



PRESENTER

Nora Fayed

Background

Health insurers, service providers, patients and their caregivers identified that ‘medical technology’ should be a priority outcome in pediatric complex-care service-delivery¹.

A Patient-Reported Outcome Measure (PROM) has been developed with caregiver and child-centered content. Classical Test Theory approaches were used to complete the first wave of psychometric tests.

Methods

Design: Sequential mixed methods
Phase 1 - Qualitative: interview data forms measure content
Phase 2 - Quantitative: preliminary psychometric tests

Eligibility: Caregivers of children:
18 months- 25 years old with
Chronic disease (>6months) who have
High-health utilization and use
Medical technology-user (e.g., feeding tubes, ventilators, vascular access device, etc.)

Recruitment/Setting: Clinical (Canada) and Community-Based (Internet Canada, US, & UK)

Participants

Participants were non-overlapping between phases

	Phase 1: Qualitative Obtain Content		Phase 2: Quantitative Psychometric Testing	
	n=33	%	n=55	%
Age of Child				
18m-4 yrs	7	21.2%	15	27.3%
5-9 yrs	12	36.4%	18	32.7%
10-13 yrs	11	33.3%	12	21.8%
14-16 yrs	2	6.1%	6	10.9%
17-18 yrs	0	0.0%	3	5.5%
19-25 yrs	1	3.0%	1	1.8%
Caregiver's Gender				
Male	0	0.0%	4	7.3%
Female	33	100.0%	50	90.9%
Non-Binary	0	0.0%	1	1.8%
Child's Gender				
Male	17	51.5%	32	58.2%
Female	16	48.5%	23	41.8%
Country				
Canada	33	100.0%	48	87.3%
US	0	0.0%	5	9.1%
UK	0	0.0%	2	3.6%
Primary Household Language				
English	25	75.8%	46	83.6%
French	8	24.2%	4	7.3%
Other	0	0.0%	5	9.1%
Highest Level of Education Completed by Caregiver				
Secondary-School	3	9.1%	13	23.6%
Post-Secondary	24	72.7%	38	69.1%
Missing	6	18.2%	4	7.3%
Primary Medical Technology				
G-Tube	23	69.7%	37	67.3%
GJ-Tube	4	12.1%	3	5.5%
J-Tube	1	3.0%	0	0.0%
NG-Tube	1	3.0%	0	0.0%
Vascular Access Device*	2	6.1%	1	1.8%
Ventilation Device*	1	3.0%	6	10.9%
Other*	0	0.0%	3	5.5%
Missing	2	6.1%	5	9.1%
# of Medical Technologies In Current Use				
1	11	33.3%	16	29.1%
2	5	15.2%	11	20.0%
3	3	9.1%	10	18.2%
4	1	3.0%	2	3.6%
5+	12	36.4%	11	20.0%
Missing	0	0.0%	5	9.1%

*Vascular Access Device=PORT, PICC-line, Central-Line; Ventilator=invasive/non-invasive; BiPAP/CPAP; Other= Cough Assist, Glucometer/ Oximeter



Experience with medical technology is a patient-important outcome. We are measuring that.

Content

	Theme Content	Quote	Exemplar Item
Feelings About Med-Tech 	Thoughts and feelings about their child's medical technology	"...and ahh, the G-tube is the best thing that we've ever done"	I accept that my child needs medical technology
Child Health Perceptions 	The child's emotional and physical health and wellbeing	"Well it just went so well. Her breathing was instantly flipped and in those three months with the NG tube she gained over a kilo and was flourishing"	My child's health is better because of their medical technology
Self-Efficacy 	Caregiver's confidence or lack thereof with their ability to use, clean, or troubleshoot the medical technology	"So the button™, we're both very comfortable with just popping in a replacement. We buy special needs bodysuits because of the button™ because she does pull on it...So we're comfortable, you know what I mean? We're willing to do it."	I know how to keep my child's medical technology clean and hygienic
Sleep 	Impact of medical technology on child and caregiver sleep	"I am a light sleeper, I cannot sleep, I hear every single beep of the stupid feeding pump"	My child's medical technology disturbs their sleep
Family 	How medical technology impacts or is supported by, family.	"I guess, in the family. It's just not a big deal. My extended family, on the other hand, it took my mom a whole year to attempt one feed. And she used to be my main babysitter..."	My child's medical technology helps them be included in family activities
Health Provider Supports 	Patient-centered support (or not), caregivers receive and perceive from health providers	"I could call them, what was it, 18 hours of the day and they'd be there within two hours. They were fantastic"	My provider listens to my concerns about my child's medical technology
School 	School staff competency, peer responses, and the child's ability to engage in schooling with medical technology	"if she has a sub-EA, I have to go down there, I have to do the training and take the call or she can't go."	My child's daycare/school supports their medical technology
Community 	The caregiver and child's ability to move-around outside the home, near or far, despite, or because of, medical technology	"But now, we can say, "Let's plan for an outing." And we can go out for more than 2 hours and knowing that she'll have her feed properly."	I feel confident using my child's medical technology outside of the home

All correlation coefficients were found to be significant p<0.05 (2-tailed)

Psychometrics

Domain	# of Items	Alpha Non-Standardized	Alpha Standardized	Test-Retest
General Feelings	17	0.87	0.89	0.84
	17	0.76	0.80	0.88
Perceived Child Health	17	0.76	0.80	0.88
Self-Efficacy	12	0.70	0.72	0.79
Sleep	10	0.85	0.85	0.81
Family	14	0.79	0.80	0.77
Health Provider Supports	6	0.95	0.98	0.92
School	12	0.88	0.89	0.80
Community	19	0.92	0.92	0.84

What's Next?

Multi-domain research scales of patient perceptions of medical technology are research-ready.

A shorter scale based on the underlying uni-dimension of patient-centered experience with medical technology, will require larger samples to be developed using Rasch analysis. Shortened scales will be useful for quality-improvement, benchmarking, and trials of patient-centered tertiary care and home care.



FAYED N, MAJOR N, & COHEN E



1-Fayed N, Guttman A, Chiu A, Gardecki M, Orkin J, Hamid JS, Major N, Lim A, Cohen E. Family-provider consensus outcomes for children with medical complexity. Developmental Medicine & Child Neurology. 2019 Sep;61(9):1093-100.