Parental decision-making for a child with a life-limiting condition

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Presenter Disclosure

Presenter Name: Nahal Stoppels

Relationships with commercial interests: None
Objectives

• Review of study

• Discuss preliminary findings
Background

- Parents are making frequent decisions on behalf of their children (Jackson et al., 2008)
- Often a lack of an obvious ‘best choice’ (Stacey et al., 2006)
- Decisions may be value-sensitive (Stacey et al., 2006 & Stacey et al., 2005)
- Parents at risk for decisional conflict (Jackson et al., 2008 & Feenstra, 2012)

- Majority of studies have focused on ‘critical decisions’ (withdrawal of life-sustaining therapies, high-risk pregnancy, etc.) in specific settings (NICU/PICU, Emergency dept, etc.) rather than decisions across the illness trajectory (Allen, 2014)
Decisional Conflict:

* a state of uncertainty arising from decision-making that navigates two or more options involving risk, loss, potential for future regret, and/or challenges personal values and beliefs

(Feenstra, 2012)
Background

Factors

- Medical
- Social
- Personal

Uncertainty

- Psychosocial burden
- Regret
- Blame
- Delay/avoidance
- Reduced compliance

Consequences
Framework

Ottawa Decision Support Framework
(AM O’Connor, 2006)
Purpose

To explore parents’ decision-making experiences as they relate to their child with a life-limiting condition.

1. What are parents’ decision-making needs?
2. From a healthcare providers’ (HCPs) perspective, what are the decision-making needs of parents?
3. How are the decisional needs of parents of children with life-limiting conditions supported?
Methods

- Qualitative study: Interpretive Description (Thorne, 2016; Thorne et al., 2004)
- For the purposes of enhancing and informing existing clinical understanding
- Ethics approval from the research ethics board of both CHEO and the University of Ottawa
- Semi-structured interviews conducted
- Interview guide based on the Ottawa Decision Support Framework (ODSF)
- Qualitative thematic analysis was conducted: identify, analyze, and report themes (Vaismoradi et al., 2013)
- No *a priori* framework was applied to analysis
## Participants

### Parents
- Children <18 yrs old, life-limiting diagnosis, and cognitively unable to contribute to decision-making
- English
- Followed by the CHEO Palliative Care team
- N=6

### HCPs
- CHEO or Roger Neilson House clinician
- Involved in family’s circle of care as they made health or social decisions
- English
- N=6
Findings - Needs

Opportunities to advocate on behalf of their child

- Self-identified as primary stakeholder
- Seeking to advocate even without “realizing that was what [they] were doing”
- Feeling like a ‘good parent’ and validated accordingly

Consideration of their values and beliefs

- Relying on “heart and gut” to mitigate decisional conflict and reconcile with “moral code”
- Health care provider focus on quality of life

Early engagement on the part of health care providers

- Support throughout the decision-making process and “navigating through it all”
- Wanting the “whole picture” as early as possible in order to fully consider implications and potential subsequent decisions
Findings - Supports

Expanding support network

- Utilizing parent/peer network to discuss with others who have “gone through similar challenges” and knowledgeable of “day to day” experience
- Widening clinical circle of care: advocated for by parents, facilitated by clinicians and/or pursued in partnership

Sharing decision with health care providers

- Parental preference and a sign that they are “really trusted” and when not possible, interactions and decisions “stressful and more difficult”
- Health care provider describing role as “empowering parents making these difficult decisions”

Supportive Strategies

- No specific tools, aids, or strategies identified
- Social worker: ‘solution based focus therapy’
Discussion

In keeping with previous studies:

• Reinforce the desire to be “good parents” (Feudtner et al., 2015 & Hinds et al., 2009)

• Interactions with HCPs are deemed effective in supporting decision-making when felt to be “humane” and parents reassured (Davies et al., 2017)

• Parents indicate that they prefer shared decision-making and engagement from HCPs (Feudtner et al., 2015; Madrigal et al., 2012; & Verberne et al., 2017)
Discussion

Of interest:

• Value of formalized parent/peer networks and/or matching programs

• HCPs described interactions with parents as ‘information-transfer transactions’
  • Reflection of limited access/availability/knowledge of resources available to clinicians?

• Guides/supports for HCPs may:
  • Bridge the gap between evidence and ‘real world’ implications
  • Reduce clinician anxiety
  • Allow clinicians to focus
  • Likely not pediatric and/or palliative care specific
Conclusions

• Parents and HCPs are able to articulate key decision-making needs
• Parents describe means by which they feel supported
• HCPs organically provide support with heavy focus on ‘information-transfer transactions’
• Much to be desired regarding clinician supports
References


Thorne S. Data analysis in qualitative research. *Evid Based Nurs*. 2000;3:68-70. doi:10.1136/ebn.3.3.68
