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Patients, Caregivers, and Clinicians Differ in Performance Status Ratings: Implications for Pediatric Cancer Clinical Trials

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Abstract

Background: The Lansky Play-Performance Scale (LPPS) is often used to determine child performance status for cancer clinical trial eligibility. Differences between clinician and caregiver LPPS ratings and their associations with child-reported functioning have not been evaluated.

Methods: Children (7-18 years) receiving cancer treatment and their caregivers were recruited from 9 pediatric cancer centers. Caregivers and clinicians reported LPPS scores and children completed PROMIS® Pediatric functioning and symptom measures before (T1) and after (T2) treatment. T-tests and mixed-linear models assessed differences in caregiver and clinician LPPS scores; polyserial correlations quantified associations between PROMIS and LPPS scores.

Results: Of 482 children, 281 had matched caregiver- and clinician-reported LPPS T1/T2 scores. Caregivers rated children significantly worse on LPPS than clinicians at both T1 (means: 73.3 vs. 87.4, $p<0.01$) and T2 (means: 67.9 vs. 83.1, $p<0.01$). These differences were not related to child's age ($p=0.89$), diagnosis ($p=0.17$), sex ($p=0.64$), or time point ($p=0.45$). Small-moderate associations existed between caregiver- and clinician-reported LPPS

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with child-reported PROMIS scores for mobility (caregiver T1/T2 r=0.51/0.45, $p<0.01$; clinician T1/T2 r=0.40/0.35, $p<0.01$), fatigue (caregiver T1/T2 r=−0.46/−0.37, $p<0.01$; clinician T1/T2, r=−0.26/−0.27, $p<0.01$), and pain interference (caregiver T1/T2 r=−0.32/−0.30 $p=<0.01$; clinician T1/T2 r=−0.17/−0.31, $p<0.01$). Caregivers and clinicians assigned significantly lower LPPS scores at T2 (caregiver Δ=−5.37, $p<0.01$; clinician Δ=−4.20, $p<0.01$), while child-reported PROMIS scores were clinically stable.

Conclusions: Significant differences between clinician and caregiver LPPS ratings of child performance were sustained over time; their associations with child reports were predominantly small-moderate. These data suggest that clinician-reported LPPS ratings by themselves are inadequate for determining clinical trial eligibility and should be supplemented by appropriate measures of a child's functional status reflecting the child and caregiver perspectives.

Precis:

The Lansky Play Performance Scale (LPPS) is commonly used by clinicians for determining eligibility for pediatric cancer clinical trials. In this prospective cohort study of children receiving cancer treatment, LPPS ratings differed between clinicians and caregivers and were poorly correlated with child reports, challenging use of the LPPS for that purpose.

Keywords

Pediatric Oncology; Clinical Trials; Eligibility; Patient Reported Outcomes; Lansky Play Performance Scale

INTRODUCTION

The Lansky Play-Performance Scale (LPPS) was developed to measure and monitor the performance status (ability to perform activities of daily living) of children with cancer before, during, and after treatment.[1] Validated in parents rating performance of both their ill and well children based on ability to play, the LPPS was designed to be convenient, reproducible, and amenable for use by "non-professional persons" (i.e., family, caregiver).[1, 2] Over the last 30 years, LPPS has become widely-used in pediatric oncology research for measuring treatment tolerance[3, 4] and outcomes,[3, 5, 6] as a risk factor for treatment-related morbidity,[7] and to guide treatment decisions on clinical trials.[4] Incorporation of the LPPS in clinical trials is attractive because it represents a simple, single, readily available measure for estimating overall performance status based on the child's observed ability to play.[2] Today, minimum LPPS scores are a commonly specified eligibility criterion for pediatric phase I, II, and III cancer clinical trials to ensure the child's ability to tolerate cancer-directed therapy.[8-10] Collectively, these applications of the LPPS demonstrate how clinician-reported scoring has expanded to influence significant medical decisions in seriously ill children.

Despite being developed for parental/caregiver reporting, it is now common for clinicians to assign LPPS scores both to ensure cancer clinical trial eligibility and to monitor performance status throughout treatment. There have not been studies to validate clinician LPPS scores, evaluate agreement amongst clinician and caregiver LPPS reporting, correlate LPPS scores

with child-reported symptom and function measures, or test the use of either caregiver- or child-based reporting tools in determining eligibility for cancer clinical trials.

To address these gaps, we undertook an analysis of LPPS ratings that were collected as part of our recent study focused on developing a novel patient-reported treatment toxicity measure for children undergoing cancer treatment.[11] Our aims were to (1) compare LPPS ratings by caregivers and clinicians during times of low and high expected symptom burden; and (2) examine agreement of those ratings with a validated measure of child-reported symptoms and functioning. Our overall objective was to determine what each perspective – clinician, caregiver, and child – contributes to assessment of a child's performance status and its implications in clinical trial enrollment.

METHODS

The study employed a prospective observational cohort design for development of a pediatric patient-reported outcome (PRO) version of the Common Terminology Criteria for Adverse Events (Ped-PRO-CTCAE) conducted at nine geographically and demographically diverse pediatric cancer treatment centers in the United States and Canada.[11] Eligible participants were children and adolescents age 7-18 years recently diagnosed with any form of cancer; receiving frontline chemotherapy, radiation, or bone marrow transplant; had completed at least one month of therapy; were at least 3-6 weeks post-surgery; and could read or hear and understand English without clinically significant cognitive impairment. The child's caregiver must have agreed to participate. All sites obtained institutional review board approval. Caregivers provided written informed consent, and children/adolescents provided assent. The study enrolled 482 children and has been previously described in detail.[11] To compare caregiver- and clinician-reported performance status and examine changes over time, for this analysis, we restricted the sample to subjects with complete data from both caregivers and clinicians at each time point. As a sensitivity analysis, we repeated the analyses reported here with data including children having missing caregiver or clinician scores at T1 or T2; similar results were obtained.

Enrolled participants completed questionnaires during clinic visits at two time points, one with lower expected symptom burden just before treatment (T1) and another with higher expected symptom burden after treatment (T2). The interval between T1 and T2 was 7-28 days depending on the treatment. At both time points, caregivers and clinicians independently completed the LPPS.[2] LPPS scores ranging from 10 ("No play, does not get out of bed") to 100 ("Fully active, normal") in increments of 10 were recorded. LPPS scores of 10-40 are categorized by the developer as "moderate-severe restriction", 50-70 as "mild-moderate restriction", and 80-100 as "able to carry on normal activity."[2, 12] Clinicians and caregivers were masked to each other's ratings and, at T2, to the ratings they assigned at T1. Children were not aware of the LPPS ratings assigned to them. By site report, clinicians assigning LPPS ratings included attending physicians, physicians in fellowship training, advanced practice providers, and, rarely, nurses.

At both T1 and T2, children completed Patient-Reported Outcomes Measurement Information System® (PROMIS®) Pediatric measures of physical function-mobility,

pain interference, psychological stress experiences, fatigue, depressive symptoms, and anxiety.[13-17] Higher PROMIS symptom scores reflect worsening symptoms, and higher PROMIS mobility scores reflect better functioning. The recall period is “the past 7 days." A minimally important difference (MID) in scores is 3 points.[18]

Differences between caregiver and clinician LPPS ratings at each time point were assessed by two-group t-tests and Bowker’s symmetry test of the 10 LPPS ratings. Changes in ratings from T1 to T2 were assessed using paired t-tests for both clinicians and caregivers. We examined whether differences between caregiver and clinician LPPS scores varied by timepoint or demographics using a mixed-linear model with fixed effects of time, child’s sex, age, and diagnosis, while random intercept was included to adjust for within-child data dependency. Associations between PROMIS measures and LPPS were assessed using polyserial correlations. If statistically different from zero, magnitudes of correlation estimates were classified as: small (0.10–0.29), moderate (0.30–0.49), strong (0.50–0.69), and very strong (>0.70), consistent with Cohen’s recommended effect sizes for correlations.[19, 20] We used a 2-tailed significance level of α=0.05 for all assessments. Statistical analyses were conducted using SAS software, Version 9.4 of the SAS System for Linux.

RESULTS

Participant Characteristics

This analysis included 281 each of caregivers, children, and clinicians that had complete caregiver- and clinician-reported LPPS data at T1 and T2. Child and caregiver characteristics are provided in Table 1. The children’s mean age was 12.7 years (SD=3.4) and the majority were male (52.1%) and white (67.1%). Most children had leukemia/lymphoma (59.1%) while 25.6% had solid tumors and 15.3% had central nervous system malignancies. The majority (93.6%) were receiving chemotherapy as opposed to radiation or bone marrow transplant. Caregivers average age was 40.3 years, and a majority were female (87.2%) and married (74.3%).

Caregiver and Clinician LPPS Reporting

Mean caregiver ratings at T1 were 73.31 (standard deviation [SD]=20.62), and at T2 were 67.94 (SD=22.41). Clinician LPPS scores had a mean of 87.33 (SD=12.29) at T1 and a mean of 83.13 (SD=14.72) at T2. Clinician mean ratings were significantly higher at T1 (t[DF=280]=−12.11, p<0.01) and T2 (t[DF=280]=−12.21], p<0.01) than caregiver mean ratings. At both time points, clinicians had less LPPS rating variation (lower SD) than caregivers, with clinicians clustering scores at the higher end of the scale. Paired comparisons between clinicians and caregivers illustrated these differences at T1 (Table 2) and T2 (Table 3). Asymmetry among ratings between caregivers and clinicians at T1 (X^2[45]=116.57, p<0.01) and T2 (X^2[45]=136.61, p<0.01) was identified. Regression models with outcome of differences between caregiver and clinician LPPS ratings were not associated with timepoint (p=0.45), child age (p=0.89), child gender (p=0.64), diagnosis (p=0.17), or time between T1 and T2 (p=0.99). Caregiver age (p=0.41), race (p=0.68), ethnicity (p=0.42), gender (p=0.28), income (p=0.44), and marital status (p=0.52) were

also not associated with LPPS concordance; caregivers with “some college/university” had greater discordance with clinician LPPS scores than those with a college/university degree (p=0.01). (results not shown).

When LPPS scores were categorized by established levels of restriction, about half of participants had caregiver-clinician agreement at T1 (154/281, 54.8%) and T2 (145/281, 51.6%) (Table 4). Several children (13 [4.6%] at T1 and 26 [9.3%] at T2) were rated by clinicians as able to carry on normal activities while their caregivers rated them as moderate-severely restricted. At the minimum LPPS rating of 60, commonly used for clinical trial eligibility, comparison of clinician and caregiver ratings showed sizeable proportions of children would have been rated eligible by clinicians but ineligible by caregivers (52 [18.5%] at T1 and 72 [25.6%] at T2) (Table 4).

LPPS Correlation with PROMIS Pediatric Measures

Correlations between caregiver and clinician LPPS scores and child-reported PROMIS Pediatric mobility scores were moderate to strong (caregiver T1/T2 r=0.51/0.45, p<0.01; clinician T1/T2 r=0.40/0.35, p<0.01). Notably, caregiver-reported PROMIS Parent Proxy scores for mobility had strong polyserial correlations with their LPPS scores at both T1 (r=0.61) and T2 (r=0.64). Caregiver LPPS scores moderately correlated with child-reported fatigue (caregiver T1/T2 r=−0.46/−0.37, p<0.01), while small correlations were observed for clinician reported LPPS (clinician T1/T2 r=−0.26/−0.27, p<0.01). Moderate correlations between child-reported pain interference and caregiver LPPS (T1/T2 r=−0.32/−0.30, p<0.01) and clinician LPPS scores at T2 (r=−0.31, p<0.01) existed. Clinician T1 LPPS (r=−0.17, p<0.01) had a small correlation with child-reported pain interference. LPPS ratings from both clinicians and caregivers demonstrated small correlations with child-reported scores for depressive symptoms, anxiety, and psychological stress at both T1 and T2 (Table 5). At T1, the correlation of caregiver LPPS ratings with child-reported PROMIS measures were significantly stronger than correlations of clinician LPPS ratings with child-reported PROMIS measures for the domains of mobility (p=0.02), pain interference (p<0.01) and fatigue (p<0.01). At T2, caregiver and clinician LPPS ratings correlations with child-reported PROMIS measures were similar in size (p>0.05).

Changes in Caregiver and Clinician LPPS Ratings over Time

At T2 relative to T1, mean caregiver LPPS ratings were 5.37 points lower (t[DF=280]=−4.27, p<0.01) while clinician ratings were 4.20 points lower (t[DF=280]=−5.49, p<0.01). However, children’s self-reported mobility (p=0.82), pain interference (p=0.15), or fatigue (p=0.50) did not change significantly from T1 to T2 (Table 6). Children’s self-reported depressive symptoms (p<0.01), anxiety (p=0.02), and psychological stress (p<0.01) did improve slightly from T1 to T2 but did not exceed the MID of 3 points. The child’s age was not associated with changes in PROMIS scores from T1 to T2.

DISCUSSION

For more than three decades, the LPPS has been a widely used tool in pediatric oncology to facilitate decision making in both clinical care and research. Although validated only for parent report, it is common for clinicians to render and use LPPS scores as an eligibility criterion and a marker of clinical status in pediatric cancer clinical trials.[8-10] This application of the LPPS has not been validated. In this longitudinal study, we found that the LPPS detected statistically significant reductions in performance status ratings of children by caregivers and clinicians following a given cancer treatment. Not expected was the discovery of discordant LPPS ratings between caregivers and clinicians and between those ratings and the self-reported functioning and symptoms by children. These findings suggest that clinicians, caregivers, and children have different, and important, views on performance status during cancer treatments. Deciding whose perspective to measure and prioritize has substantial implications for clinical trial eligibility and treatment of children with cancer.

Caregivers reported significantly lower (worse) LPPS ratings than clinicians at both time points of low and high expected symptom burden. Nearly half of the children were placed in different performance categories by their clinicians versus caregivers. Because the LPPS may be used by clinicians to evaluate tolerance of therapy, this discordance could result in altered clinical management depending on whose perspective is taken. Regarding clinical trial eligibility, this difference has significant impact, where over one fifth of the children received an LPPS performance rating of ≥ 60 from their clinician but not their caregiver. With an LPPS rating of 60 being a common threshold for clinical trial eligibility, a substantial proportion of children could be placed at risk for poor tolerance of experimental therapy, on one hand, or a missed opportunity to receive its potential benefit, on the other. Further, knowledge of the eligibility threshold (whether set at 60 or another level) by either the parent or clinician creates an opportunity for desirability bias in determining eligibility status.

There are several potential reasons for these rating discrepancies. First, clinicians typically make LPPS assessments after relatively brief interactions with the child in a clinical environment, whereas caregiver interactions are sustained at home. Second, clinicians familiar with LPPS may base ratings on their broad perception of a child's overall performance, whereas parents may base their ratings only on symptoms related to play, which are often under-recognized by clinicians.[21-23] Third, clinicians and caregivers have distinctly different perspectives in applying the LPPS. The caregiver perception was measured by both PROMIS and LPPS. These scores correlated well at both time points, indicating that this distinct vantage is not a measure-specific outcome, but a consistently different perspective over both time and measure. When asked how a child is performing, clinicians may draw on their experience of treating many children to inform their impression of the child in front of them. They may also be influenced by typical standards for minimum LPPS ratings set by clinical trials, their knowledge about the protocol-specified therapy, its general prospects for benefit and burden, and their enthusiasm for the child's participation in the study. The caregiver perspective may differ in that their point of reference is the child's current state compared to the child they knew prior to cancer, and their ratings may be influenced by the physical and emotional strain of witnessing the child's cancer

experience.[24] These differing perspectives may also explain why the responses of clinicians in our sample clustered near the top (better performing) end of the scale, while those of parents were more evenly distributed and typically lower than clinicians.

Distinct from both caregiver and clinician perspectives, children may report based on how they feel in the moment. As such, LPPS ratings from neither caregivers nor clinicians correlated well with children's self-reported PROMIS functioning and symptom measures. Correlations with mobility, fatigue, and pain interference were expected because the LPPS uses play as a guide for the child's functionality, but even these were relatively small. This suggests that neither parental nor clinician LPPS ratings satisfactorily reflect the child's self-reported functioning or symptom burden, and agree with studies showing clinicians underreport symptoms in children with cancer.[21, 22, 25] While, unlike the LPPS, PROMIS measures were not developed to directly reflect the ability to play, they contain questions on play in the mobility measure, and caregiver-reported PROMIS measures and their LPPS scores were strongly correlated at both time points. Additionally, the functional domains used were general and likely relevant to play as measured by the LPPS, and the distribution of PROMIS scores for all domains but pain were distributed broadly enough at both T1 and T2 to establish congruence between LPPS and PROMIS ratings. Consistent with previous literature reporting discordance between clinician and child or caregiver reports of symptoms and psychological distress, there was little to no correlation between the LPPS score and PROMIS measures for depression, anxiety, and psychological stress.[21, 22, 25] This is important because it is difficult to disentangle psychological distress from the child's experience with, or tolerance of, cancer therapy, and the LPPS fails to reflect this aspect of the child's wellbeing.

Comparing LPPS ratings at sequential time points during cancer treatment, both clinician and caregiver scores dropped significantly (worsened) in similar proportions. In contrast, child self-report by PROMIS measures did not show significant change for physical health-related measures (e.g., mobility, fatigue, pain interference). Given that T2 was defined to be a time with expected high symptom burden across multiple treatment regimens, clinicians completing the LPPS may have similarly expected lower patient performance. While the drops in LPPS scores between time points were statistically significant, they may not have been clinically significant to the child; however, these data bolster evidence that while the LPPS may reflect caregiver and clinician perceptions or expectations of the child's functionality, those ratings are not congruent with the child's.

This study has both strengths and limitations. This multicenter study enrolled a large, racially diverse sample with multiple diagnoses and treatments, enhancing its generalizability. The use of PROMIS provides a recent, well-validated comparison to the widely used LPPS measure.[26] Limiting our analysis to participants with both clinician and caregiver LPPS scores at both time points provides uniformity of the data but could bias or reduce representativeness of the sample. The inclusion of fewer male caregivers underplays an important perspective. Not collecting detailed clinician demographics limited the ability to account for levels of experience and training. Finally, clinician raters likely varied between time points within treatment sites; although this reflects real-world staffing

and lends generalizability to our findings, it detracts somewhat from the uniformity of the reporting sample.

The LPPS remains a pioneering scale, the first to capture parental perspectives in quantifying the impact of cancer therapy on children. However, our data suggest its appropriation by clinicians for determining pediatric cancer clinical trial eligibility is problematic because clinician and caregiver scores are divergent. Given that the LPPS was not validated for clinicians to apply in this way, its continued use for this purpose seems difficult to justify. Throughout our work, we heard three distinct voices: the clinician, caregiver, and child. Knowing that validated measures now exist that capture parental and patient perceptions in meaningful and reproducible ways, the opportunity is at hand for further study directed toward standardizing the formal integration of these voices in determining a child's suitability for enrollment on a cancer clinical trial. Until this important research is completed, and more inclusive approaches are specified, oncologists and clinical trialists can immediately be aware of these two additional perspectives and make every effort to incorporate them with their own clinical judgement when assessing the appropriateness of offering a clinical trial.

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REFERENCES

1. Lansky LL, List MA, Lansky SB, Cohen ME, Sinks LF. Toward the development of a play performance scale for children (PPSC). Cancer. 1011985;56(7 Suppl):1837–40. [PubMed: 4027922]
2. Lansky SB, List MA, Lansky LL, Ritter-Sterr C, Miller DR. The measurement of performance in childhood cancer patients. Cancer. 1011987;60(7):1651–6. [PubMed: 3621134]
3. Grewal AS, Li Y, Fisher MJ, et al.Tumor bed proton irradiation in young children with localized medulloblastoma. Pediatr Blood Cancer. 122019;66(12):e27972. [PubMed: 31512390]
4. Heiss JD, Jamshidi A, Shah S, et al.Phase I trial of convection-enhanced delivery of IL13-Pseudomonas toxin in children with diffuse intrinsic pontine glioma. J Neurosurg Pediatr. 1272018;23(3):333–342. [PubMed: 30544335]
5. Tso WWY, Liu APY, Lee TMC, et al.Neurocognitive function, performance status, and quality of life in pediatric intracranial germ cell tumor survivors. J Neurooncol. 12019;141(2):393–401. [PubMed: 30460632]
6. Carceller F, Bautista FJ, Jimenez I, et al.Prognostic factors of overall survival in children and adolescents enrolled in dose-finding trials in Europe: An Innovative Therapies for Children with Cancer study. Eur J Cancer. 112016;67:130–140. [PubMed: 27662616]
7. Dandoy CE, Kim S, Chen M, et al.Incidence, Risk Factors, and Outcomes of Patients Who Develop Mucosal Barrier Injury-Laboratory Confirmed Bloodstream Infections in the First 100 Days After Allogeneic Hematopoietic Stem Cell Transplant. JAMA Netw Open. 132020;3(1):e1918668. [PubMed: 31913492]
8. Fangusaro J, Onar-Thomas A, Young Poussaint T, et al.Selumetinib in paediatric patients with BRAF-aberrant or neurofibromatosis type 1-associated recurrent, refractory, or progressive low-grade glioma: a multicentre, phase 2 trial. Lancet Oncol. 72019;20(7):1011–1022. [PubMed: 31151904]

9. Robinson GW, Rudneva VA, Buchhalter I, et al.Risk-adapted therapy for young children with medulloblastoma (SJYC07): therapeutic and molecular outcomes from a multicentre, phase 2 trial. Lancet Oncol. 62018;19(6):768–784. [PubMed: 29778738]
10. Geoerger B, Kang HJ, Yalon-Oren M, et al.Pembrolizumab in paediatric patients with advanced melanoma or a PD-L1-positive, advanced, relapsed, or refractory solid tumour or lymphoma (KEYNOTE-051): interim analysis of an open-label, single-arm, phase 1-2 trial. Lancet Oncol. 12020;21(1):121–133. [PubMed: 31812554]
11. Reeve BB, McFatrich M, Mack JW, et al.Validity and Reliability of the Pediatric Patient-Reported Outcomes - Common Terminology Criteria for Adverse Events. J Natl Cancer Inst. 1302020;
12. Schag CC, Heinrich RL, Ganz PA. Karnofsky performance status revisited: reliability, validity, and guidelines. J Clin Oncol. 31984;2(3):187–93. [PubMed: 6699671]
13. DeWitt EM, Stucky BD, Thissen D, et al.Construction of the eight-item patient-reported outcomes measurement information system pediatric physical function scales: built using item response theory. J Clin Epidemiol. 72011;64(7):794–804. [PubMed: 21292444]
14. Lai JS, Stucky BD, Thissen D, et al.Development and psychometric properties of the PROMIS((R)) pediatric fatigue item banks. Qual Life Res. 112013;22(9):2417–27. [PubMed: 23378106]
15. Irwin DE, Stucky B, Langer MM, et al.An item response analysis of the pediatric PROMIS anxiety and depressive symptoms scales. Qual Life Res. 52010;19(4):595–607. [PubMed: 20213516]
16. Hinds PS, Wang J, Cheng YI, et al.PROMIS pediatric measures validated in a longitudinal study design in pediatric oncology. Pediatr Blood Cancer. 52019;66(5):e27606. [PubMed: 30663254]
17. Quinn H, Thissen D, Liu Y, et al.Using item response theory to enrich and expand the PROMIS(R) pediatric self report banks. Health Qual Life Outcomes. 10252014;12:160. [PubMed: 25344155]
18. Thissen D, Liu Y, Magnus B, et al.Estimating minimally important difference (MID) in PROMIS pediatric measures using the scale-judgment method. Qual Life Res. 12016;25(1):13–23. [PubMed: 26118768]
19. Cohen JA power primer. Psychol Bull. 71992;112(1):155–9. doi:10.1037//0033-2909.112.1.155 [PubMed: 19565683]
20. Cohen JStatistical power analysis for the behavioral sciences. 2nd ed. L. Erlbaum Associates; 1988.
21. Hockenberry MJ, Hinds PS, Barrera P, et al.Three instruments to assess fatigue in children with cancer: the child, parent and staff perspectives. J Pain Symptom Manage. 42003;25(4):319–28. [PubMed: 12691683]
22. Zhukovsky DS, Rozmus CL, Robert RS, et al.Symptom profiles in children with advanced cancer: Patient, family caregiver, and oncologist ratings. Cancer. 11152015;121(22):4080–7. [PubMed: 26218240]
23. Ullrich CK, Dussel V, Orellana L, et al.Self-reported fatigue in children with advanced cancer: Results of the PediQUEST study. Cancer. 9152018;124(18):3776–3783. [PubMed: 30291811]
24. Schepers SA, Sint Nicolaas SM, Maurice-Stam H, Haverman L, Verhaak CM, Grootenhuis MA. Parental distress 6 months after a pediatric cancer diagnosis in relation to family psychosocial risk at diagnosis. Cancer. 1152018;124(2):381–390. [PubMed: 28902391]
25. Collins JJ, Devine TD, Dick GS, et al.The measurement of symptoms in young children with cancer: the validation of the Memorial Symptom Assessment Scale in children aged 7-12. J Pain Symptom Manage. 12002;23(1):10–6. [PubMed: 11779663]
26. Reeve BB, McFatrich M, Mack JW, et al.Expanding construct validity of established and new PROMIS Pediatric measures for children and adolescents receiving cancer treatment. Pediatr Blood Cancer. 42020;67(4):e28160. [PubMed: 31904157]

Table 1:

Characteristics of participating children and caregivers

	Value
Children (n=281)	
	Mean, SD
Age (years)	12.7, 3.4
	n (%)
Gender (female)	134 (47.9)
Race	
White	188 (67.1)
Black	57 (20.4)
Asian	10 (3.6)
Other	25 (8.9)
Ethnicity (Hispanic)	36 (12.8)
Cancer Type	
Leukemia or lymphoma	166 (59.1)
Solid tumor	72 (25.6)
Central nervous system	43 (15.3)
Treatment Received	
Chemotherapy	263 (93.6)
Radiation	13 (4.6)
BMT	5 (1.8)
Caregivers (n=281)	
	Mean, SD
Age (years)	40.3, 12.8
	n (%)
Gender (female)	245 (87.2)
Race	
White	180 (64.1)
Black	59 (21.0)
Asian	11 (3.9)
Other	31 (11)
Ethnicity (Hispanic)	30 (10.7)
Married/Living with partner	208 (74.3)
Education	
High school	58 (20.8)
Some college	80 (28.7)
College degree	104 (37.3)
Graduate degree	34 (12.2)

Table 2:

Comparison of caregiver and clinician LPPS ratings for each child at T1 (n=281).

Caregiver Rating^	**Clinician Rating**^ *No. of children*										
	10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**	**Total**
10	0	0	0	0	0	0	0	0	0	0	0
20	0	0	0	0	1*	0	2*	1**	2**	1**	7
30	0	0	0	0	0	0	0	0	0	0	0
40	0	0	0	0	0	4*	3*	3**	3**	3**	16
50	0	0	0	0	1	1	5	9*	11*	4*	31
60	0	0	0	1**	2	5	2	26*	16*	10*	62
70	0	0	0	0	0	0	2	4*	9*	4*	19
80	0	0	0	0	1*	1*	3*	6	16	19	46
90	0	0	0	0	0	0	2*	7	19	18	46
100	0	0	0	0	0	1*	2*	3	20	28	54
Total	0	0	0	1	5	12	21	59	96	87	281

^Classification of LPPS ratings (play category): 80-100 (no restriction), 50-70 (mild-moderate restriction), 10-40 (moderate to severe restriction)

Green: clinician rating = caregiver rating

Orange: clinician rating > caregiver

Blue: clinician rating < caregiver

*Different rating results in changing one play category

**Different rating results in changing two play categories

No asterisk indicates different rating but no change in play category

Table 3:

Comparison of caregiver and clinician LPPS ratings for each child at T2 (n=281).

Caregiver Rating^	**Clinician Rating**^ *No. of children*										
	10	**20**	**30**	**40**	**50**	**60**	**70**	**80**	**90**	**100**	**Total**
10	0	1	0	0	1*	1*	0	0	0	0	3
20	0	1	0	0	0	0	2*	4**	1**	1**	9
30	0	0	0	0	0	1*	0	0	2**	0	3
40	0	0	0	3	0	3*	3*	9**	7**	2**	27
50	0	0	0	3*	5	6	2	14*	10*	4*	44
60	0	0	0	1*	0	4	8	17*	18*	7*	55
70	0	0	0	0	0	0	1	6*	6*	5*	18
80	0	0	0	0	0	1*	3*	10	18	13	45
90	0	0	0	0	0	0	1*	11	17	6	35
100	0	0	0	0	0	1*	2*	6	19	14	42
Total	0	2	0	7	6	17	22	77	98	52	281

^Classification of LPPS ratings (play category): 80-100 (no restriction), 50-70 (mild-moderate restriction), 10-40 (moderate to severe restriction)

Green: clinician rating = caregiver rating

Orange: clinician rating > caregiver

Blue: clinician rating < caregiver

*Different rating results in changing one play category

**Different rating results in changing two play categories

No asterisk indicates different rating but no change in play category

Table 4:

Comparison of caregiver and clinician LPPS classification by time point (n = 281).

Caregiver Rating^	**Clinician Rating**^ *No. of children (%)*				
	10-40	**50-70**	**80-100**	**<60**	**≥ 60**
T1					
10-40	0	10 (3.6)	13 (4.6)		
50-70	1 (0.4)	18 (6.4)	93 (33.1)		
80-100	0	10 (3.6)	114 (40.1)		
< 60				2 (0.7)	52 (18.5)
≥ 60				4 (1.4)	223 (79.3)
T2					
10-40	5 (1.7)	11 (3.9)	26 (9.3)		
50-70	4 (1.4)	26 (9.3)	87 (30.1)		
80-100	0	8 (2.8)	114 (40.1)		
<60				14 (4.9)	72 (25.6)
≥ 60				1 (0.4)	194 (69)

^Classification of LPPS ratings (play category): 80-100 (no restriction), 50-70 (mild-moderate restriction), 10-40 (moderate to severe restriction)
Note: LPPS ≥ 60% is a typical cutoff for clinical trial eligibility.

Table 5:

Polyserial correlations of caregiver and clinician-rated LPPS with child-reported PROMIS® Pediatric measures.

Child-Reported PROMIS Measure	Caregiver-Reported LPPS			Clinician-Reported LPPS		
	n	Polyserial r	*p*	n	Polyserial r	*p*
T1						
Mobility	280	0.51	<0.01	280	0.40	<0.01
Pain interference	280	−0.32	<0.01	280	−0.17	<0.01
Depressive Symptoms	280	−0.25	<0.01	280	−0.13	0.03
Anxiety	280	−0.23	<0.01	280	−0.12	0.05
Fatigue	279	−0.46	<0.01	279	−0.26	<0.01
Psychological Stress	278	−0.30*	<0.01	278	−0.14	0.02
T2						
Mobility	276	0.45	<0.01	276	0.35	<0.01
Pain interference	276	−0.30	<0.01	276	−0.31	<0.01
Depressive Symptoms	276	−0.20	<0.01	276	−0.14	0.02
Anxiety	275	−0.19	<0.01	275	−0.11	0.07
Fatigue	276	−0.37	<0.01	276	−0.27	<0.01
Psychological Stress	276	−0.23	<0.01	276	−0.13	0.03

Note: T1 refers to a time point prior to treatment, and T2 occurs after treatment.

*Actual value is −0.297 and was classified as a small correlation.

Table 6:

Child-reported Patient-Reported Outcomes Measurement Information System® (PROMIS®) Pediatric measures by time point.

	T1 (n = 281)		T2 (n = 281)	
PROMIS Pediatric measure	**Mean**	**95% Confidence Interval**	**Mean**	**95% Confidence Interval**
Mobility *	45.58	(44.40, 46.75)	45.84	(44.58, 47.10)
Pain Interference	42.22	(42.19, 43.26)	42.89	(41.76, 44.02)
Depressive Symptoms	44.74	(43.53, 45.96)	43.01	(41.75, 44.27)
Anxiety	42.93	(41.76, 44.09)	41.63	(40.40, 42.86)
Fatigue	43.73	(42.34, 45.12)	43.28	(41.72, 44.83)
Psychological Stress	47.50	(46.38, 48.62)	46.15	(44.99, 47.30)

* The interpretation of the scoring of mobility is the opposite of the other symptom measures (i.e., higher scores are better for mobility, worse for the remaining symptoms).