



Net News

Pediatric Palliative Care Research— What's Happening?

We had a great turnout to the CNPCC meeting at the CHPCA Conference in Winnipeg in October. Our special interest group discussed what the CNPCC should focus on in the future. To access the minutes for our meetings, please go to the CNPCC website at:

<http://cnpcc.ca>

A point that was brought up at the meeting was the need for research being undertaken in Canada in pediatric palliative care to be highlighted. So we (alright, me—see what being the editor of the newsletter allows you to do?), decided to focus an issue of the CNPCC newsletter each year on research that is happening

in our fair country! So, I sent out an email and a few of you responded. I have included the responses I received and if you have a burning desire to send me something for the next newsletter, you know you can always find me at:

newsletter@cnpcc.ca

Written by Simone Stenekes

CNPCC Net News

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Special points of interest:

- *Research—what's happening in Canada? Find out here!*
- *Conferences—some great opportunities coming up in the new year!*

Recently Published PedPalNet Research

Siden H, Tucker T, Derman S, Cox K, Soon GS, Hartnett C & Straatman L. (2009). Pediatric Enteral Feeding Intolerance: a new prognosticator for children with life-limiting illness? *Journal of Palliative Care*, 25 (3), 213-7.

Siden H, Straatman L, Miller T, Hamm J. (2009) Madison Clinic: Evaluation of a collaborative outpatient paediatric palliative care clinic. *Paediatrics & Child Health*, 14(6), 379-384.

Cadell, S., Ho, G., Jacques, L., Wilson, K., Davies, B., & Steele, R., (Letter to the editor) (2009). Considerations for Ethics in Multisite Research in Pediatric Palliative Care. *Journal of Palliative Medicine*, 23 (3), 274-5.

Submitted by: Nichole Austin—Research Coordinator, New Emerging Team (NET) - Transitions in Pediatric Palliative and End-of-Life Care Developmental Neurosciences and Child Health



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

newsletter@cnpcc.ca

Pediatric Palliative Care Research—What's Happening?

IWK Research Initiatives

Several research initiatives are being undertaken with members of the Palliative Care Service at the IWK in Halifax, Nova Scotia. They include the following:



1) Music Therapy in the NICU

Gerri Frager, Darrel Cameron, Pat Randel & Meena Natarajan

Quantitative study of nurses in the NICU. Poster presentations at a variety of conferences; manuscript for publication is underway

2) "Nurses' Experiences in providing Bereavement follow-up"

Grace MacConnell, Megan Aston, Nick Zwaagstra

IWK & Canadian Nurses Foundation funding. Analysis of data underway.

Qualitative study, conducted with pediatric and perinatal nurses.

3) Network for End-of-Life Studies: Interdisciplinary Capacity Enhancement Group

"Quality Palliative Care for Children and Youth with Chronic Disease"

Gerri Frager, Pat Randel, Louise Parker, Walter Robinson, Mark Bernstein, Noni MacDonald, Fred Burge, Bev Lawson, Kim Widger

Funds are designated for pediatric palliative care research. Several meetings have been held to bring together others interested in end of life research. Discussions are under way for a project with EHS and palliative care. Currently one study is underway: Jennifer Barnes is currently doing interviews and focus groups with health care providers using appreciative inquiry to evaluate end-of-life care in the NICU.

4) Youth Facing End-of-Life: Listening and Learning

Gerri Frager, Grace MacConnell, Dr. Walter Robinson, Dr. Shauna Flauvelle, Dr. Emma Burns, Dr Karen Black, Meena Natarajan, Raewyn Bassett

Analysis of an adolescent's journal is nearing completion. Shauna completed the analysis and is preparing her manuscript for publication. Qualitative interviews with health care providers have also taken place. Mary Colin Chisholm, a playwright, who is developing a play based on the research.

Submitted by: Grace MacConnell

Coordinator/Clinical Nurse Specialist—IWK Pediatric Palliative Care Service

Winnipeg Research Update

The Manitoba Pediatric Palliative Care Research Group had its first meeting this fall. The group works together to promote research in Manitoba, which includes two current projects:

- 1) Perinatal Palliative Care—this study is going through ethics approval. It is a qualitative study using focus groups of health care providers to determine their experiences with palliative care. Funding received from the TRACPG Innovation Fund In Children's Palliative Care Research
- 2) A retrospective chart review of intranasal and buccal transmucosal Fentanyl use in infants. This project is in the ethical review stage.

Submitted by: Simone Stenekes—Clinical Nurse Specialist, WRHA Palliative Care Program



Canuck Place Children's Hospice has the following job postings currently available for advanced practice nurses:

Two temporary positions
full-time & part-time

CLINICAL NURSE SPECIALISTS

*Leadership opportunities in an
inspiring team environment*

For more information, please see
detailed posting:

<http://www.canuckplace.org>

Information on the Parent Caregiver Study

The first paper to be published from the results of the Parent Caregiving Study "Caregiving Parents of Children with Life-Limiting Illnesses: Beyond Stress and Coping to Growth" is Schneider, M., Steele, R., Cadell, S., & Hemsworth, D. (in press). Differences on psychosocial outcomes between male and female caregivers of children with life-limiting illnesses. *Journal of Pediatric Nursing*.

The research team has been granted funding from CIHR this past April to continue the Parent Caregiver Study over the next 3 years which will follow the current cohort of parents over two additional timepoints and also recruit bereaved parents and follow them over a total of two timepoints to explore stress and growth longitudinally. The second phase of the study is entitled "Stress and Growth Over Time: Caregiving and Bereaved Parents of Children with Life-Limiting Illnesses". The total funding amount is \$348,241 over 3 years and the research team is Dr. Susan Cadell (P.I), Dr. Hal Siden, Dr. Rose Steele, Dr. Lynn Straatman, Dr. Betty Davies, Dr. Stephen Liben, and Dr. David Hemsworth. The lay abstract of the study:

Caring for a child with a life-limiting illness is a stressful experience that compounds the usual challenges of parenting. The negative aspects of caring for a child with a life-limiting illness are well documented. In the face of such adversity, however, we also know that parent caregivers can experience positive changes caring for children with even the most serious conditions. In a previous study, *Caregiving Parents of Children with Life-Limiting Illnesses*, we developed and tested a model that helps us understand the factors that contribute to personal growth and stress in caregivers of these children; the purpose of the proposed study is to further develop this model. This extended study will allow us to learn more from the parents caring for very sick children as they share their changing experiences over time and also from a second group of parents: those who are bereaved. As a result, we will be able to investigate the differences in the stress, personal resources, and growth between both parent caregivers and bereaved parents. This is a unique opportunity to study the positive and negative aspects of caregiving and bereavement over time. New knowledge obtained from this study will be of tremendous value to parents, practitioners and policy makers concerned with childhood life-limiting illness. Pathways leading to positive outcomes will be identified through this study and will then be used to optimize the emotional, social, and spiritual care available to patients and families receiving paediatric palliative services, including bereavement care.

Submitted by: Susan Cadell—Associate Professor and Director, Manulife Centre for Healthy Living Wilfrid Laurier University, Lyle S. Hallman Faculty of Social Work

Update from Edmonton

Recent Publications: 1) **Davies DE**. Palliative Care Research Involving Children and Adolescents. *Paediatric Research in Canada*, 2009. Avarad, Samuel, Knoppers Eds. Les Editions Themis Press. pp. 191-224.

2) **Davies DE**, DeVlaming D, Haines C. "Methadone Analgesia for Pediatric Patients with Advanced Cancer." *Ped Blood Cancer* 51(3) September 2008, pp. 393-7.

Current research initiatives that I am involved with include:

- 1) collaboration with Dr. Lang, general pediatrician: clinical indicators of poor neurological outcome or death in children with strangulation/hanging injuries (manuscript stage)
- 2) parent-delivered massage in pediatric oncology patients: pilot feasibility study (in collaboration with Centennial College, Toronto; patient enrolment will be complete Dec. 2009)
- 3) attitudes of pediatricians to withdrawal/withholding of artificially provided hydration/nutrition in pediatric patients (in collaboration with Bioethics Committee, Canadian Paediatric Society (fellow research project, survey stage)
- 4) Albertan palliative care providers experience with harm related to opioid use in the community with reference to diversion or intentional self-harm (resident research project (ethics approval stage)
- 5) collaborator with Dr. Donna Johnston, CHEO: Children's Oncology Group (COG) based study re: quality of life for children who receive palliative care involvement compared to those who do not in oncology patients who have a poor prognosis.(full proposal stage)
- 6) collaboration with Drs. Friebert, Zeltzer, Roth: a survey of pediatric oncologists (USA/Canada) regarding their use. Attitudes towards, and barriers to use of methadone in pain management of children with cancer (survey stage)
- 7) I've started a two year Masters degree thru the University of Manchester School of Law: Health Law and Ethics (distance learning) to be complete May 2011.

Submitted by: Dawn Davies—Medical Director, Pediatric Palliative Care Program, Associate Professor, Dept. of Pediatrics, University of Alberta



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/>



18th 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



International Multi-Professional Paediatric Palliative Care Course

11th - 16th April 2010 in Haltern, Germany

organised by the

Vodafone Foundation Institute and Chair
for Children's Pain Therapy and
Paediatric Palliative Care

under the auspices of the

European Association for
Palliative Care (EAPC)

and

The Association for
Children's Palliative Care (ACT)



Vodafone Stiftungsinstitut und Lehrstuhl
für Kinderonkotherapie und
Palliative Palliativmedizin



Westliche Kinder- und
Jugendklinik Datteln
Universitätsklinikum Witten/Herdecke

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3rd Annual

Pediatric Pain Master Class

June 12 - 18, 2010

Marquette Hotel

Minneapolis, MN



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.

For more information about our program, visit our Web site at <http://www.childrensmn.org/Services/PainPalliativeCare>.

End-of-Life Nursing Education Consortium (ELNEC)

Register today for the National ELNEC-Pediatric Palliative Care train-the-trainer course.*

This course will be held March 16-17, 2010 in Pasadena, CA. All members of the interdisciplinary team are invited to attend. Seating is limited, so registrations will be taken on a first-come, first-serve basis.

To register, go to: www.aacn.nche.edu/ELNEC

(*new, up-dated, expanded information included on perinatal and neonatal palliative care)



2010 Cardiff Conference in Paediatric Palliative Care: 'Face to Face with Interface'

July 6-8, 2010 in Cardiff, Wales, UK