Developing a Psychosocial Support Intervention for Parents of Children with a Life Limiting or Life Threatening Illness Living in Saskatchewan: A Community Based Approach

Jill M. G. Bally, Dr. L. Holtslander, Nicole Smith, Dr. H. Hodgson-Viden, Dr. C. Mpofu, Marcelline Zimmer

All Ages, All Stages: Transitions in the Continuum Of Hospice Palliative Care

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Background

• Survival rates related to life limiting (LLIs) and life threatening illnesses (LTIs) are improving. Literature about family care does not necessarily reflect this ongoing change.

• Treatment for childhood illnesses is challenging for parents.

• Hope is essential and supportive for parents who have children with LLIs and LTIs.
Keeping Hope Possible

Factors Influencing Parental Hope

Accepting Reality

Establishing Control

Restructuring Hope

Purposive Positive Thinking

Preparing for the Worst

Hoping for the Best

Bally et al., 2013
Purpose

• The overall purpose of this qualitative research study is to develop a theory-based hope intervention to improve the psychosocial and bereavement support of parents of pediatric palliative care patients
Methodology

• the research will be carried out by conducting:

✓ A **metasynthesis** of the related literature
✓ A **Delphi survey**
✓ **Focus groups**
Progress to Date

• Ethical and operational approval sought and obtained in the fall of 2013

• The metasynthesis is underway

• Recruitment began in early 2014 for the Delphi survey and data collection and analysis are currently in progress
Sampling and Inclusion Criteria

- Purposive Sampling – participants were identified by our research advisory committee and invited to participate in the study by email

- Parents, physicians, nurses, social workers, and community members who care for children with a variety of childhood illnesses who were English speaking, and freely consenting
Data Collection and Analysis

• **Methods:**
  - The first round of the Delphi survey was sent out and the responses from 64 participants have been collected

• **Analysis:**
  - Each response was entered into ATLAS.ti 7 for organization and management of the data
  - Thorne’s methods of data analysis were adhered to:
    - Three levels of coding
    - Memos
    - Constant comparative analysis
Preliminary Findings

- Data collection and analysis currently in progress:

- Four subprocesses included ‘accepting reality’, ‘establishing control’, ‘restructuring hope’, and ‘purposive positive thinking’.

- Coding ‘accepting reality’ completed.
Preliminary Findings

• Accepting Reality

✓ Support to access quality resources
✓ Encourage parents to ask questions as needed
✓ Provide anticipatory guidance
Preliminary Findings

- Provide and review test results
- Facilitate connections with other parents
- Provide time and place for parents to reflect on experience
Implications of the Findings

• These findings may inform the practice of health care providers who work within the scope of pediatric palliative care in the acute care, community health, and home settings where, currently, there is very little in place to support such caregivers and families.

• Additional research is required to test and develop the hope based intervention.
Comments and Questions

Thank you!

jill.bally@usask.ca; n.r.smith@usask.ca