

THE PEDIATRIC SUPPORTIVE CARE SCALE (PSCS): AN INSTRUMENT TO ASSESS QUALITY OF LIFE IN CHILDREN WITH TERMINAL MALIGNANCY

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Purpose: The Pediatric Supportive Care Scale (PSCS) was developed as a measure of quality of life (QOL) for children with a poor prognosis/incurable cancer. The measure has undergone several steps using standard instrument development techniques including; construct generation, in which relevant QOL domains were identified through qualitative interviews of bereaved parents and a literature review, item selection, review by a panel of parents, and review and evaluation of face validity by experts in the field of pediatric oncology and palliative care.¹ Four developmentally-appropriate versions of the measure have been developed: a child-report (8-12 yrs.), teen-report (13-18 yrs.), parent-proxy (5-18 yrs.), and parent-toddler-proxy (2-4yrs). The following abstract reports the next step in the measure's development, in which comprehensibility of the items and of the response scale devised were evaluated with the population for which the measure was intended.

Methods: Participants were recruited from 4 Canadian pediatric oncology centres. Cognitive probing procedures were used to assess understandability of the items. During the cognitive probing interviews, participants were asked to explain what each item meant in their own words. The participants' ability to understand each item in the way in which it was intended was scored by a research assistant using a 4-point scale (4= fully correct; 1 = completely incorrect). Participants were also asked to indicate how they might respond to an item using the response scale selected for the measure, and to explain why they chose that response. These explanations were scored either a 1 ("Able to distinguish between choices") or 0 ("Not able to distinguish between choices").

Results: A total of 73 participants were accrued over a 1-year period. Average total scores (range) for the item-comprehension on each version of the PSCS were: Child, 3.40 (2.86 – 4.00); Teen, 3.53 (2.83 – 4.00); Parent, 3.66 (2.93 – 4.00), and Parent-toddler, 3.69 (3.00 – 4.00). Based on these results, multiple items were modified or deleted on all four versions of the measure (See Table 1 for a summary of item decisions). An overall percentage of the respondent's ability to accurately distinguish between response choices was calculated. Percentage ranged from 84% (child-report) to 98% (parent-toddler report) for the four versions of the PSCS. These results suggest that the vast majority of participants were able to correctly interpret the current response options, and as a result, no changes were made to the response scale developed for the measure.

Conclusions: The current versions of the PSCS are consistently and accurately understood by the target population. The next phase in the development of this measure to obtain validity, feasibility and internal consistency is underway at 9 Canadian pediatric oncology centers with a target accrual of around 150 participants.