

Fundamentals for Families

Parenting an Infant on Dialysis: Psychologist Perspective

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Impact on Parents

Qualitative interview studies:

- Absorbing the clinical environment
 - Confronting diagnosis
 - Invasive procedures
 - Worry about relationships with staff/providers
 - Variable quality of care
 - Losing ownership

Tong et al. 2008; Tong et al. 2010; Kirk et al. 2005; Sanchez et al. 2013

Impact on Parents

Qualitative interview studies:

- Medicalizing Parenting
 - A consuming routine
 - Pressure and isolation
 - Struggles with feeding
 - Psychological trauma of medical care
 - *Not agents of comfort and protection, but rather agents of pain and distress.*

Tong et al. 2008; Tong et al. 2010; Kirk et al. 2005; Sanchez et al. 2013

Impact on Parents

Qualitative interview studies:

- Disruption of family norms
 - Household and financial stress
 - Social restrictions
 - Impact on family planning
 - Tension with partner
 - Sibling neglect

Tong et al. 2008; Tong et al. 2010; Kirk et al. 2005; Sanchez et al. 2013

Impact on Child

- Interruption of typical activities, impacting developmental milestones
 - Gross motor, movement
 - Oral motor skills, feeding
 - Sleep
 - Potty-training
- Interruption of routines
- Medical stress/trauma
 - Distress/pain/anxiety with injections, lab draws, procedures
 - Questions about long-term emotional health
- Results in significant impact on quality of life

Impact on Child

Research on neurodevelopment:

- Mostly small, single-center studies
- Diagnosis in infancy associated with developmental delays
- Motor skills seem more likely to be affected
- Delays associated with severity of disease, earlier onset, and comorbidities (e.g., prematurity, events affecting the brain, genetic syndromes)
- Some evidence that transplant benefits neurodevelopmental catch up

Comfort is Important

Christine Chambers, PhD

<https://itdoesnthavetohurt.ca>



<https://www.yummymummyclub.ca/it-doesn-t-have-to-hurt-press-highlights>

Children's Mercy Comfort Promise: Preventing pain during needle procedures;

4 simple steps for Routine Needle Procedure!

(Numbing, Sucrose/ Breast Feeding, Positioning, Distraction)

–Age appropriate –Per patient preference



Coping and Adjusting

- Marathon, or maybe a marathon plus many sprints
- For some things . . . good enough is good enough
- Mobilize social support
 - Caregivers
 - Adults who can support siblings
- What will improve quality of life for child, caregivers, family?
- What will promote resiliency?
- Effects of COVID-19 pandemic

Resiliency

- Routines
- Warm, firm, consistent parenting
- Touch, physical affection
- Building self-efficacy
 - Daily tasks
 - Self-care
 - Reminiscing about success and/or getting through
- Build coping



Thank you!