on the health and well-being of surviving family members.

Kimberley Widger RN MN CHPCN(C)  
PhD Candidate  
Lawrence S. Bloomberg Faculty of Nursing  
University of Toronto

## Recently Completed Research

### Patients Receiving Pediatric Palliative Care Consultations: A Prospective Multicenter Cohort Study

While the number and size of hospital-based pediatric palliative care (PPC) teams are growing, scant information exists regarding the patients referred for PPC consultations. Our objective was to describe the demographic and clinical characteristics and outcomes of patients who received PPC consultations. A prospective observational cohort study design was used to obtain information about a cohort with 12-month follow-up. The study involved 6 sites in the US and Canada with established hospital-based PPC teams and Children's Hospices including Canuck Place Children's Hospice in Vancouver, BC. Look for the article to be published shortly!

#### Study Sites and Affiliations of Researchers:

- 1 Chris Feudtner, MD, Tammy I. Kang, MD and Kari R. Hexem, MPH - Children's Hospital of Philadelphia, PA, United States
- 2 Stefan J. Friedrichsdorf, MD and Kaci Osenga, MD - Children's Hospitals and Clinics of Minnesota, Minneapolis, MN, United States
- 3 Hal Siden, MD, Centre for Community Child Health Research, Vancouver, BC, Canada
- 4 Sarah Friebert, MD - Akron Children's Hospital, OH, United States
- 5 Ross M. Hays, MD - Seattle Children's Hospital, WA, United States
- 6 Veronica Dussel, MD and Joanne Wolfe, MD - Dana-Farber Cancer Institute and Children's Hospital Boston, MA, United States

## Research Studies Currently Recruiting

### Charting the Territory: Determining and Documenting Trajectories for Families Where a Child Has a Life-Threatening Condition

Looking for eligible families to participate in study led by Dr. Hal Siden and Dr. Rose Steele.

Rare Diseases, like many disorders, come in a spectrum. Some rare disease conditions are mild within childhood or the teenage years. Others are almost always life-threatening, and some have a wide range of severity. We are recruiting children whose health is challenged and who are experiencing rapid declines to participate in a new research study. This study is funded by the Canadian Institute of Health Research (CIHR).

The Charting the Territory study will ask parents about their child to see how any symptoms are progressing over time. The study also invites families to answer questions about their quality of life. Researchers aim to improve understanding of how to best care for these vulnerable children in the future.

The study is enrolling families through the Neurology, Biochemical Disease, Metabolic & Genetics and Complex Care clinics at six Children's Hospitals (Halifax, Montreal, Ottawa, Toronto, Calgary, Edmonton, and Vancouver) and three Children's Hospices (Canuck Place, Roger's House and Rotary Flames House) across the country. Families whose child has a rare, progressive or life-threatening genetic, metabolic or neurological disease are eligible to participate.

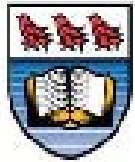
For more information, please call our toll-free number at 1-877-945-2775 or visit the study website:

<http://www.chartingterritory.com/>

Thank you!

Dr. Hal Siden, University of British Columbia, Principal Investigator, [hsiden@cw.bc.ca](mailto:hsiden@cw.bc.ca)

Dr. Rose Steele, York University, Principal Investigator, [rsteale@yorku.ca](mailto:rsteale@yorku.ca)



**University  
of Victoria**

# **RESEARCH PROJECT**

## **An Anthropology of Bereavement: A Sociocultural Analysis of Parental Grief & Mourning**

**A RESEARCH PROJECT IS BEING CONDUCTED WITH BEREAVED  
PARENTS AND WITH BEREAVEMENT CARE PROVIDERS  
IN MONTREAL, VANCOUVER AND VICTORIA.**

Project Principal Investigator: Dr. Mary Ellen Macdonald  
Assistant Professor, Oral Health and Society, Faculty of Dentistry Medical Scientist, Palliative  
Care Program, Montreal Children's Hospital of the McGill University Health Centre

As part of a study on the experiences of parents who are bereaved after the death of their child, we are interviewing bereavement and palliative care providers.

If you are providing care as a certified professional or have worked as palliative/bereavement care volunteer for at least one year, we would like to hear your perspectives on the needs and care of bereaved parents.

Interviews are confidential and will take place outside of work hours.

**Please contact the Study Co-Investigators, Dr. Peter Stephenson and Dr. Lisa M. Mitchell (Dept of Anthropology, University of Victoria) at:**

**1-888-721 7351 (Toll free) or at [bereavementstudy@uvic.ca](mailto:bereavementstudy@uvic.ca)**

THIS RESEARCH IS FUNDED BY THE SOCIAL SCIENCES AND HUMANITIES  
RESEARCH COUNCIL.



**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.**

DVD ORDER Form for

# Ed's Story

The Dragon Chronicles

*Ed is a trickster, a skater, a gamer, a brother, son and friend. He's the kid who moons the whole school on a dare and the guy who always sticks up for the underdog. Ed is a sensitive young man with an aggressive cancer. From Ed's Journal entries, and interviews with his circle of family, friends and healthcare team, a "verbatim" portrait is drawn of a boy on the verge of adulthood fighting not only a medical battle, but a battle to experience his life on his terms.*



**2010  
Atlantic  
Fringe Festival  
★★★★★  
FRINGE  
HIT**

Written by Mary-Colin Chisholm

Directed by Simon Bloom

With Ona Archibald, Paul D'Alessandro, Iain Soder, Schoel Strang

Produced by Dr. Gerri Frager

Videographer John Hillis of TRUEFAUX Films

All Proceeds from Sale of DVD to the IWK's  
Pediatric Palliative Care Service

Ship to:

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DVD \$40 CDN each

**Total** \_\_\_\_\_

+ Shipping and Handling

For further information contact: Schoel Strang—Administrative Assistant  
Pediatric Palliative Care Service, IWK Health Centre Tel: (902) 470-7262  
[schoel.strang@iwk.nshealth.ca](mailto:schoel.strang@iwk.nshealth.ca)

As the delighted recipient of the prestigious Rotman Award for Paediatric Home Care Innovation, the IWK Pediatric Palliative Care Service (PPCS) is presenting a number of education and research initiatives on pediatric palliative care. We already had a few sessions in the Maritimes, and we would like to extend the invitation to the national palliative care community.



The URL to access the webinar is: <http://dal.na4.acrobat.com/peds-palliative/>

You can join us by typing in your name, no password is needed. We would like to keep track of participant numbers & location. So when you sign in, can you just type in a message on the chat board to let us know who is on-line and where you are from (especially if there are two-three of you at one computer).

The IWK will send an email to the CNPCC listserv with the sessions that will take place in 2011.

Please contact Schoel Strang if you have any questions, at: [schoel.strang@iwk.nshealth.ca](mailto:schoel.strang@iwk.nshealth.ca)

### Pediatric Pain Master Class

June 11-17, 2011 at the Marquette Hotel in Minneapolis

*Presented by*

Children's Institute for Pain and Palliative Care (CIPPC) Pain and Palliative Care Program  
Children's Hospitals and Clinics of Minnesota



This seminar offers state of the art education in pain management for the pediatric patient from a holistic and multidisciplinary perspective. The program features a faculty of internationally recognized experts, who will cover pharmacological, medical, psychosocial, and integrative therapies in the management of children's acute and complex/chronic pain. Pain assessment and management of somatic, visceral, neuropathic, and psychosocial/spiritual pain, as well as end-of-life management of pain and distressing symptoms will be discussed in depth using lectures, workshops, and small-group approach.

The Master class is primarily designed for physicians and advanced practice nurses to develop their expertise in the field of pain management in a highly interactive seminar format. Space is limited.

For more information, or to request a registration packet, please contact Children's Institute for Pain and Palliative Care (CIPPC) at (612) 813-6450, or e-mail at [cippc@childrensmn.org](mailto:cippc@childrensmn.org).



## Canadian Hospice Palliative Care Conference

## Congrès canadien de soins palliatifs

Navigating Safe Pathways to Quality Hospice Palliative Care

DELTA ST. JOHN'S HOTEL AND CONFERENCE CENTRE

ST. JOHN'S, NEWFOUNDLAND

SEPTEMBER 8-11, 2011

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