TH-3: *Go Wish-Pediatrics*: Pilot Study of a Conversation Tool in Pediatric Palliative Care

**Purpose:** The twofold purpose of this embedded mixed method pilot study is to explore the use of an advance care planning conversation tool with parents caring for children suffering from a life threatening illness and to examine the parent experience of a child’s illness while caring for a child receiving pediatric palliative care.

**Background:** Difficult conversations and decisions are an unfortunate reality for parents caring for children facing life threatening conditions. Confusing, inadequate, and inconsistent communication by health care providers makes advance care planning difficult in pediatrics.

**Research Aims:**
1. Describe parents’ experience of having a child in pediatric palliative care as measured by the Parent Experience of Childhood Illness (PECI) tool.
2. Explore relationships among the parents’ experience (PECI) and pediatric disease demographics.
3. Identify the effect of *Go Wish- Pediatrics* on parents’ experience of having a child in pediatric palliative care.
4. Describe parents’ experience of using *Go Wish- Pediatrics*.

**Design:** An embedded mixed methods design was utilized to evaluate the effectiveness of an advance care planning conversation tool, *Go Wish- Pediatrics*, on the emotional resources and distress experienced by parents caring for children in palliative care. For this pilot study, a mailed invitation to participate was sent to 134 parents of children currently enrolled in palliative care which yielded a total of ten participants. The intervention was adapted from *The Go Wish™ Game* developed by Dr. Elizabeth Menkin and the Coda Alliance for use in the geriatric population.

**Findings:** The *Go Wish- Pediatrics* intervention resulted in no change in pre-post comparison of guilt and worry, unresolved sorrow and anger, long term uncertainty, and emotional resources. For the qualitative portion of the study, data was collected using semi-structured interviews and analyzed using a thematic analysis. The three emerging themes of the parents’ perception of the *Go Wish- Pediatrics* intervention included *operationalizing thoughts into action*, *empowered to join the conversation*, and *a lighthouse in the fog*. The mixed methods analysis utilized comments from the participant interviews to explore a deeper explanation of how parents experienced the parental distress and emotional resources subcategories.

**Clinical Implications:** Parents identified that the *Go Wish- Pediatrics* intervention was beneficial in helping initiate conversations related to topics that are often difficult to approach. The intervention also served a communication bridge to support communication between spouses or significant others as well as with the healthcare team.

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**NAPNAP Research Agenda Priority:** Mental Health for Children and Families
GO WISH-PEDIATRICS:
PILOT STUDY OF A CONVERSATION TOOL IN PEDIATRIC PALLIATIVE CARE

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IRB Approval from South Dakota State University and University of Nebraska Medical Center/Children’s Hospital Omaha

BACKGROUND
• In the U.S. less than 10% of the children who could benefit from palliative care are actually receiving these services (CHI, 2010).
• Difficult conversations and decisions are an unfortunate reality for parents caring for children facing life threatening conditions.
• Families report decreased level of care and increased sense of hopelessness because of barriers created when open communication is not facilitated (Price, Jordan, Prior, & Parkes, 2011).
• Confusing, inadequate, and inconsistent communication by health care providers makes advance care planning difficult in pediatrics.

PURPOSE
The twofold purpose of this embedded mixed method pilot study is to:
1. Explore the use of an advance care planning conversation tool with parents caring for children suffering from a life threatening illness.
2. Examine the parent experience of a child’s illness while caring for a child receiving pediatric palliative care.

CONCEPTUAL FRAMEWORK

RESULTS

• What is the parents experience of having a child in palliative care?

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt &amp; Worry</td>
<td>10</td>
<td>2.09</td>
<td>0.98</td>
<td>1.00 - 3.00</td>
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<tr>
<td>Unresolved Sorrow &amp; Anger</td>
<td>10</td>
<td>3.00</td>
<td>0.75</td>
<td>2.00 - 3.50</td>
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<tr>
<td>Long-term Uncertainty</td>
<td>10</td>
<td>3.00</td>
<td>0.50</td>
<td>2.00 - 3.25</td>
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<tr>
<td>Resolved Emotional Resources</td>
<td>10</td>
<td>2.45</td>
<td>0.50</td>
<td>2.00 - 3.00</td>
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</table>

• Does the intervention Go Wish Pediatrics, a facilitated advance care planning conversation tool, impact the parent’s experience of having a child in pediatric palliative care as measured by the PECI?

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pre</th>
<th>Post</th>
<th>Wilcoxon Test</th>
</tr>
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<tbody>
<tr>
<td>Guilt &amp; Worry</td>
<td>2.3</td>
<td>2.5</td>
<td>17</td>
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<tr>
<td>Unresolved Sorrow &amp; Anger</td>
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<td>26</td>
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<tr>
<td>Long-term Uncertainty</td>
<td>2.2</td>
<td>2.2</td>
<td>20</td>
</tr>
<tr>
<td>Resolved Emotional Resources</td>
<td>2.2</td>
<td>2.2</td>
<td>20</td>
</tr>
</tbody>
</table>

CONCLUSION
• Go Wish Pediatrics intervention gave parents an active voice in the care of their child.
• The Go Wish Pediatrics intervention facilitated conversations related to advance care planning.
• Overall, parents appreciated the intervention and the pilot study data demonstrated there was no negative impact on the parents experience of their child’s illness.

FUTURE WORK
• Adaptation of the intervention for involving adolescents in the conversation.
• Utilization of the intervention to create documented advance care plans in various settings.
• Consideration of a new conceptual framework of a “Sharing Conversation”

ACKNOWLEDGEMENTS: Winefred Pinch Research Monetary Award, Sigma Theta Tau Iota Tau Chapter

METHODS

Population
• 10 participants (6 female; 4 male)
• Child actively enrolled in palliative care

Instruments
• Parent Experience of Child Illness (PECI)

Mixed Methods Design

Quan / Qual Data Analysis
Quantitative Data Analysis
Interpretation
Qualitative Data Analysis
Go Wish Pediatrics
Go Wish Pediatrics Pre and Post Tool
Go Wish Pediatrics Data Collection
Go Wish Pediatrics Qualitative Data Collection
Go Wish Pediatrics Intervention Pilot Study

RESULTS

Qualitative Themes
• Operationalizing thoughts into action
  • “to have the cards where you can actually physically see them and lay them out instead of trying to see them in your head was really helpful, this made it more real for me.”
  • “opened her eyes to things she wouldn’t have even thought to ask about but really wanted to talk about with someone.”
  • A lighthouse in the fog
  • “This fog of medical terminology and words that we were living everyday was so overwhelming that we didn’t even know what to ask, the cards gave me a focused point to organize my thoughts.”

Very Important to Parents
Least Important to Parents

• “my relationship to my spouse or significant other” (n=6)
• “discuss my fear of my child having an event when I am not there” (n=7)
• “maintaining my child’s memories” (n=8)
• “define the palliative care team’s role in caring for my child and family” (n=7)
• “my child being free from machines” (n=7)