



RESEARCH UPDATE Winter 2006

There have been lots of things happening in research over the last year. In particular the New Emerging Team in Pediatric Palliative Care has been launched and is taking students to foster the talents of new researchers in the field of pediatric palliative care. In addition, this research team is currently conducting a Delphi Process aimed at identifying research priorities in pediatric palliative care. If you are interested in participating please see the link on the CNPCC home page and main research page to the questionnaire the group has posted.

As well, Mary Ellen MacDonald, a researcher with a pediatric focus has joined the New Emerging Team in Family Caregiving in Palliative and End-of-life Care as a New Investigator. A brief description of the goals of both of the teams and a link to their websites is included on the main research webpage.

Below are lists of projects and publications/abstracts from people working in pediatric palliative care from across Canada. Please see the separate update from Sickkids for additional projects that are being worked on. These lists are not exhaustive but are meant to give people an idea of what is happening in Canada and to link people with similar interests. Please contact the research chair at research@cnpcc.ca if you have additions for future research updates.

Current Research Projects

Spicer, S.L. & Strother, D. Intravenous pamidronate for pain in children with primary or metastatic tumors of bone.

Claude Cyr Étude pilote sur l'utilisation des essais cliniques randomisés à un seul sujet en soins palliatifs pédiatriques.

Guertin, M.H., Côté-Brisson, L., Major, D., Bédard, C., & Brisson, J. Emergency use at the end-of-life by children with complex chronic conditions in Québec 1997-2001, Institut de santé publique du Québec (INSPQ)

Guertin, M.H., Major, D., Bédard, C., & Brisson, J. End-of-life palliative care among children in Québec 1997-2001: definition and measure of indicators, Institut de santé publique du Québec (INSPQ)

Fillion, L. & Morin, D. Optimiser la qualité de l'exercice infirmier en soins palliatifs dans le contexte du virage ambulatoire.

Fillion, L. & Morin, D. Essai randomisé sur l'efficacité d'une intervention existentielle à augmenter la satisfaction au travail et la qualité de vie des infirmières en soins palliatifs
Financé par la Fondation canadienne de la recherche sur les services de santé (2003-2006). Faculté des sciences infirmières, Université Laval, Québec, Canada

Humbert N., Cyr C., Le Grand Sébille C., Morin N. Pour une prévention des traumatismes intergénérationnels, la place des grands-parents auprès de l'enfant gravement malade hospitalize

Humbert N., Duval M., Danault S., Cabot I., Lacroix J. Mise au point d'une échelle de mesure de l'asthénie chez l'enfant.

Olivier-d'Avignon, M. Elaboration and validation of an instrument to measure the needs of siblings of terminally ill children. Université Laval, supported by a doctoral scholarship from IRSC-CIHR

Woodgate, R., Irani, P., Degner, L., Yanofsky, R., West, C., & Watters, C. Title of Project: Development and Testing of a Computer Video-Game Approach Designed for Self-Assessment and Management of Meaning-Centred Symptom Experiences by Children with Cancer. Canadian Institutes of Health Research – CIHR Operating Grant. **Amount of Funding: \$132,888.00 per year** for four years, 2006 – 2010.

Woodgate, R. Dean, R., Shapiro, C., Sneiderman, S., Grant, K., & Cham, B. Title of Project: Perceptions and Assessment of the Risks to Involving Children in Research: Perspectives of Research Ethics Board Members, Child Health Researchers, and Parents, *CIHR - RFA for Empirical and Conceptual Research on Ethical, Legal and Social Issues in Studies Involving Pregnant Women and Children. **Amount of Funding: \$92,095.00 per year** for three years plus \$4,250.00 in equipment, October 2005 – September 2008.

Publications

Carnevale, F.A., Alexander, E., Davies, M., Rennick, J. & Troini R. (2006). Daily living with distress and enrichment: The moral experience of families with ventilator-assisted children at home, Pediatrics, 117;48-60

deJong, M.A., & deVlaming, D. (2005). Bereavement care for families Part 1: a review of a paediatric follow-up programme. International Journal of Palliative Nursing 11, (10); 533-39.

Davies, DE., Parental suicide by ingestion of child's medication in aftermath of child's expected home death. Accepted for publication, BMJ.

Davies, D., (2005). Blindsided. Journal of Palliative Medicine, 8(4); 870-2.

Davies, D.E. (2005). Talking about death with dying children. New England Journal of Medicine 352:1; 91-2.

Davies, D.E. & DeVlaming, D. (2006). Symptom control at the end of life. Textbook of Paediatric Palliative Care, Oxford: Oxford University Press.

Macdonald, M.E., Liben, S., Carnevale, F.A., Rennick, J.E., Wolf, S.L., Meloche, D., & Cohen, S.R. (2005). Parental Perspectives on hospital staff member's acts of kindness and commemoration after a child's death. Pediatrics, 116, 884-890.

Mongeau, S., Champagne, M., Carignan, P. (2006). Au-delà du répit et des activités... un message de solidarité. Les cahiers de soins palliatifs, 6 (2).

La mort d'un enfant- Fin de vie de l'enfant, le deuil des proches.

Mongeau, S, Carignan P, & Viau-Chagnon, M. (Jan. 2006). Les conditions de vie des familles ayant un enfant atteint d'une maladie à issue fatale. Sous la direction de Michel Hanus, Collection Espace éthique, Éditions Vuibert.

Wilkins, K., & Woodgate, R. L. Transition: A conceptual analysis in the context of siblings of children with cancer. Journal of Pediatric Nursing. In Press.

Wilkins, K., & Woodgate, R. L. (2005). A review of qualitative research on the childhood cancer experience from the perspective of siblings: A need to give them a voice. Journal of Pediatric Oncology Nursing, November/December, 22, 305–319.

Wilkins, K., Woodgate, R. L., Degner, L., & Schroeder, M. (2005). Siblings of pediatric bone marrow transplant recipients: Their lived experience as they transition through the bone marrow transplant trajectory. Pediatric Blood and Cancer, 45(4), 424.

Woodgate, R. L. Living in a World Without Closure: Reality for Parents who have Experienced the Death of a Child. Journal of Palliative Care. In Press

Woodgate, R. L. The importance of 'being there': Perspectives of supportive relationships by adolescents. Journal of Pediatric Oncology Nursing, In Press.

Woodgate, R. L. Life is never the same: Childhood cancer narratives. European Journal of Cancer Care, 15, 8-18.

Woodgate, R. L., Clarke, J., Gibson, F., Hallström, I, Kline, N., Monterosso, L., von Essen, L., & Wettergren, L. (2005). Development of an International Pediatric Oncology Research Network: Setting the stage for international collaborative psychosocial-behavioral research. Pediatric Blood and Cancer, 45(4), 400.

Woodgate, R. L. (2005). The childhood cancer experience of healthy siblings. Pediatric Blood and Cancer, 45(4), 538.

Woodgate, R. L. (2005). A different way of being in adolescents with cancer. Pediatric Blood and Cancer, 45(4), 538.

Conference Presentations/Abstracts:

Macdonald, ME, Liben, S, Carnevale, FA, Cohen SR. Signs of Life and Signs of Death: Brain Death and Other Mixed Messages at the End of Life. Canadian Society of Transplantation Annual Scientific Meeting, Tremblant, QC, March 2006.

Macdonald, ME, Carnevale, FA, Liben, S, Cohen SR. Critically Caring: Displacing And Re-Placing Parenthood In A Pediatric Intensive Care Unit. American Anthropology Association, Washington DC, November 2005.

Macdonald, ME, Liben, S, Cohen SR, Rennick, J, Carnevale, FA, Critical Incidents in Critical Care: Bereaved Parents' Memories of the PICU. The 29th Australian and New Zealand Annual Scientific Meeting on Intensive Care/10th Paediatric & Neonatal Meeting, Melbourne, Australia, October, 2004. Published in: Australian Critical Care 2004 17(3)

Macdonald, ME, Liben, S, Cohen SR. The Role of Staff Participation in Commemorating a Child's Death. 15th International Congress on Care of the Terminally Ill, Montreal, September 2004. Published in: Journal of Palliative Care 2004:20(3):219

Stenekes, S. Grégoire, M., Frager, G., & Hughes, A. Pain and dyspnea: A survey of Maritime Canadians living with cystic fibrosis. Canadian Hospice and Palliative Care Association (CHPCA) National Conference. September 2005, Edmonton, Alberta.

Stenekes, S. Grégoire, M., Frager, G., & Hughes, A. Pain and dyspnea: A survey of Maritime Canadians living with cystic fibrosis. 15th Annual Provincial Hospice Palliative Care Conference, September 2005, Winnipeg, Manitoba

Woodgate, R. L. "Closure: Who is it for?" Canadian Hospice and Palliative Care Association (CHPCA) National Conference. September 2005, Edmonton, Alberta.

Woodgate, R. L. A different way of being in adolescents with cancer. 37th Congress of the International Society of Paediatric Oncology (SIOP), September 2005, Vancouver, Canada.