



# Developing a Children's Palliative Care Research Team: A Careful Journey

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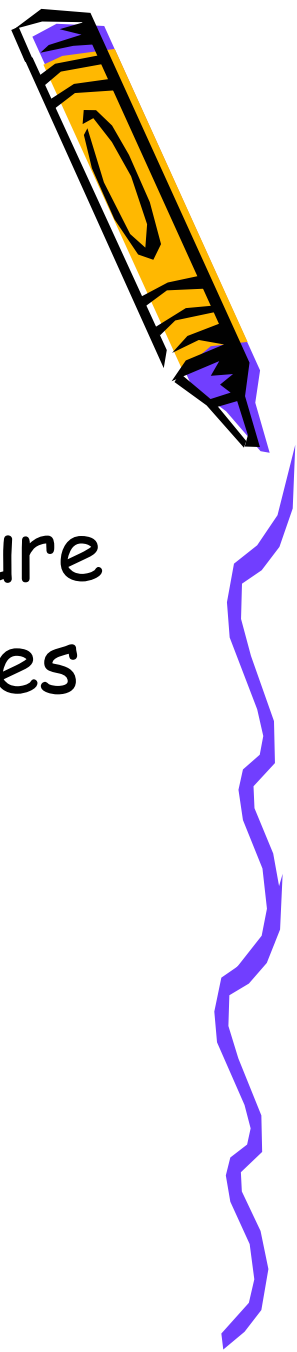
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CHPCA Conference November 2007

# Overview



- Introduction to TRAC-PG
- Overview of the Research Literature
- Ethical & Methodological Challenges and Possible Solutions
- Dissemination & Translation
- Benefits of Research
- Discussion



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- Team for Research with Children and Adolescents in Palliation and Grief
- 15 members from various disciplines & agencies

*Acknowledgement to Dr. Beverley Antle*



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Why?

To better understand child and parent perspectives so that we can improve the care of infants, children and adolescents with palliative needs.

To expand on a knowledge base of end-of-life, palliative and grief/bereavement care.

To test interventions and treatments.



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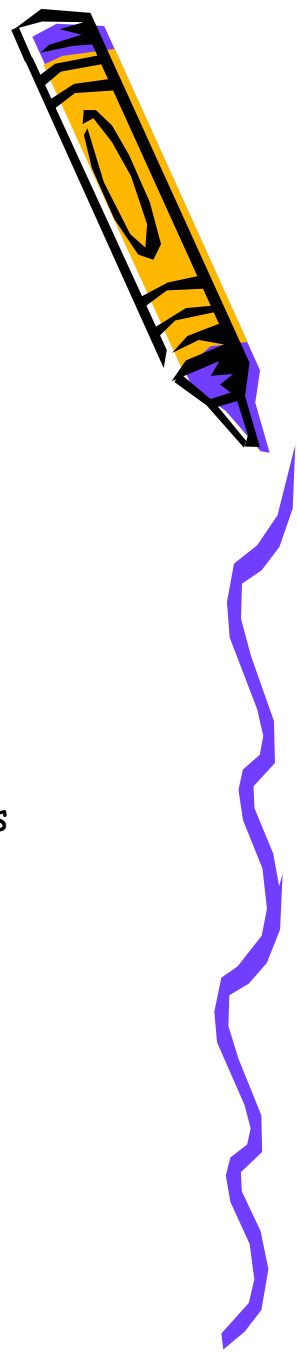


## Vision

*To generate and disseminate knowledge about infants, children and adolescents with a potentially life limiting illness and their families in order to optimize quality of palliative, end-of-life and bereavement care.*



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## Research Overview (examples)

- Program Evaluation (Care transitions)
- Psychosocial Experiences of SARS
- Psychosocial issues at home and at school of being a bereaved sibling
- Psychosocial issues of bereaved parents
- The role of hope
- Stress and Growth in Caregivers
- Parental and Health Care Professionals Preferences for Supportive Care versus Chemotherapy
- Professional Knowledge & Attitudes towards Advance Directives with Children
- Improving communication strategies for the non-verbal child at end of life
- Efficacy of sublingually delivered atropine for the control of oral secretions in children



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## Grants & Funding

(examples)

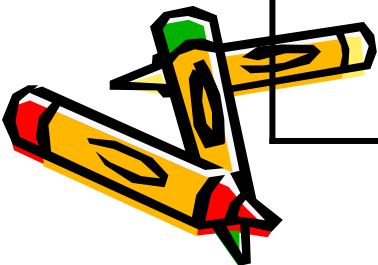
- Canadian Institutes of Health Research
- National Institute of Cancer (US)
- SickKids Foundation - National Child and Youth Home Care Competition
- B.R.A.I.N Child
- National Cancer Institute of Canada
- Social Sciences and Humanities Research Council
- National Institutes of Health (US)
- Max Bell Foundation



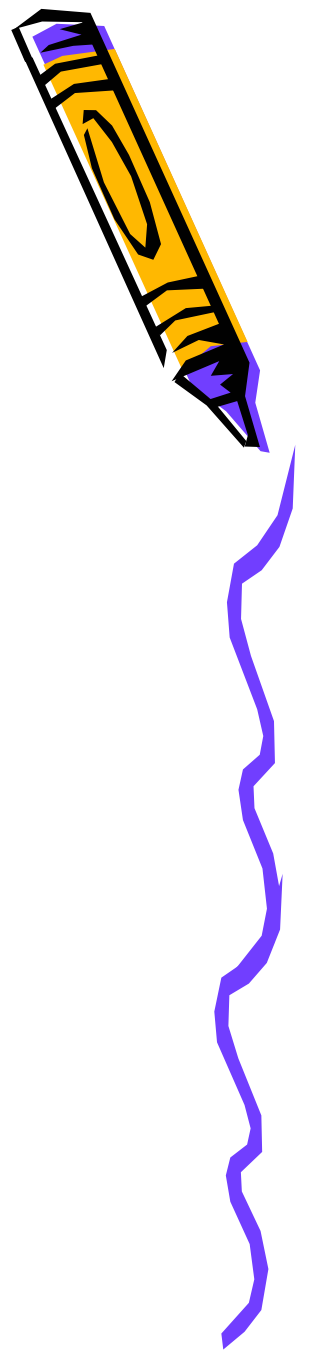
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10 Year Overview of the Research Literature  
Multiple Database search (557 = 54 research articles)

Subjects	Sample Size	Design
<ul style="list-style-type: none"><li>•22 % Children</li><li>•22% Families &amp; Staff</li><li>•24 % Parents</li><li>•31 % HCP</li></ul>	<ul style="list-style-type: none"><li>•15 % 1-20</li><li>•24 % 21-50</li><li>•17 % 51-100</li><li>•31 % 101 - 500</li><li>• 6 % over 500</li><li>• 6 % unclear</li></ul>	<ul style="list-style-type: none"><li>•26 % Qualitative</li><li>•31 % Quantitative (surveys*)</li><li>•33% Mixed Method</li><li>• 9 % Unclear</li></ul>



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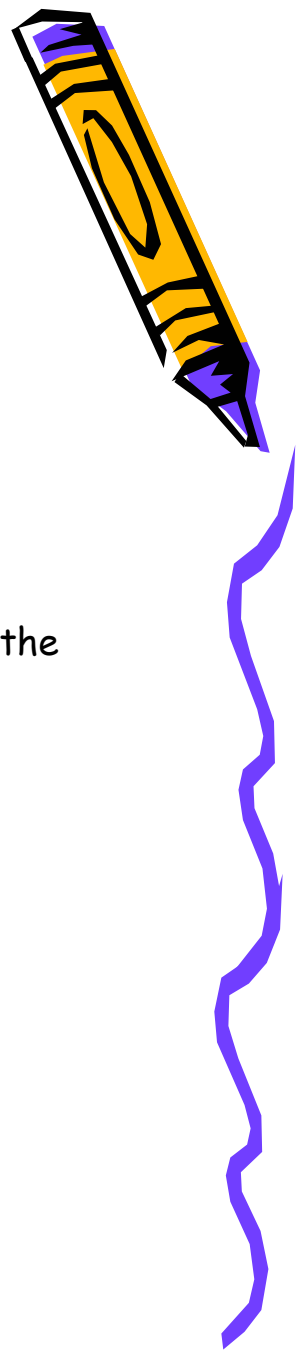


## Journals

- Palliative Medicine
- Archives of Pediatric Adolescent Medicine
- Journal of Palliative Care
- Journal of Clinical Oncology
- Death Studies
- Social Science & Medicine
- Psychological Medicine
- Pediatrics
- Cancer Nursing



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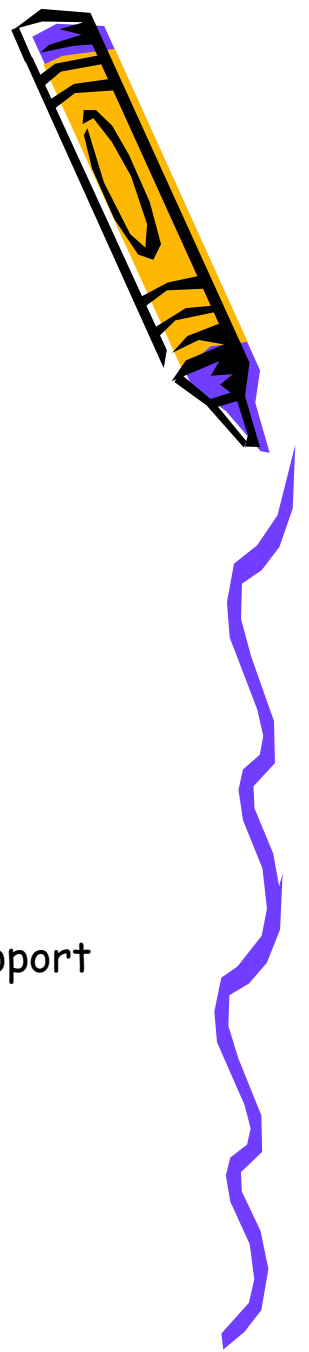


## Ethical Challenges

- **The Child's Voice\***  
Consent & assent with children  
Lack of understanding re the developing autonomy of children & adolescents & the right to decide on participating in research  
Over protectiveness & misconceptions regarding the value of the child's voice
  - Perceptions that research is burdensome and harmful
  - Beliefs that benefits are minimal
  - Vulnerability significantly influences consent or ability to decline
  - Beliefs regarding accuracy of bereaved parents' recall
- Personal responses & experiences of REB reviewers



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## Methodological Challenges

- **Recruitment Barriers\***
  - Definitions of eligibility & prognostics
  - Gatekeeping
  - Study design
  - Logistics around access to patients
- Child & Family focused vs family related research
- Lack of standardized measures & data collection methods that support the child's voice
- Limitations of REB's with topic and qualitative methods



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## Possible Solutions

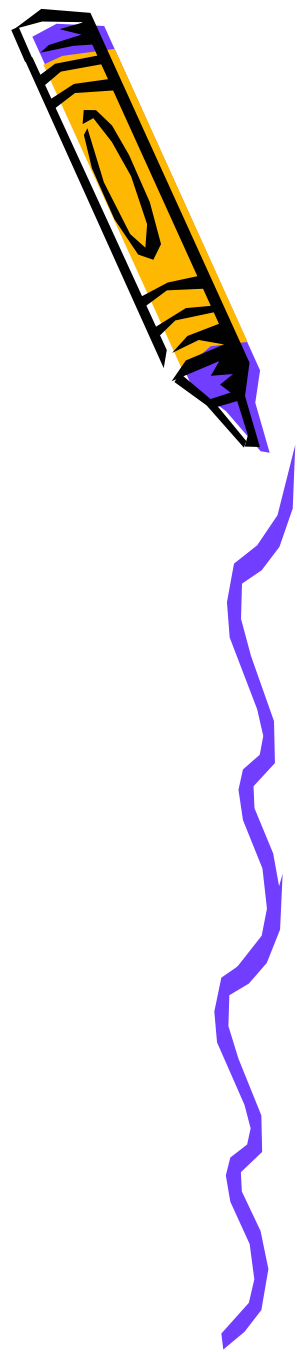
- Flexible recruitment strategies (letter, written info)
- Family/child decisions around best methods of data collection
  - May include, online diaries/blogs/chatrooms, art, play & music to capture childrens' voices
- Trained RA's & interviewers in illness, anticipatory grief and bereavement
- Offer follow up after the research (ie. Contact, results, reports)
- Consistency in institutional ethical reviews to promote multi-site studies
- Family and clinical team participation in the research design process, interview script and onward



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## Dissemination & Translation

Strategies to transfer research knowledge to potentially inform decisions about health and health care.



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## Dissemination & Translation Ideas

- Academic Journals (including no cost online versions)
- Newsletters
- **Web Pages\***
- Television, radio and newspapers
- Conferences (including patient led)
- Seminars & round tables
- One on one meetings and exchange (interaction at all stages of research process)
- Presentations to selected groups of clinicians & or decision makers
- Existing networks of stakeholders
- Continuous & interactive education
- Opinion leaders



- ABOUT TRAC-PG
- PATIENTS & FAMILIES
- CLINICIANS & VOLUNTEERS
- POLICY MAKERS & RESEARCHERS
- JOIN A STUDY



**inspiring**  
family centered, research based  
palliative care

**Dr. Beverley Antle**  
1959 - 2006

[>read more](#)

Welcome to TRAC-PG's website for families, health care providers, researchers, volunteers and decision makers interested in learning together about the care of seriously ill and dying children and their families.

**ABOUT TRAC-PG**

A research interest group within Child Health Evaluative Sciences, Research Institute, SickKids was initiated in 2003 by Dr. Beverley Antle, PhD, Dr. Maru Barrera, PhD and Laura Beaune, MSW.

Our initial aim was to collaborate and develop a cohesive program of research with respect to further understanding the living, dying and bereavement experience of children with life threatening illnesses and their families to generate new knowledge and integrate evidence based palliative care across health care systems.

[> read more](#)

**LATEST RESOURCES**

**Literature & Book Review**  
Title, Date & Families

[> view all](#)

**Studies & Publications**

Date, Title. Lorem ipsum dolor sit amet, consectetur adipiscing elit.

[> view all](#)

**Events**

Weekend retreat. Pellentesque nisi leo, sodales eu, venenatis id,

[> view all](#)

**News**

Reports on the 2007. Ut ultricies neque nec est. In nunc ligula,

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**Newsletter**

October 2007 - Lorem ipsum dolor sit amet, consectetur adipiscing,

[> view archive](#)

**SERVICES**



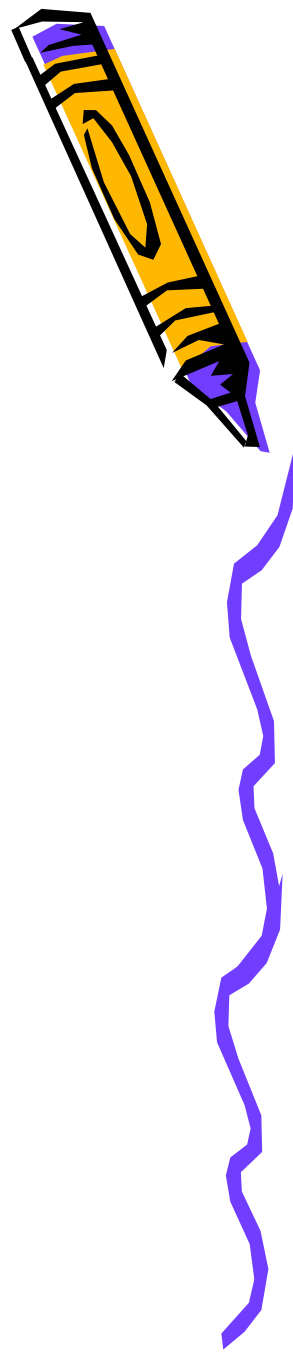
**WHO USES THIS SITE?**

Tell us about yourself to find out.

**I am a ...**

- Patient
- Family
- Clinician
- Volunteer
- Policy Maker
- Researcher

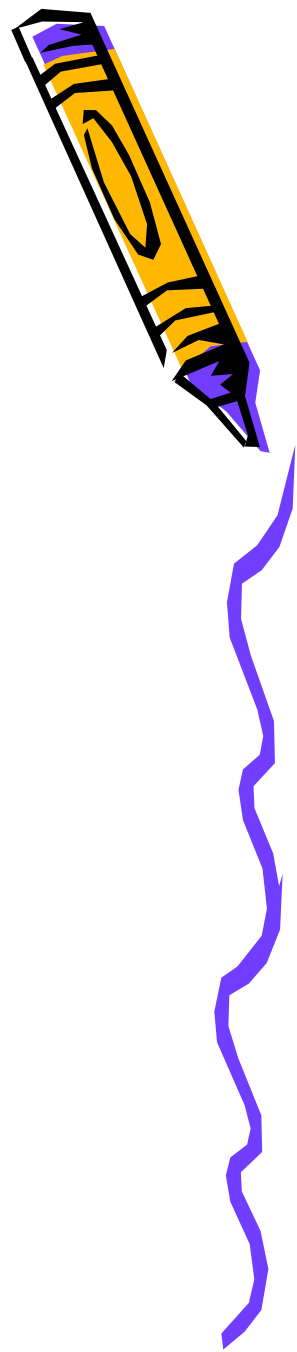
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## Benefits of Research for Participants

- Helping others to have good evidence based palliative and bereavement care - altruism
- Personal benefits for research participants :
  - 1) enabled grief expression
  - 2) opportunity to share and honour their experience and the life of the child who died



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## Bibliography

On request by email to:  
[laura.beaune@sickkids.ca](mailto:laura.beaune@sickkids.ca)

