

Keeping a Positive Outlook – Strategies, threats, and outcomes for parents of children with cancer and other serious illness

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Speaker disclosure statement

- Neither Katherine P. Kelly PhD RN nor Kathleen A. Knafl PhD FAAN have any industry relationships to disclose



How parent constructs affect parent and family well-being after a child's death

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Study Aim 2

Develop an **integrated formal grounded theory** from the two substantive grounded theories and **other evidence** to generalize the theoretical framework to other parent populations and to family well being.





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- Co Investigators

- **CNHS Oncology team**

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- **CNHS PICU team**

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- Cheryl Reggio
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 - **Kathy Knafi**
 - Cathy Charmaz, Roberta Woodgate, Chris Feudtner, Lori Wiener, Suzanne Feetham



Purpose of our presentation

- Identify how concepts that ultimately inform pediatric oncology nursing practice are researched
- Describe synthesis strategies developed to address Aim 2 and their potential application in future research
- Identify the influencing factors, parent actions, and outcomes related to Keeping a Positive Outlook



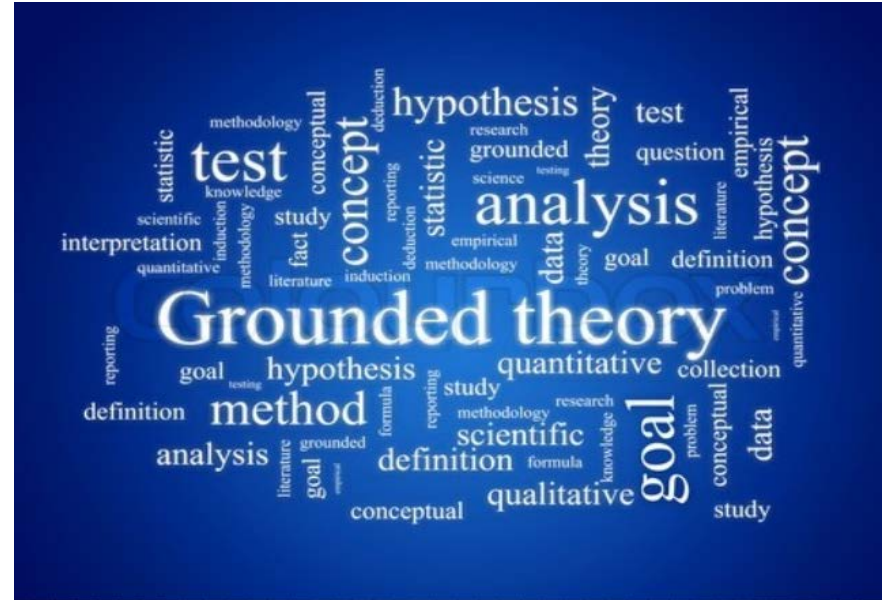
Good Parent Themes* Hinds; *October*; Feudtner

- Doing Right by My Child; Making informed Medical Decisions; Putting my child's needs above my own when making medical care decisions
- Being There for My Child; Staying at My Child's Side
- Conveying Love to My Child; Making Sure My Child Feels Loved
- Being a Good Life Example
- Being an Advocate for My Child; Advocating for My Child (with Medical Staff)
- Letting the Lord Lead; Maintaining Faith; Focusing on My Child's Spiritual Wellbeing
- Not Allowing Suffering; Focusing on My Child's Quality of Life; Focusing on My Child's Comfort
Combined with below
- Making My Child Healthy; Focusing on My Child's Health and Longevity; Focusing on My Child's Health; Focusing on My Child Having as Long a Life as Possible
- *Having a Legacy*
- **Keeping a positive; Keeping a realistic outlook**



Our Approach

- Applying established methods
 - Meta-synthesis
 - Formal grounded theory
- Developing a new method
 - Expanding thematic analyses to grounded theory



Using Existing Grounded Theories to Validate and Expand the Good Parent Themes

- Sample: Purposive sample of 25 published grounded theory studies
 - English language primary research reports published between 1/1/2000 – 6/30/2018; Currently being updated for future publication of this work.
 - Focused on one or more of the following topics:
 - The experience of being the parent of a child with cancer or other life threatening condition, excluding parents of premature babies in NICU
 - The experience of being the parent of a child who experienced an unexpected accidental trauma – either before or after the child has died



Our theory building process:

A series of abstracting GP theme findings to a higher level



Theory Building: Final summary and synthesis for each theme



- Supporting Data – tally of:
 - # of studies
 - Sample size and family member composition
 - Countries of origin
- Positioning of GP-relevant theme in study results
 - Depicted in model
 - Theme/Subtheme – use same or equivalent term
 - Example under theme or subtheme
 - Inferred with rationale
- Summary table of parent actions, influences and outcomes (key components of grounded theories)
- Final synthesis



Supporting data for Keeping a Positive Outlook



- Studies – 13 (52%) of 25 in the GT sample studies; 19 reports
 - 220 families
 - At least 126 mothers; 68 fathers – family member not always specified
- Conditions – Cancer (n=153 families), Life limiting condition (n=43); Cardiac (n=24)
- Countries – Canada (8), US (2), UK (2), Taiwan



Summarizing process level findings related to Keeping a Positive Outlook

Study	Parent Actions – Cognitive (only 2 vague behavioral parent actions reported)	Influences on Actions	Outcomes of Actions
Study 1. Bally et al 2014	<p>Purposive positive thinking (model element). Accepting reality (model element). Not contemplating child's life too far into the future.</p>	<p>Hope as depicted by Hoping for the best and Preparing for the worst. Parental assessment of child health status. Knowledge and experience. Connecting with others. Being in the loop. Reaffirming faith.</p>	<p>Keeping Hope Possible – Maintain hope by resolving main concern of losing hope.</p> <p>Helps parents to focus on child caregiving.</p>
Study 7. Eaton Russell et al, 2016	<p>Containing illness (reframing illness as something they can manage) Focusing on the positive (Day by day) "Fight the tumor" i.e. get medical help, strengthen their children. Seek distraction from stress and grief.</p>	<p>None reported</p>	<p>Reclaiming health</p> <p>Balancing grief and survival (i.e. counterbalancing grief and recognizing that survival might be possible.</p> <p>Positive outlook</p>

Synthesis of GT process elements: Cognitive parent actions

- Process elements identified in multiple studies
 - Purposive positive thinking
 - Accepting reality
 - Reframe illness as something manageable
 - Faith
 - Maintain emotional well being
 - Recognition of the situation (illness as child's destiny – one study only Asian sample)
 - Looking for signs
- Process element identified in one study
 - Keeping spirit alive



Synthesis of GT process elements: Behavioral parent actions

- Maintaining self
- “Fight the tumor” – get medical help; strengthen the child; seek distraction from stress & grief



Synthesis of GT process elements: Influences on parent actions

- Hope
 - Hope for the best; Prepare for the worst
- Parent assessment of child's condition
- Knowledge and experience
- Psychosocial support
- Faith
- Being in the loop
- Belief that positive attitude linked to better outcomes



Synthesis of GT process elements: Outcomes of parent actions

- Keeping hope possible
 - Future and present oriented hope
 - Maintaining hope
- Focus on caregiving (day to day focus)
- Reduce/endure uncertainty
- Reclaiming health - Increase strength for self; balance needs
- Balance grief and survival – recognize survival is possible
- Positive outlook
- Ability to support child and themselves
- Develop a way of being in the world



Distinctive findings from non-cancer samples

- Cognitive actions
 - Keeping options open
 - Normalizing
 - Focus on couple
 - Safeguarding child's survival
 - Downward comparisons
- Behavioral actions
 - None reported



Distinctive findings from non-cancer samples (con't)

- Influencing factors
 - Sense of obligation to child
 - Support from partner
 - Child developmental level
 - Perceived degree of uncertainty
 - Surviving sequenced cardiac surgeries
 - Caregiving demands
- Outcomes of parent actions
 - View self as parent not caregiver
 - Not feeling overwhelmed
 - Find meaning in child's death



Preliminary theoretical summary excerpt

“What strikes me most as I complete this analysis is that Keeping a positive outlook is a purposeful cognitive action that parents use to be able to care for and make treatment decisions for their child who has a serious or terminal illness. A number of studies used the commonly used phrase “living one day at a time.” Keeping a positive outlook lived in the present not the future.”



Final Reflections & Next Steps

- Strength of meta-synthesis methods to generate theory
 - New method developed: Thematic Expansion
 - Takes thematic analyses to higher level conceptualizations (manuscript under development)
- Variability of adherence to grounded theory methods across studies limited our ability to extract full range of process element findings from each



Final Reflections & Next Steps (cont'd)

- Need a strong partnership and willingness to challenge each others' thinking (Methods expert + Clinical expert and member of primary study team)
- Finalize our summaries and await completion of substantive cancer and ICU grounded theories for developing integrated formal grounded theory

