



BCKD₂₀₁₇
BC KIDNEY DAYS

Caregiving and ESKD

Today's Talk

- The experience of caregiving / Journey to understanding
- What do we think we know about caregiving ?
- Consider using an additional “lens for understanding”
- Caregiving: A testament from the field

Journey to understanding?



Research on Caregiving? What does it tell us?

- Managing demands of caregiving can have a profound effect on caregivers (*dialysis) (Tong, Sainsbury & Craig, 2008)
- Consistently has shown caregivers experience depression, anxiety, fatigue, social isolation, relationship / financial strain (Cukor, Cohen, Peterson, et al, 2007).
- Interventions?
 - Education
 - Social / Practical Support (informal & formal)



My research on the experience of caregiving?

- Phenomenology (meaning making, lived experience)
- Clinical/anecdotal experience
- The context of the illness experience not captured by the literature- I.e. even when children are ‘doing well’ parents report ongoing family difficulties.
- **“Not going to say it’s suffering; we’re going to say it’s an experience” (Pediatric)**

Findings ?

- Importance of relationships (peers, health care team)
- Uncertainty
- Development of strengths and personal growth

Which relationship is most challenging for caregivers to manage?

- a. Extended family members
- b. Health care team
- c. Patient
- d. Friends
- e. Other

[Live Poll Results](#)

Importance of self in relation to others

- Practical supports ‘second pair of hands’ & “ a good set of ears”
- Barometer for how caregivers saw themselves
- Health care professionals
 - Greatest tension (best support vs stress)

Clinical implications?

- **Ensure we are giving caregivers a voice/ hearing that voice**

I personally enjoy the feeling of uncertainty in my life

- A. Most of the time
- B. Some of the time
- C. Never
- D. Hate it more than you know

[Live Poll Results](#)

Uncertainty and fear of rejection

- Significant element of caregiving experience
- Multifaceted
- Rarely is acknowledged by health professionals (?)

Clinical implications?

- **Provide a space to explore the role of uncertainty in caregiver/patient day to day experience of illness.**
- **Validate the uncertainty as real and ever present. (comfortable with the unknowns)**

Which of the following are you least likely to hear from a caregiver?

- A. “Sometimes I get frustrated with having no time”
- B. “I get confused with all the medications”
- C. “This experience has changed me in so many ways”
- D. “Is it possible to get more in home supports?”

[Live Poll Results](#)



Development of Strengths and personal growth (post traumatic growth)

- Growth (coexist with stress/distress).
 - Stronger self
 - Enhanced relationships
 - Appreciation of life and Spiritual change
- **Provide a space for caregivers to talk about areas of growth and personal development that have derived from the experience. Build capacity for future challenges?**

More details about the study

Mantulak, A. & Nicholas, D. (2014). “We’re not going to say it’s suffering; we’re going to say it’s an experience”: The lived experience of maternal caregiving in pediatric kidney transplantation. *Social Work in Health Care*, 55(8), 580-594.

“THERE IS NO
ONE ALIVE
WHO IS YOUER
THAN YOU.”



-DR. SEUSS



The experience of caregiving

