



Net News

OPPORTUNITY FOR RESEARCH

Caregiving Parents of Children with Life-Limiting Illnesses: Beyond Stress and Coping to Growth

OVERVIEW

When parents are caring for ill children, the stress is often compounded. Indeed, caring for a child with a life-limiting illness represents one of the most traumatic experiences a parent can endure. The negative aspects of caregiving are well documented in the literature. In the face of such adversity, however, there are

suggestions that caregivers can also experience personal growth and positive change. Nevertheless, little is known about positive outcomes of caregiving, particularly of parents caring for seriously ill children.

The primary aim of this research addresses the question "What are the factors that allow parent caregivers to survive and

even grow in the face of the stressful circumstances of caring for a child with a life-limiting illness?"

The outcome of this research will be a better understanding of whether personal growth occurs in this context and if so, the factors that contribute to it.

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CNPCC Net News

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Special points of interest:

- Opportunity for caregivers to participate in research
- PedPalNET Update—great things happening!

NEWS FROM THE CANADIAN HOSPICE PALLIATIVE CARE ASSOCIATION

Project Funding for Pediatric Hospice Palliative Care in Canada

CHPCA is pleased to report that the association has received a grant from Ronald McDonald House Charities to complete work related to pediatric hospice palliative care norms and standards of practice

for Canada. The Canadian Network of Palliative Care for Children (CNPCC) Executive Committee will act in an advisory capacity for this project with the outcomes expected in time for the 2007 Ca-

nadian Hospice Palliative Care Conference taking place in Toronto in November of this year. The CHPCA would like to thank the Ronald McDonald House Charities for supporting this important project.

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PedPalNET Update

Canada has been a leader in the development of pediatric palliative care with programs in the major Canadian geographic centres, as well as North America's first free-standing children's hospice, and in 2004 the Canadian Institutes of Health Research (CIHR) funded a research program in Pediatric Palliative and End of Life Care through a New Emerging Team (NET) grant. At its halfway mark, the NET, also called PedPalNET, is rapidly creating capacity in the field, spurring on new research projects and learning to navigate the challenges of working in a multi-disciplinary, multi-national model, with a focus on engaging in an online collaborative setting.

Since its inception, the PedPalNet has had the opportunity to build capacity by supporting 8 Research Trainees and 10 Affiliated Students at the Masters and PhD level in various disciplines, including Nursing, Social Work, Psychology, Counseling Psychology, Medical Education and Interdisciplinary Studies. Moreover, the team is currently recruiting students for the upcoming year and hopes to have a post-doctoral student in place by the summer of 2008. The team has also recruited a Clinical/Research Fellow from Costa Rica who will be starting in July 2007. In addition, a library sciences student has been recruited as a part-time staff mem-

ber for information services.

The PedPalNet also continues to make significant progress in establishing new research programs. Currently there are several projects underway and over \$213,000 supplementary dollars in funding have been generated thus far including, but not limited to:

- ✦ An Exploration of Families' Transition into a Children's Hospice Program: The purpose of this internally funded pilot study was to describe the experiences of children and families as they transitioned into the Canuck Place Hospice program.

- ✦ A Newly Defined Clinical Phenomenon: Pediatric Progressive Enteral Feeding Intolerance (PPEFI): Children with progressive, life-threatening diseases often present with worsening intolerance of enteral feeds during the end of life phase.

- ✦ Caregiving Parents of Children with Life-Limiting Illnesses: Beyond Stress and Coping to Growth: Funded by a CIHR Operating Grant, this research addresses the question "What are the factors that allow parent caregivers to survive and even grow in the face of the stressful circumstances of caring for a child with a life-limiting illness?" Recruitment for this study is underway in Canada and the US.

- ✦ Research Priorities in Pediatric Palliative Care: A Delphi Study:

The PedPalNet initiated this formal process to establish research priorities in Pediatric Palliative Care as identified by clinicians and researchers in Canada.

- ✦ Parental and Professional Decision-Making Regarding Benefits and Burdens of Interventions for Children with Life-Limiting Conditions: A multi-disciplinary team of researchers and clinicians is exploring the phenomenon of frequent, multiple, escalating medical-surgical interventions in children with complex chronic illnesses.

- ✦ Chinese Families' Experiences in Pediatric Palliative Care: Influence of Chinese families' cultural beliefs on their experience of pediatric palliative care.

The PedPalNet's multi-disciplinary core team of five researchers represents a range of organizations including Canuck Place Children's Hospice, University of British Columbia, University of California San Francisco, York University, and Wilfrid Laurier University. In addition to the core team, the PedPalNet collaborates with many researchers and clinicians in various disciplines (Pediatrics, Palliative Care, Nursing, Social Work, Ethics, Anthropology, Nutrition/Dietetics, Psychology, Theology, Genetics, Physiology, Gastroenterology & Occupational Therapy).

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PedPalNET Update - continued...

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The PedPalNet has also had the opportunity to work with the other Palliative Care NETs.

In order to meet the goals of communicating across multiple provinces and disciplines, our communications activities include a website, an electronic newsletter (two issues have been produced) and face-to-face meetings and presentations. At this time, the website is used as the primary method to engage the PedPalNet members, collaborators and students, whose communication is facilitated via online discussion areas, a shared calendar, and folders housing a range of

documents. The external website is presently being updated. In the near future, the external website will be a useful forum for disseminating research findings to a general audience and recruiting research participants, as well as providing information about pediatric palliative care and the PedPalNet.

It takes some time to build capacity and a strong foundation for research, however, the NET has been able to establish a solid program since the CIHR grant was awarded in 2005. As the team moves forward from this halfway point in funding, the NET expects to experience further

growth over the next several years with new students and research projects currently being developed. By creating an online model of communication, the NET hopes to continue meeting the challenge of collaborative multi-disciplinary and multi-institutional work in pediatric palliative care.

For further information, contact:

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OPPORTUNITY FOR RESEARCH - continued...

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This understanding will enable policy makers and practitioners alike to better understand the reality of caregivers and to enable intervention and support strategies to be designed. This research will contribute to knowledge in the fields of family caregiving, pediatric palliative care, and personal growth.

This research will occur under the auspices of a CIHR-funded New Emerging Team (NET) grant entitled Transitions in pediatric palliative and end-of-life care. This NET was conceived to develop a sustainable research program focused on creating knowledge and evidence to optimize provision of care for children with life-limiting conditions.

THE STUDY

This research is comprised of two phases. Phase One will use 8 short

scales to study demographics, personal resources, spirituality, stress and growth. Phase Two consists of in-depth interviews, conducted with up to 25 Phase One participants who have requested a follow-up interview. Participants will be asked to dedicate approximately 1 to 1.5 hour(s) to fill out the questionnaires and approximately 1.5 to 2 hour(s) to complete the interview.

PARTICIPANTS

Mothers, fathers, and other caregivers (e.g. grandparents, guardians) of children with life-limiting conditions are invited to participate and more than one parent caregiver per family may participate in the study. Parents will be recruited regardless of the length of time they have been caregiving and at any stage in the child's illness, so long as the child is under the age of 18.

All recruitment materials request

interested parents to call a toll-free number and leave a message. At this point, the Research Coordinator at Wilfrid Laurier University will return their call. When parents/guardians agree to participate, questionnaires will be mailed to them. A stamped envelope will be included in the package in order to return the questionnaires. There will also be an information sheet included in the package which explains the study. Additionally, participants will be asked if they are willing to be contacted for a follow-up interview.

For more information please contact:

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**Canuck Place Children's
Hospice: An
Exceptional Place to
Work in Vancouver**

Come and be part of a supportive interdisciplinary team and a wonderful group of nurses who are extraordinary caregivers... and people. Canuck Place is the first freestanding children's hospice in North America and is located near B.C. Children's Hospital in the heart of a residential area in Vancouver. You can learn more about us at

www.canuckplace.org

We are expanding our services and have **job opportunities for Registered Nurses**; permanent fulltime, part-time and casual positions. Previous experience in pediatrics, and/or palliative care nursing are an asset.

If you are interested in a job where you can truly make a difference in the lives of children and families, please send a cover letter indicating your interest along with your resume to:

Human Resources

Moira Morgan

Canuck Place Children's Hospice

1690 Matthews Avenue
Vancouver, BC V6J 2T2

Fax: 604-739-4376

recruitment@canuckplace.org

**Paediatric Hospice Palliative Care:
Offering Excellence Together
September 17th, October 1st,
October 15th & October 29th, 2007**

Interested in learning more about paediatric palliative and bereavement care? How to communicate with your colleagues and children with life-threatening illnesses and their families as they cope with death and end-of-life decisions? How to assess and manage pain and other symptoms at the end-of-life? How to care for yourself as you work with these children and their families? Do you have other unanswered questions?

This fall, the Palliative & Bereavement Care Service in partnership with Hospice Toronto and the Max & Beatrice Wolfe Centre for Children's Grief and Palliative Care is again offering a 4 day course, Paediatric Hospice Palliative Care: *Offering Excellence Together*, at SickKids. The course is aimed at health care professionals and volunteers who work with and care for children with life-threatening illnesses and their families.

Course Overview

Bio-ethical Considerations, Communication

Decision Making, Team Dynamics
Working with Children & Families

Assessment and Management of Pain & Other Symptoms

End of Life Care, Anticipatory Grief, Mourning & Bereavement
Care for the Caregiver, Spirituality

4 Day Registration Fee: \$450.00 per learner (includes lunch and breaks)

(Payable by cash or cheque made payable to "The Hospital for Sick Children")

Applications are available by calling 416.813.6905

Space is limited to 30 applicants - Register Today!

For more details contact the Palliative & Bereavement Care Service at 416.813.6905



NHPCO's Pediatric Track at the 8th Clinical Team Conference

November 29 to
December 1, 2007

New Orleans, Louisiana

NHPCO presents Pediatric Innovative Sessions at the 8th Clinical Team Conference. Preview this special education track and register today!

Preconference Seminar - Before and After: Creative Approaches to Working with Children and Families

For further information see:
www.nhpc.org/ctc2007

The Ohio Pediatric and Palliative & End-of-life care Network presents

Leaders, Learners and
Families Hand in Hand:
Building Pediatric Palliative
Care Best Practice

October 4 to 7, 2007

Akron, Ohio

This three-day conference will focus solely on pediatric palliative care. The conference will provide a forum to discuss current issues, find out what is happening across the country, learn from other's models and experiences and discuss future developments in this exciting and evolving field.

For further information visit:
www.ohpc.org



Children's Hospice International 18th World Congress

Pan Pacific Hotel
Singapore

September 6-9, 2007

This conference is the most significant educational effort by Children's Hospice International (CHI). It was first held in 1983, and helps educate those who care for children with life-threatening conditions and their families about the latest trends in the field and provides real-world examples of innovative approaches to pediatric curative, palliative and hospice care.

For further information:
www.chionline.org



Canadian Hospice Palliative Care Conference

Congrès canadien de soins palliatifs

Hospice Palliative Care: At a Crossroads ▪ Westin Harbour Castle Hotel
Toronto, Ontario Canada ▪ November 4 - 7, 2007

The 2007 Canadian Hospice Palliative Care (CHPCA) Conference will be a dynamic event that aims to engage you in a process of learning, skills building, reflection, networking and renewal. The conference will showcase innovative developments, explore current issues, challenge your concept of hospice palliative care, and provide opportunities to reflect on the meaning and impact of working in the field of hospice palliative care.

The program includes a meeting of the Canadian Network of Palliative Care for Children Interest Group on Sunday, November 4th in the morning.

Further information is available on the CHPCA website at: www.chpca.net

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