

BACKGROUND

- Childhood cancer survivors often experience treatment-related late effects which impact their health-related quality of life (HRQOL).
- Differences in preferences for content and clinical relevance of HRQOL items are understudied among clinicians, parents, and childhood cancer survivors.
- PROMIS Pediatric measures contain cutting-edge item banks. It is useful for clinicians, parents, and cancer survivors to rate the HRQOL items that are important for survivorship care.

OBJECTIVE

- To compare the importance ratings of PROMIS items between **clinicians, parents of childhood cancer survivors, and survivors** across **pain interference, psychological stress, fatigue, and positive affect** domains. *We hypothesize that there is a larger difference in the importance ratings for items between clinicians and childhood cancer survivors than between survivors' parents and survivors.*

METHODS

Participants

- 101 childhood cancer survivors and their parents recruited from the St. Jude Lifetime (SJLIFE) Cohort Study.
- 36 St. Jude's health professionals including clinicians, nurse practitioners, psychologists, and social workers.
- Inclusion criteria:
 - Cancer survivors: 1) 8–17.9 years of age; 2) ≥ 2 years off therapy; 3) ≥ 5 years since diagnosis; 4) ≥ a 3rd grade reading level; and 5) able to read English.
 - Parents: 1) parents/legal guardians of eligible survivors; and 2) able to read English.
 - Clinicians: ≥ 2 years of survivorship care expertise.

Data Collection

- Clinicians, parents, and children completed respective HRQOL surveys at St. Jude using an online program (OptimalSort©).
- Participants were asked to identify eight items from each of the PROMIS item banks that are useful for clinical decision making and communication between survivors and their clinicians.

PROMIS Pediatric Item Banks

- Pain Interference: impact of pain on daily activities (20 items).
- Psychological stress: emotional and mental response to internal and external challenges (19 items).
- Fatigue: subjective feeling of being tired to an overpowering, crippling sense of exhaustion (23 items).
- Positive affect: temporary affirmative experiences (37 items).

Statistical Analysis

- For each item, the percentages of clinicians, parents, and children who rated it as important were calculated.
- Odds ratios (ORs) of an item's importance rating among respective clinicians and parents vs. children (the reference) were calculated.

RESULTS

Table 1: Characteristics of Clinicians, Parents, and Survivors

	Mean (SD)
Child's Age at Evaluation	13.9 (2.9)
	N (%)
Health Professional's Position	
Oncologist	13 (36%)
Non-Physician	23 (64%)
Parent's Sex	
Male	15 (15%)
Female	86 (85%)
Parent's Race/Ethnicity	
White, non-Hispanic	74 (72%)
Black, non-Hispanic	23 (22%)
Other	6 (6%)
Child's Sex	
Male	50 (49%)
Female	51 (51%)
Child's Race/Ethnicity	
White, non-Hispanic	70 (69%)
Black, non-Hispanic	24 (24%)
Other	7 (7%)
Child's Diagnosis	
Non-CNS Solid Tumor	46 (46%)
Leukemia	30 (30%)
CNS Malignancy	16 (16%)
Lymphoma	9 (9%)

RESULTS

Figure: Difference in Ratings for Pain and Stress Item Banks

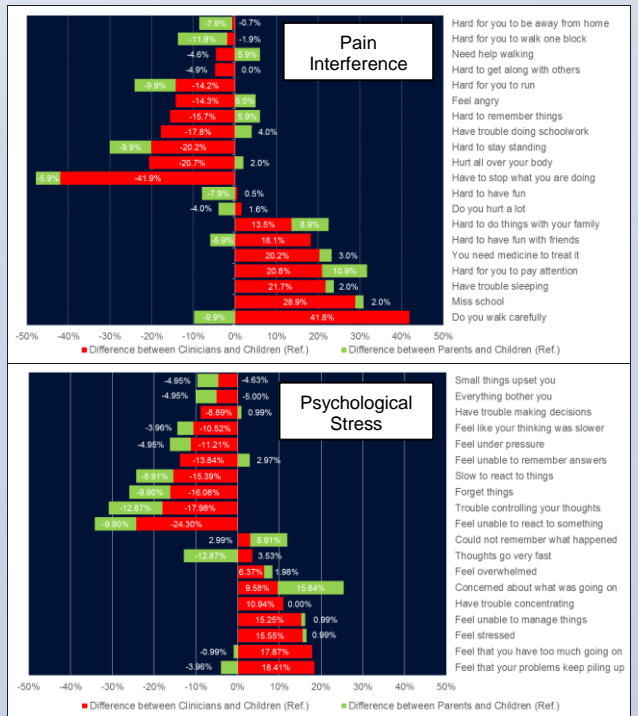


Table 2: Odds Ratio of Items Rated as Important by Clinicians vs. Children and by Parents vs. Children

	Clinician vs. Child	Parent vs. Child
Pain Interference Domain		
Do you walk carefully	6.01***	-
Miss school	3.70**	-
Have trouble sleeping	2.93*	-
You need medicine to treat it	2.50*	-
Hard for you to pay attention	2.33*	-
Hurt all over your body	0.36*	-
Hard to stay standing	0.31*	-
Have to stop what you are doing	0.13***	-
Hard for you to walk one block	-	0.37*
Psychological Stress Domain		
Trouble controlling your thoughts	0.42*	-
Slow to react to things	0.22*	-
Feel unable to react to something	0.14**	-
Concerned about what was going on	-	1.93*
Thoughts go very fast	-	0.33**
Fatigue Domain		
Sleep during the day	3.80***	-
Too tired to spend time with friends	2.85*	-
Too tired to enjoy things you like to do	2.22*	-
Hard to pay attention	0.27**	-
Feel weak	0.20***	-
Keep you from having fun	-	0.42**
Feel tired	-	0.37***
Positive Affect Domain		
Feel happy	2.93**	-
Feel comfortable	0.35*	-
Feel calm	0.28*	-
Feel active	0.21**	-
Feel appreciated	0.19**	-
Feel wide-awake	0.19*	0.47*
Feel refreshed	0.17**	0.43*
Feel content	-	2.25*
Feel great	-	0.43*
Feel satisfied	-	0.41*
Feel joyful	-	0.33**
Feel strong	-	0.30***
Feel delighted	-	0.25*

* P-value < 0.05, ** P-value < 0.01, *** P-value < 0.001

CONCLUSIONS

- Clinicians, parents, and survivors hold differing views on what content of HRQOL items are important to survivorship care.
- When designing HRQOL measures, methods to synergize heterogeneous preferences across stakeholders should be applied.

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