

2022

Positive Psychosocial Attributes Associated with Parent-Appraised Quality of Life in Children with Movement Limitations (Poster)

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PARENT ASKED

“Taking into account all the ways your child’s disability affects them, do you consider their current state to be satisfactory?”

YES

Much higher scores for Meaning & Purpose and Peer Relationships!

NO

All scored below US average by 1 to 3 SDs!



PARTICIPANTS

- 30 parent respondents (96.7% mothers)
 - mean age = 46.3 ± 6.2 yrs
- Children ages 8-17 yrs; 70% Caucasian
- Diagnoses:
 - 33.3% CP
 - 16.7% DCD
 - 13.3% Down syndrome
 - 10.0% spina bifida
- 70.3% walk as primary mode of mobility
- PROMIS® Mobility T-score = 31.0 (14.9 to 41.3)



METHODS

- Online anonymous survey tool
- Parent proxy responses for child
- Asked Patient Acceptable Symptom State (PASS)
 - “Taking into account all the ways...”
- Completed 4 PROMIS® CAT scales
 - US average T-score is 50
 - standard deviation (SD) is 10
- DATA ANALYSIS:
 - Mann-Whitney U - PASS Yes vs. No
 - Chi-squared - T-score cut-off ≤ 40



RESULTS (n=30)

- PROMIS T-score mean comparisons (*$p \leq .01$*)

PROMIS Scale	PASS Yes (n=21)	PASS No (n=9)
Meaning & Purpose	42.3	32.4
Peer Relationships	38.6	29.0
Positive Affect	44.3	42.2

- Crosstabs: T-score cut-off ≤ 40 vs. PASS response

Meaning & Purpose	PASS Yes	PASS No
>40	14	0
≤ 40	7	9

$\chi^2=11.3$, $p<.01$ (100% specificity)

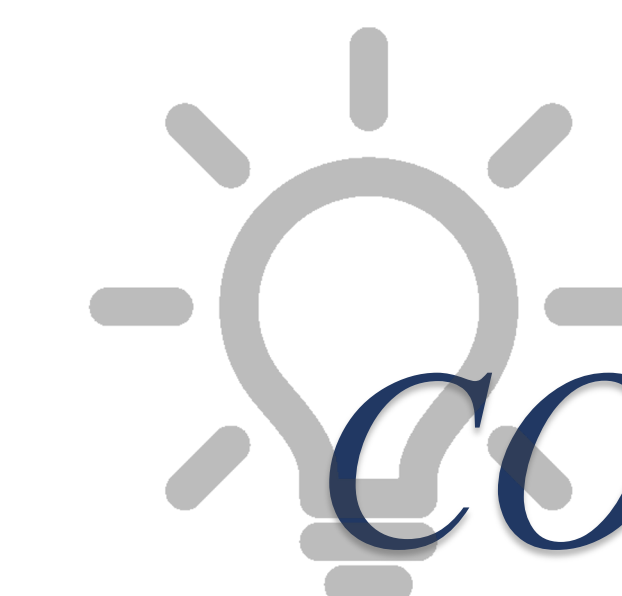
Peer Relationships	PASS Yes	PASS No
>40	9	0
≤ 40	12	9

$\chi^2=5.5$, $p=.02$ (100% specificity)

Positive Affect	PASS Yes	PASS No
>40	12	5
≤ 40	9	4

$\chi^2=0.0$, $p=.94$

- For PASS Yes respondents, 85.7% had at least one T-score >40, 52.4% having two or all three >40.



CONCLUSIONS

Quality of relationships and life meaning/purpose were associated with parents deeming their child’s current state of functioning as satisfactory—momentary affective experiences were not. This might reflect a parent prioritization of child self-fulfillment needs in this older pediatric age group.

How should I use this information?

- Pediatric clinicians might consider measuring psychosocial variables to gain a more holistic picture of current quality of life.
- Resulting PROMIS® scores for *relationships* and *purpose* can guide discussions with families on priorities for therapies and goals for participation.

What should I be mindful about?

- Small sample of convenience.
- Only 23% reported income below \$50,000/yr.
- Few studies exist using a PASS question for children—association with quality of life, health, and participation is not clear.