

Self-Reported Well-Being of Family Caregivers of Children with Medical Complexity

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Examine the well-being of family caregivers of children with medical complexity (CMC) and compare to the general US adult population.

Cross-sectional survey of 143 family caregivers of CMC receiving medical care at a children’s hospital’s complex care clinic in Western Pennsylvania (May 2021 to March 2022).

Patient-Reported Measurement Information System Short-Form (PROMIS-SF) instruments assessing: global mental health, emotional distress, psychological strengths, and sleep-related health. T-score distribution; standardized mean of 50; higher scores indicate more of the measure (e.g., more anxiety).

Future Directions: (1) Develop and test a strengths-based psychosocial intervention targeting CMC family caregivers’ self-efficacy and sense of meaning (Dr. Yu’s current NICHD K23 application); and (2) longitudinal examination of CMC caregiver well-being in nationally representative sample

Table 3. PROMIS Mean T-Scores Among Caregivers of CMC and Comparison to US Population Norms

PROMIS Measure	General US Population Mean (SD)	Caregivers of CMC Mean (SD)	T-score Mean Difference (CMC vs US)	Student's <i>t</i> -test <i>P</i> -value*
Global Mental Health	50.0 (10.0)	44.2 (9.9)	-5.8	< .01
<i>Emotional Distress</i>				
Anxiety	50.0 (10.0)	58.1 (8.7)	+8.1	< .01
Depression	50.0 (10.0)	53.3 (8.9)	+3.3	< .01
Anger	50.0 (10.0)	53.7 (9.5)	+3.7	< .01
<i>Psychological Strengths</i>				
Meaning and Purpose	50.0 (10.0)	51.9 (10.4)	+1.9	.03
Self-Efficacy	50.0 (10.0)	50.4 (10.1)	+0.4	.64
Emotional Control	50.0 (10.0)	46.4 (7.1)	-3.6	< .01
<i>Sleep-Related Health</i>				
Fatigue	50.0 (10.0)	56.9 (6.5)	+6.9	< .01
Sleep-Related Impairment	50.0 (10.0)	55.1 (7.7)	+5.1	< .01

Box Plot of PROMIS-SF T-scores among CMC Family Caregivers. For each measure, boxes extend from the 25th to the 75th percentiles, with median values listed and denoted by the middle line. Horizontal extending lines indicate each measure’s range of values.

