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Validity and reliability of the French version of the Pediatric Quality of Life Inventory™ brain tumor module

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Abstract

Introduction Assessing health-related quality of life (HRQoL) is an increasingly important aspect of standard care in pediatric oncology. Currently, there is a gap in the availability of French questionnaires to assess the quality of life of French-speaking pediatric brain tumor (PBT) patients, which has important implications in the care of this population. The first aim of this study was to translate the original English Pediatric Quality of Life Inventory™ (PedsQL) brain tumor module version into French. The second aim was to describe the stability, repeatability and convergent validity of the French PedsQL brain tumor module.

Methods A total of 61 PBT patients were included in this study. Among them, 15 children and 20 parents participated in the translation process. As part of the validation study, 48 children and 48 parents answered the PedsQL brain tumor module twice, and the PedsQL generic core scales and the patient-reported outcomes measurement information system (PROMIS-37 pediatric profile v2.0) questionnaire were administered once to the participants. The mean age of the 25 boys and 23 girls was 8.3 ± 4.8 years. For temporal stability, we used intraclass correlation coefficients (ICCs), for repeatability, we used the Bland and Altman method to assess the accuracy at a 1-week interval, and we used Pearson's correlation coefficients for convergent validity between the PedsQL brain tumor module, PedsQL general module and the PROMIS.

Results Temporal stability for the parent proxy-reports (average ICC = 0.98) and the child self-reports (average ICC = 0.98) were excellent. There was a high absolute stability over a 1-week interval for the parent proxy-reports (ICC > 0.96) and child self-reports (ICC > 0.96). Convergent validity between parent proxy-reports and child self-reports was supported by positive correlations for five subscales. Children reported higher scores in cognitive problems and the movement and balance parameters than their parents and reported lower scores on the worry parameter than their parents.

Conclusion The strong psychometric properties of the French version of the PedsQL brain tumor module indicate that it is a validate and reliable questionnaire to measure HRQoL in PBT patients. The availability of a French version of the PedsQL brain tumor module supports the wider dissemination of the assessment of HRQOL in PBT patients.

Keywords Pediatric brain tumors · Children · Pediatric Quality of Life Inventory · Health-related quality of life · Psychometric properties · Translation

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Introduction

Pediatric brain tumors (PBT) are the most common type of solid tumor, and they are the second leading cause of cancer death in patients aged 0 to 19 years [1, 2]. Over the last decades, progress in medical treatments has considerably improved the survival rate of children with brain tumors [3]. However, as a result of their disease and treatment, PBT patients may experience significant sequelae, including paralysis or sensory disturbances, personality changes, epileptic seizures, and neurological and cognitive impairments. Moreover, it has been observed that PBT patients live with a reduced health-related quality of life (HRQoL), independently of the treatment period compared to their healthy peers or other cancer patients [4–8].

Since 1948, the World Health Organization (WHO) constitution has defined health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity [9]. Complementary to and as WHO defines health, the HRQoL refers to patients' functioning and well-being in physical, psychological, and social domains [10]. Moreover, according to Ebrahim [11] HRQoL may also refer to "those aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment". In this sense, the follow-up of patients' HRQoL prior and subsequently to treatments has become a standard of care in PBT patients over the last decades [7, 12]. To do so, researchers and clinicians use questionnaires to assess patients' HRQoL. However, many of them are generic questionnaires and may not be relevant for some cancer patients [13]. The improvement of research in psycho-oncology in the last two decades allowed to use of specific questionnaires to assess patients' HRQoL. Varni et al. [14, 15] developed one of them destined to children with cancer and their parents in order to assess children's HRQoL and to assess parents' perceptions of their child's HRQOL. Thus, the use of multidimensional tools, such as the PedsQL questionnaires, is therefore necessary to comply with the standards to help patients' follow-up and monitoring. Multidimensional tools are also increasingly being used to assessed outcomes. The Pediatric Quality of Life Inventory™ (PedsQL) questionnaire has been used in many studies in pediatric oncology [5, 7, 16–18]. The PedsQL brain tumor module was developed to specifically measure the HRQoL of young diagnosed with brain tumors. The PedsQL brain tumor module includes a child self-report for children aged between 5 and 18 years, and a parent proxy-report for toddlers (ages 2–4), young children (ages 5–7), children (ages 8–12), and adolescents (ages 13–18) that aim to assess parents' perceptions of their child's HRQOL. It has excellent psychometric properties in its original English version, with a Cronbach's coefficient alpha of around 0.70 for most scales [7].

The translation of the PedsQL brain tumor module to French finds its importance in allowing for better access to standardized care, while simultaneously addressing and meeting the assessment needs of the French-speaking PBT patient population. This specific, vulnerable population is too often left out of care/psychosocial research as a result of inclusion/exclusion criteria in some medical studies. The translation of the PedsQL to French will allow to address the lack of measurement questionnaires that can be used with French-speaking populations as a result of language barriers, allowing to address a common limiting factor for participation of this population in studies. Despite significant needs, there is currently no French translation of the PedsQL brain tumor module. Thus, the first aim of this study was to translate the original English PedsQL brain tumor module version into French. The second aim was to describe the stability, repeatability and convergent validity of the French PedsQL brain tumor module since systematic investigation of reliability is still scarce with this instrument.

Methods

Participants' recruitment

This study included 61 PBT patients, diagnosed and treated at the Sainte-Justine University Health Center (SJUHC) in Montreal (Quebec), Canada. Participant inclusion criteria were established according to the previously published study of PedsQL in pediatric cancer [15]: (a) diagnosed with a brain/spinal tumor; (b) newly diagnosed on-treatment; (c) recurrent cancer on-treatment; (d) remission off-treatment; (e) being ≤ 18 years old at the enrollment; and (f) had to be able to speak, read and understand the French language. Participants were identified, and eligibility was verified by the clinical neuro-oncologist through the medical records of children and adolescents treated in the Charles-Bruneau Cancer Care Center at SJUHC in Montreal (Canada) before participants were approached for the study. Eligible participants were recruited during regular clinical follow-up visits. Eligible participants were enrolled between August 2018 and April 2020. Written informed consent was obtained from every patient and parents. This study was conducted in accordance with the Declaration of Helsinki and the protocol was approved by the Ethics Review Committee of SJUHC (number 2019-1939).

Translation process

To start the translation process, an agreement was obtained from the MAPI Research Trust and Dr. James W. Varni,

who owns the copyright to translate the PedsQL™ 3.0 Brain Tumor Module to French. The translation process was performed in accordance with the MAPI Research Trust linguistic validation guidelines [19], as follows:

- The first step of the translation process was the forward translation, which included the production of a reconciliation version, from English to French, performed by two independent local professional translators, native French speakers and bilinguals in the English language. Each of the professional translators independently produced a forward translation of the original items, instructions and response choices. A single reconciled version was produced after discussions between the professional translators and the authors.
- The second step of the translation process was the backward translation, from the French produced version to the English sourced version, performed by one independent local professional translator, native English speaker and bilingual in the French. In accordance with the MAPI Research Trust linguistic validation guidelines, the translator did not have access to the original English version of the PedsQL™ 3.0 Brain Tumor Module. A comparison of the backward version with the original source version was conducted by the principal author and the backward translator in order to detect any misunderstandings, mistranslations or inaccuracies in the intermediary forward version of the questionnaire. The backward translation was sent to Dr. James W. Varni, who owns copyright of the PedsQL™ 3.0 Brain Tumor Module, for review and comment before patient testing.
- The third step of the translation process was patient testing, with a total of 15 children and 20 parents who completed the translated questionnaire in order to determine whether the translation (instructions, items and response choices), the understanding and the language of the French version used was acceptable. Each participant and their parents completed questionnaires at a scheduled visit to the Charles-Bruneau Cancer Care Center at SJUHC in Montreal (Canada). Parents had to be involved in the child's treatments since the diagnosis of cancer. A total of five child self-reports and parent proxy-reports were included in each age range (2–4, 5–7, 8–12, 13–18 years) according to the MAPI Research Trust linguistic validation guidelines [19]. Children and parents took place separately and they were native speakers of the target language. If a participant had any difficulty in understanding the questionnaire, the patient's interpretation of all items was checked. In case of any problems, the psychologist proposed or tested alternative translations (when this problem was anticipated) or asked the person to propose alternatives. A report on the translation process (Supplementary file named "report on the translation process") was sent to the MAPI Research Trust and to Dr. James W. Varni. The final version of the PedsQL™ 3.0 Brain Tumor Module in French was proof-read by a native target language speaker in order to perform a final check of the spelling, grammar and page layout before its use in the following steps of the study.

Validation process of the French version of the PedsQL brain tumor module

A first meeting was coordinated with each participant after their follow-up medical visit with the clinical neuro-oncologist. Demographic information about the participants' age (years), sex (male or female), cancer diagnosis was obtained. A total of 48 participants and their parents answered psychosocial questionnaires to measure HRQoL (PedsQL brain tumor module, PedsQL generic core scales, PROMIS-37 pediatric profile v2.0). Parents had to be involved in the child's treatments since the diagnosis of cancer. One week (±2 days) following the first assessment, children and their parents again completed the PedsQL brain tumor module. Psychosocial questionnaires were self-administered for parents and for children aged of 8–18 years and assistance was provided (measure read aloud) for children aged of 5–7 years. When necessary, children > 7 years received support and help from research assistant to complete the psychosocial questionnaires. The final study group was composed of 48 children and 48 parents and all the scores of the instruments were computed in the analyses since 100% of the items were completed in the database by children and their parents enrolled in the study.

Measurements

PedsQL 3.0 brain tumor module

Children's HRQoL specific to brain tumors was assessed according to the PedsQL brain tumor module [7], translated in French by our research team. The PedsQL brain tumor module is composed of 24 items multidimensionally distributed on six scales: (1) cognitive problems (7-items), (2) pain and hurt (3-items), (3) movement and balance (3-items), (4) procedural anxiety (3-items), (5) nausea (5-items), and (6) worry (3-items). The questionnaire consists of 5-point Likert-scale questions (0 = never; 1 = almost; 2 = sometimes; 3 = often; 4 = almost always) with a child self-report (aged between 5 and 18 years old) format in order to assess the child's HRQoL over the last week and a parent proxy-report (aged between 2 and 18 years old) format to assess the parent's perceptions of their child's HRQoL. It should be noted that the parent proxy-report for toddlers (aged 2–4) did not include the cognitive problems scale. A higher score indicated a good HRQoL. We used different age versions of

the questionnaires for child self-report, as follows: young child (ages 5–7), child (ages 8–12), and adolescent (ages 13–18). We also used different age versions of the questionnaires for parent proxy-report, as follows: toddler (ages 2–4), young child (ages 5–7), child (ages 8–12), and adolescent (ages 13–18). The original English PedsQL brain tumor module has excellent psychometric properties with Cronbach's alpha coefficients for the total scale score of an average $\alpha = 0.76$–0.87 for child self-report and an average $\alpha = 0.78$–0.92 for parent proxy-reports [7].

PedsQL 4.0 generic core scales

Children's HRQoL was assessed according to the PedsQL generic core scales [14], already available in French [20]. The PedsQL generic core scales are composed of 23 items multidimensionally distributed on four scales: (1) physical functioning (8-items), (2) emotional functioning (5-items), (3) social functioning (5-items), and (4) school functioning (5-items). The questionnaire consists of 5-point Likert-scale questions (0 = never; 1 = almost; 2 = sometimes; 3 = often; 4 = almost always) with a child self-report (ages between 5 and 18 years old) format in order to assess the child's HRQoL over the last month and a parent proxy-report (age between 2 and 18 years old) format to assess the parent's perceptions of their child's HRQoL. A higher score indicated a good HRQoL. We used different age versions of the questionnaires for child self-report, as follows: young child (ages 5–7), child (ages 8–12), and adolescent (ages 13–18). We also used different age versions of the questionnaires for parent proxy-report, as follows: toddler (ages 2–4), young child (ages 5–7), child (ages 8–12), and adolescent (ages 13–18). The PedsQL generic core scales have excellent psychometric properties in pediatric cancer with Cronbach's alpha coefficients for the total scale score of $\alpha = 0.88$ for child self-report and $\alpha = 0.93$ for parent proxy-report [14, 15].

Patient-reported outcomes measurement information system (PROMIS)

Children's HRQoL was also assessed according to the PROMIS-37 pediatric profile v2.0 [21], translated in French [22]. The PROMIS questionnaire is composed of 37 items multidimensionally distributed on six scales: pain interference (7-items), peer relation (6-items), depression and sadness (6-items), fatigue (6-items), anxiety and fear (6-items) and mobility (6-items). The questionnaire consists of 5-point Likert-scale questions (0 = never; 1 = almost never; 2 = sometimes; 3 = often; 4 = almost always) with a child self-report (ages 8–18) format in order to assess the child's HRQoL over the last week and a parent proxy-report (ages 5–18) format to assess the parent's perceptions of their child's HRQoL. A higher score indicated that the measured symptom was experienced at a greater level, whether the symptom was desirable (e.g., peer relation, mobility) or undesirable (e.g., pain interference, depression and sadness, fatigue, anxiety and fear). The PROMIS-37 pediatric profile questionnaire had excellent psychometric properties with a Cronbach's alpha coefficient of $\alpha > 0.90$ for child self-report and parent proxy-report [23]. A recent study showed that the use of PROMIS measures in children with brain tumors are effective to measure child's HRQoL [24].

Statistical analyses

Statistical analyses were performed using IBM SPSS statistics, version 24.0 (IBM Corp., Armonk, NY, USA) and statistical significance was set at an alpha level of $p < 0.05$ for each test. All variables were reported as mean ± standard deviation (SD) and the normal distribution of the data was verified. Descriptive statistics were performed for all measures at test and retest and to describe participants. A pairwise case deletion was used for missing values. If more than 50% of the items were missing in the database, the scores of the instruments were not computed in the analyses. A priori power analysis was performed and indicated a sample size of 44 (11 patients in each age group) that will provide > 80% statistical power analysis to detect a good effect. For temporal stability, we used intraclass correlation coefficients (ICCs) to estimate stability and classified values as poor (ICC < 0.40), moderate (0.40 to 0.59), good (0.60 to 0.74) and excellent (0.75 to 1.00) [25]. Paired sample *t*-tests and effect sizes of Cohen's *d* were performed to estimate mean-level changes and to assess differences between children's and parents' reports. For repeatability, we used the Bland and Altman method to assess the accuracy between Time 1 and Time 2, based on graphical techniques and simple calculations [26]. Thus, mean ± SD of Time 2–Time 1 differences were calculated for each test measure. Limits of Agreement (LOA were calculated for the Bland and Altman plots where LOA were defined as the mean difference with a 95% LOA calculated upper LOA = (mean + 1.96 SD) and lower LOA = (mean—1.96 SD). The Mean to Difference plot and the Kendall's τ were used to examine relationships of instability with levels on the measures. Following this, we computed the measurement error ($SD/\sqrt{2}$) and the error range ($SD/\sqrt{2}*1.96$). The error range indicated that the average of all possible measurements of the test measure were within range of the value of the error below/above the actual measurement taken. For convergent validity, we used Pearson's correlation coefficients to measure correlation between the PedsQL brain tumor module, PedsQL general module and the PROMIS-37 pediatric profile questionnaire. Correlation coefficients were considered as low (0.10 to 0.30), moderate (0.31 to 0.50) and high (> 0.50) [27].

Results

Participant characteristics

The clinical characteristics of the pediatric brain tumor patients and their parents are presented in Table 1. The study group was composed of 48 pediatric brain tumors patients (25 boys and 23 girls), and their parents. Among the children enrolled in the study, 39 children lived with both their parents (81.3%), 8 children lived with their mother (16.7%) and 1 child lived with their father (2.1%). Among the parents enrolled in the study, 27 mothers answered the questionnaires alone, 9 fathers answered the questionnaires alone, and 12 mothers and 12 fathers answered the questionnaires together for a total of 48 questionnaires answered by the parents. The group was composed of 40 parents in a relationship (83.3%), 2 single mothers (4.1%) and 7 single fathers (14.5%). The mothers' mean age was 37.5 ± 5.9 years and the fathers' mean age was 38.6 ± 6.8 years.

Table 1 Clinical characteristics of the pediatric brain tumor patients

	Children ($n = 48$)
Gender, *N* (%)	
Males	25 (52.1)
Females	23 (47.9)
Age at the interview, years	
Mean (SD)	8.3 (4.8)
Median (range)	7.5 (2.0–18.0)
Age at diagnosis, years	
Mean (SD)	8.0 (5.6)
Median (range)	6.0 (0.3–16.0)
Cancer diagnosis, *N* (%)	
Optic pathway glioma	9 (18.8)
Ependymoma	6 (12.5)
Plexiform neurofibroma	6 (12.5)
Medulloblastoma	5 (10.4)
Pilocytic astrocytoma	5 (10.4)
Germ cell tumors of the brain	3 (6.3)
Astrocytoma glioma	2 (4.2)
Craniopharyngioma	2 (4.2)
Diffuse midline glioma	2 (4.2)
Glioblastoma	2 (4.2)
Glioneuronal tumors	2 (4.2)
Medulloblastoma	2 (4.2)
Choroid plexus carcinoma	1 (2.1)
Meningioma	1 (2.1)
Treatments, *N* (%)	
Chemotherapy	38 (79.2)
Radiotherapy	19 (39.6)
Surgery	36 (75.0)
In-treatment at the time of the study, *N* (%)	
Yes	40 (83.3)
No	8 (16.7)

Questionnaires

Descriptive analyses of the PedsQL brain tumor module for parent proxy-report and child self-report by age and subscale are presented in Table 2, while descriptive analyses of the PedsQL generic core scale and the PROMIS-37 pediatric profile questionnaire for parent proxy-report and child self-report by age and subscale are presented in Supplementary Tables S1 and S2.

Temporal stability for parent proxy-report and child self-report

As summarized in Table 2, we found an excellent temporal stability for the parent proxy-report (average ICC = 0.98) and child self-report (average ICC = 0.98). For parent proxy-reports, we reported an ICC of 0.99 for cognitive problems, an ICC of 0.96 for pain and hurt, an ICC of 0.99 for movement and balance, an ICC of 0.99 for procedural anxiety, an ICC of 0.99 for nausea and an ICC of 0.97 for worry. For child self-reports, we reported an ICC of 0.98 for cognitive problems, an ICC of 0.98 for pain and hurt, an ICC of 0.96 for movement and balance, an ICC of 0.99 for procedural anxiety, an ICC of 0.97 for nausea and an ICC of 0.98 for worry. No significant differences by subscale were observed between the Time 1 and the Time 2 for the parent proxy-report, and for the child self-report (Table 2). Effect sizes using Cohen's d statistics were small, ranging from 0.00 to 0.06.

Repeatability for parent proxy-reports

Repeatability analyses of the PedsQL brain tumor module for parent proxy-reports by subscale over a 1-week interval are presented in Fig. 1. We found an excellent accuracy between Time 1 and Time 2 supported by a significant high correlation over a 1-week interval (ICC > 0.96; $p < 0.001$). The mean bias in cognitive problems was -0.40 (95% LOA = 6.04 to − 6.83) with an error range of 4.55, in pain and hurt was -0.35 (95% LOA = 10.81 to − 11.50) with an error range of 7.89, in movement and balance was 0.17 (95% LOA = 7.31 to − 6.97) with an error range of 5.05, in procedural anxiety was − 0.52 (95% LOA = 6.55 to − 7.59) with an error range of 5.00, in nausea was − 0.21 (95% LOA = 3.27 to − 3.69) with an error range of 2.46 and in worry was 0.69 (95% LOA = 8.83 to − 7.44) with an error range of 5.75. We also found an excellent uniformity in the variance of the repeated measurement for each parameter: cognitive problems ($\tau = 0.96$; $p < 0.01$),

Table 2 Descriptive analyses of PedsQL brain tumor module for parent proxy-report and child self-report by age and subscale

Scale	Toddler (2–4)		Young child (5–7)		Child (8–12)		Adolescent (13–18)		Comparisons				
	T1	T2	T1	T2	T1	T2	T1	T2	T1	T2	*p*-value	*d*	ICC
Parent proxy-report	(*n* = 12)	(*n* = 12)	(*n* = 12)	(*n* = 12)	(*n* = 12)	(*n* = 12)	(*n* = 12)	(*n* = 12)	(*n* = 48)	(*n* = 48)			
Cognitive problems	N/A	N/A	72.3 ± 19.0	71.7 ± 20.2	69.3 ± 27.7	68.8 ± 28.9	69.3 ± 24.4	69.3 ± 25.0	70.3 ± 23.3	69.9 ± 24.3	0.47	0.02	0.99***
Pain and hurt	93.1 ± 8.6	90.3 ± 12.2	86.1 ± 19.6	84.7 ± 21.9	70.1 ± 17.9	70.8 ± 18.6	72.9 ± 24.4	75.0 ± 28.4	80.6 ± 20.3	80.2 ± 21.9	0.67	0.02	0.96***
Movement and balance	77.8 ± 21.1	77.8 ± 23.4	77.1 ± 30.4	77.1 ± 30.4	72.9 ± 23.1	74.3 ± 22.6	74.3 ± 30.7	73.6 ± 30.3	75.5 ± 25.9	75.7 ± 26.1	0.74	0.01	0.99***
Procedural anxiety	68.8 ± 34.8	68.1 ± 35.0	55.6 ± 39.6	54.2 ± 41.2	52.1 ± 28.5	52.1 ± 28.2	73.6 ± 34.1	73.6 ± 34.8	62.5 ± 34.6	62.0 ± 35.2	0.32	0.01	0.99***
Nausea	94.6 ± 10.3	93.8 ± 12.1	87.5 ± 19.6	87.1 ± 20.2	81.3 ± 24.9	80.8 ± 26.0	86.7 ± 18.5	87.5 ± 18.5	87.5 ± 19.0	87.3 ± 19.7	0.42	0.01	0.99***
Worry	98.6 ± 3.2	98.6 ± 3.2	88.9 ± 14.8	90.3 ± 13.7	86.8 ± 12.0	86.1 ± 13.5	73.6 ± 20.7	75.7 ± 23.2	87.0 ± 16.4	87.7 ± 16.8	0.25	0.04	0.97***
Child self-report	–	–	(*n* = 12)	(*n* = 12)	(*n* = 12)	(*n* = 12)	(*n* = 12)	(*n* = 12)	(*n* = 36)	(*n* = 36)			
Cognitive problems	–	–	79.2 ± 19.3	78.5 ± 20.2	81.3 ± 13.8	79.8 ± 16.3	78.0 ± 14.8	77.4 ± 15.5	79.5 ± 15.7	78.5 ± 17.0	0.12	0.06	0.98***
Pain and hurt	–	–	76.4 ± 28.8	72.2 ± 30.4	72.2 ± 26.0	73.6 ± 25.3	83.3 ± 23.3	82.6 ± 23.4	77.3 ± 25.8	76.2 ± 26.2	0.23	0.04	0.98***
Movement and balance	–	–	90.3 ± 16.6	88.9 ± 16.4	81.9 ± 20.0	80.6 ± 22.6	86.8 ± 19.9	86.1 ± 20.5	86.3 ± 18.7	85.2 ± 19.7	0.23	0.06	0.96***
Procedural anxiety	–	–	55.6 ± 42.8	55.6 ± 39.8	60.4 ± 36.4	59.0 ± 35.4	86.1 ± 19.9	87.5 ± 19.9	67.4 ± 36.1	67.4 ± 35.0	1.00	0.00	0.99***
Nausea	–	–	85.8 ± 17.8	87.5 ± 18.6	77.1 ± 22.7	77.1 ± 24.3	85.4 ± 14.4	84.6 ± 15.9	82.8 ± 18.5	83.1 ± 19.8	0.71	0.02	0.97***
Worry	–	–	66.7 ± 29.3	66.7 ± 18.6	82.6 ± 22.0	81.9 ± 23.0	67.4 ± 21.7	68.1 ± 20.4	72.2 ± 25.0	72.2 ± 24.5	1.00	0.00	0.98***

***$p < 0.001$

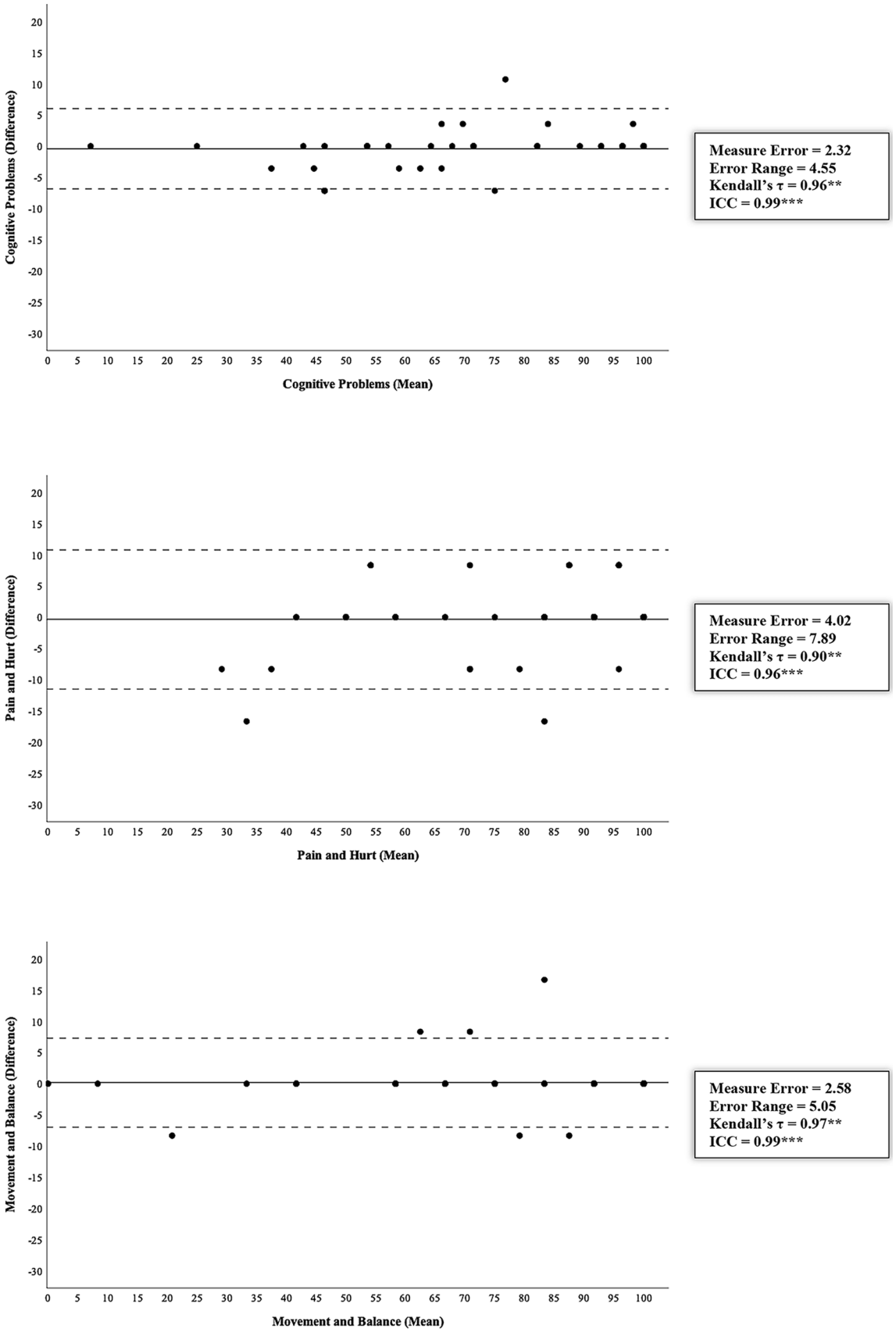

Fig. 1 Repeatability analysis of the PedsQL brain tumor module for parent proxy-report by subscale over a 1-week interval. $^{**}p < 0.01$; $^{***}p < 0.001$

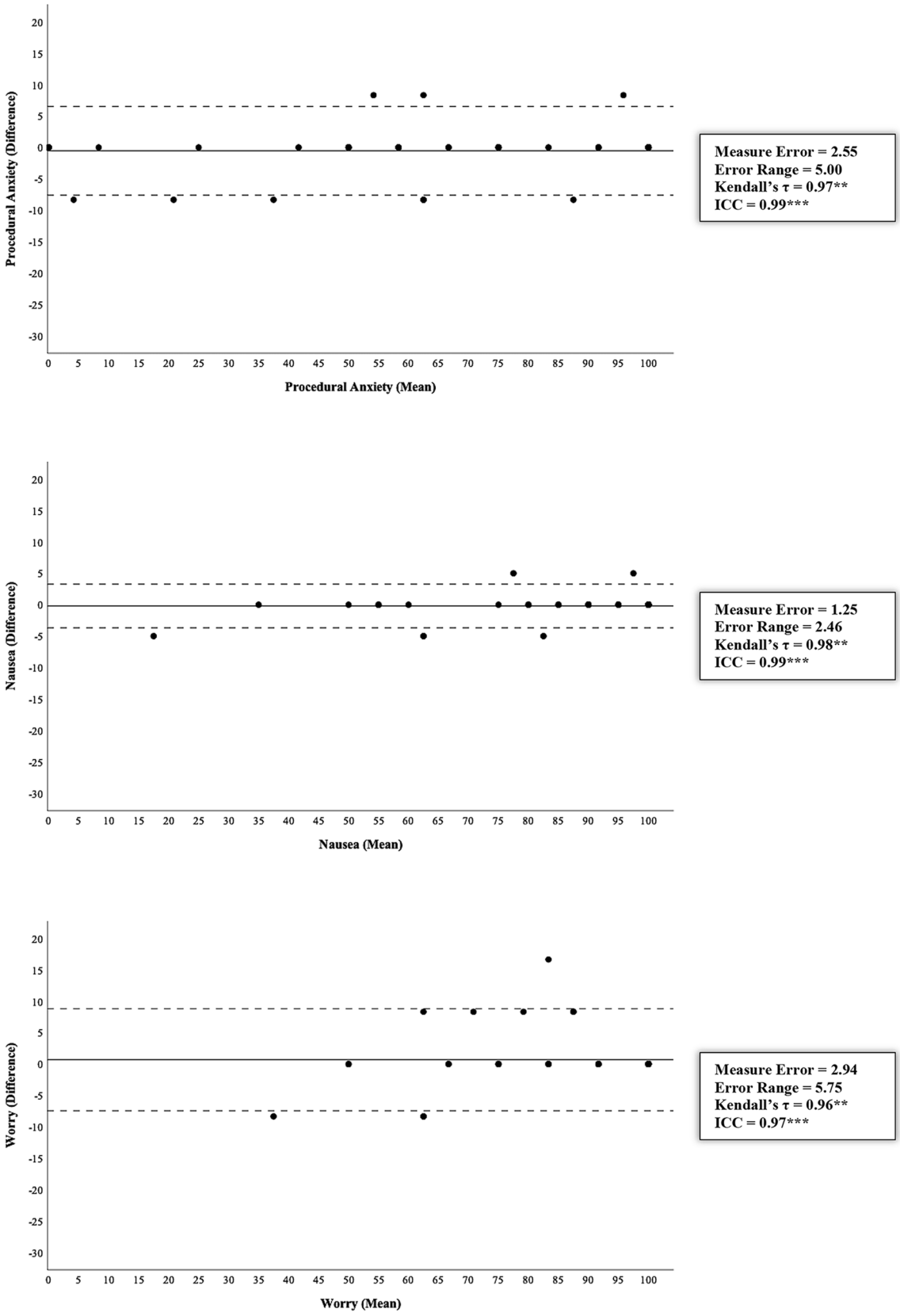

Fig. 1 (continued)

pain and hurt ($\tau = 0.90$; $p < 0.01$), movement and balance ($\tau = 0.97$; $p < 0.01$), procedural anxiety ($\tau = 0.97$; $p < 0.01$), nausea ($\tau = 0.98$; $p < 0.01$) and worry ($\tau = 0.96$; $p < 0.01$).

Repeatability for child self-report

Repeatability analyses of the PedsQL brain tumor module for child self-report by subscale over a 1-week interval are presented in Fig. 2. We found an excellent accuracy between Time 1 and Time 2 supported by a significant high correlation over a 1-week interval (ICC > 0.96; $p < 0.001$). The mean bias in cognitive problems was − 0.93 (95% LOA = 5.86 to − 7.71) with an error range of 4.80, in pain and hurt was − 1.16 (95% LOA = 9.99 to − 12.31) with an error range of 7.88, in movement and balance was − 1.16 (95% LOA = 9.99 to − 12.31) with an error range of 7.88, in procedural anxiety was 0.00 (95% LOA = 10.33 to − 10.33) with an error range of 7.30, in nausea was 0.28 (95% LOA = 9.03 to − 8.47) with an error range of 6.19 and in worry was 0.00 (95% LOA = 9.56 to − 9.56) with an error range of 6.76. We also found an excellent uniformity in the variance of the repeated measurement for each parameter: cognitive problems ($\tau = 0.91$; $p < 0.01$), pain and hurt ($\tau = 0.93$; $p < 0.01$), movement and balance ($\tau = 0.90$; $p < 0.01$), procedural anxiety ($\tau = 0.94$; $p < 0.01$), nausea ($\tau = 0.89$; $p < 0.01$) and worry ($\tau = 0.96$; $p < 0.01$).

Convergent validity between the PedsQL brain tumor module, the PedsQL generic core scales and the PROMIS-37 pediatric profile for parent proxy-reports

Convergent validity, assessed through Pearson correlation coefficient tests, between the PedsQL brain tumor module, the PedsQL generic core scales and the PROMIS-37 pediatric profile for parent proxy-reports by subscale over a 1-week interval are presented in Table 3. When examining relations with the PedsQL generic core scales, all associations with related constructs were significantly and positively correlated in the expected direction with the PedsQL brain tumor module. When examining relations with the PROMIS-37 pediatric profile all associations with related constructs were significantly and positively correlated in the expected direction with the PedsQL brain tumor module. Although most of the correlations reported were significantly and positively correlated in the expected direction and ranged between high and low, no significant correlations were observed between the worry parameter and the four scales of the PedsQL generic core scales, as well as with the six scales of the PROMIS-37 pediatric profile questionnaire.

Convergent validity between the PedsQL brain tumor module, the PedsQL generic core scales and the PROMIS-37 pediatric profile for child self-report

Convergent validity, assessed through Pearson correlation coefficient tests, between the PedsQL brain tumor module, the PedsQL generic core scales and the PROMIS-37 pediatric profile for child self-reports by subscale over a 1-week interval are presented in Table 4. When examining relations with the PedsQL generic core scales, all associations with related constructs were significantly and positively correlated in the expected direction with the PedsQL brain tumor module. When examining relations with the PROMIS-37 pediatric profile all associations with related constructs were significantly and positively correlated in the expected direction with the PedsQL brain tumor module. Similar to the parent proxy-reports, most of the correlations reported were significantly and positively correlated in the expected direction and ranged between high and low. No significant correlations were observed between the worry parameter and the four scales of the PedsQL generic core scales, as well as with the six scales of the PROMIS-37 pediatric profile questionnaire.

Differences between parent proxy-report and child self-report

Pearson correlation coefficients and differences between parent proxy-report and child self-report by subscale are presented in Table 5. When comparing parent proxy-report to child-self report results at Time 1, we found significant differences for cognitive problems ($p = 0.02$), movement and balance ($p < 0.001$), and worry ($p = 0.02$). Children reported higher scores in cognitive problems and the movement and balance parameters than their parents, and they reported lower scores in the worry parameter than their parents. Similar results were observed at Time 2 when comparing parent proxy-report to child self-report results. At Time 1, between parent proxy-report and child self-report, a poor agreement was found for cognitive problems (ICC = 0.30; $p < 0.05$), nausea (ICC = 0.39; $p < 0.01$) and worry (ICC = 0.12; $p > 0.05$), a moderate agreement was found for pain and hurt (ICC = 0.49; $p < 0.001$), and procedural anxiety (ICC = 0.50; $p < 0.001$) and a good agreement was found for movement and balance (ICC = 0.62; $p < 0.001$). At Time 2, between parent proxy-report and child self-report, a poor agreement was found for cognitive problems (ICC = 0.39; $p < 0.01$) and worry (ICC = 0.08; $p > 0.05$), a moderate agreement was found for pain and hurt (ICC = 0.51; $p < 0.001$), procedural anxiety (ICC = 0.54; $p < 0.001$) and nausea (ICC = 0.42; $p < 0.01$), and a good agreement was found for movement and balance (ICC = 0.60; $p < 0.001$).

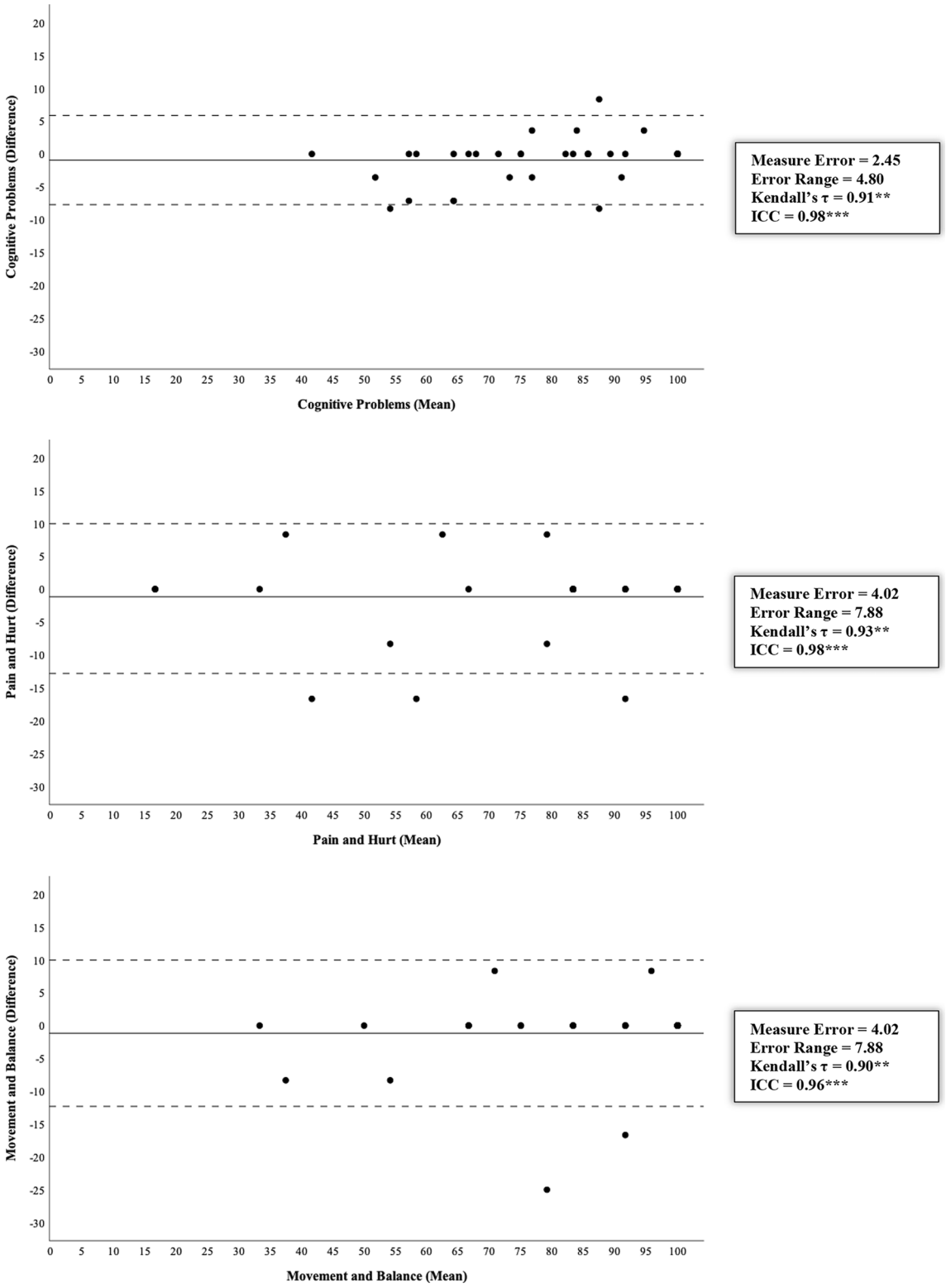

Fig. 2 Repeatability analysis of the PedsQL brain tumor module for child self-report by subscale over a 1-week interval. $^{**}p < 0.01$; $^{***}p < 0.001$

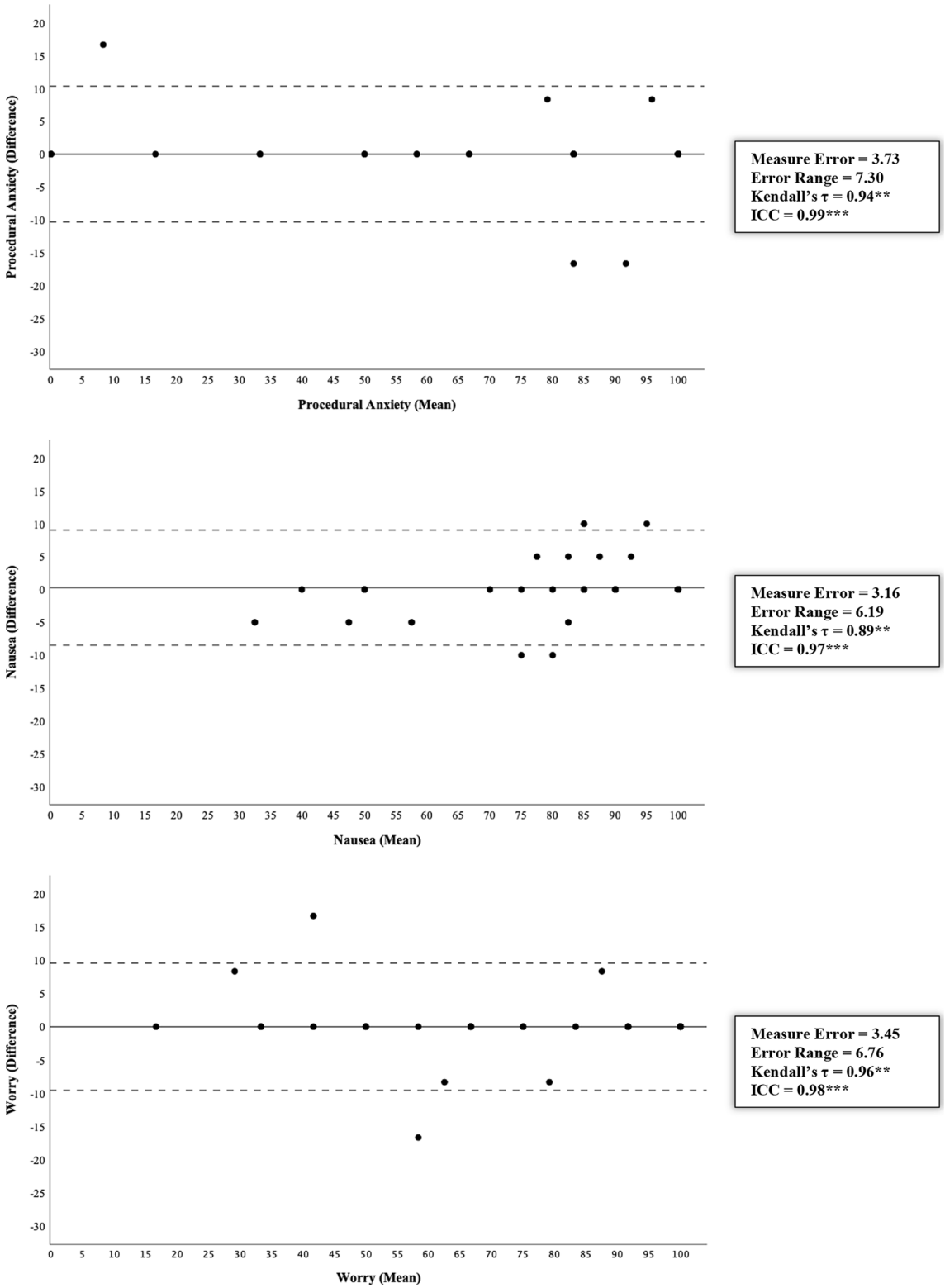

Fig. 2 (continued)

Table 3 Pearson correlation coefficient test between the PedsQL brain tumor module, the PedsQL generic core scales and the PROMIS for parent proxy-report by subscale over a 1-week interval

	PedsQL brain tumor module						PedsQL generic core escales				PROMIS questionnaire				
	Cognitive problems	Pain and hurt	Movement and Balance	Procedural Anxiety	Nausea	Worry	Physical functioning	Emotional functioning	Social functioning	School functioning	Pain interference	Peer relation	Depression and sadness	Fatigue	Anxiety and Fear
PedsQL brain tumor module															
Pain and hurt	0.40*														
Movement and balance	0.35*	0.41*													
Procedural anxiety	0.31	0.13	0.02												
Nausea	0.49**	0.48**	0.21	0.57**											
Worry	0.13	0.07	−0.22	0.31	0.34*										
PedsQL generic core escales															
Physical functioning	0.29	0.44**	0.57**	0.27	0.33*	0.10									
Emotional functioning	0.51**	0.70**	0.29	0.21	0.45**	0.21	0.41*								
Social functioning	0.44**	0.26	0.38*	−0.01	0.40*	0.14	0.30	0.33*							
School functioning	0.54**	0.41*	0.22	0.33*	0.53**	0.28	0.42*	0.50**	0.38*						
PROMIS questionnaire															
Pain interference	−0.35	−0.34	−0.32	−0.54**	−0.55**	−0.23	−0.50*	−0.51*	−0.48*	−0.35					
Peer relation	0.17	−0.30	−0.15	−0.25	−0.18	0.01	−0.34	−0.37	0.41*	0.06	0.01				

Table 3 (continued)

	PedsQL brain tumor module						PedsQL generic core escales				PROMIS questionnaire				
	Cognitive problems	Pain and hurt	Movement and Balance	Procedural Anxiety	Nausea	Worry	Physical functioning	Emotional functioning	Social functioning	School functioning	Pain interference	Peer relation	Depression and sadness	Fatigue	Anxiety and Fear
Depression and sadness	−0.42*	−0.62**	0.01	−0.68**	−0.66**	−0.36	−0.27	−0.71**	−0.17	−0.54**	0.52**	0.24			
Fatigue	−0.24	−0.35	−0.44*	−0.51*	−0.46*	−0.36	−0.72**	−0.53**	−0.34	−0.53**	0.72**	0.23	0.54**		
Anxiety and fear	−0.55**	−0.31	−0.15	−0.48*	−0.60**	−0.38	−0.3	−0.62**	−0.26	−0.36	0.52**	0.09	0.46*	0.35	
Mobility	0.18	0.07	0.60**	0.18	0.16	−0.02	0.61**	0.18	0.37	0.18	−0.45*	−0.17	−0.02	−0.64**	−0.24

*$p < 0.05$; **$p < 0.01$

Discussion

This study was the first to present the translation process, as well as the stability, repeatability and validity of the French version of the PedsQL brain tumor module in PBT patients. Our findings highlighted that the French version of the PedsQL brain tumor module is a validate and reliable questionnaire to measure HRQoL among PBT patients, since excellent psychometric properties were reported for each subscale. Our analyses demonstrated excellent temporal stability, repeatability, and validity for both parent proxy-report and child self-report by age and subscales. Convergent validity between parent proxy-report and child self-report were generally positive, with some exceptions.

Overall, our study highlighted that the French version of the PedsQL brain tumor module is a validate and reliable questionnaire to measure HRQoL in this population. A growing number of PBT patients survive their disease, but live with a reduced HRQoL, independently of the treatment period [4–7]. Current knowledge of the HRQoL of French-speaking PBT patients has been impeded by a previous lack of available measures. The use of the French version of the PedsQL brain tumor module will now allow the ability to gain more insight on the impact of a brain tumor on French-speaking children's HRQoL. The validated translation of the PedsQL will also allow the inclusion of a greater number of PBT patients in the assessment of their HRQoL, and as such, will be more representative of this specific population. The French version of the PedsQL brain tumor module will help health care, clinicians, psychologists and researchers to better understand the long-term effects of cancer treatments on PBT patient's HRQoL [28–30]. In this sense, healthcare professionals will be able to provide better follow-up in French-speaking children because of the validation of the French version of the PedsQL brain tumor module in PBT patients. In the context where children with newly diagnosed brain tumors are the most affected by a reduced HRQoL compared to other newly pediatric diagnosed cancer, our study can be considered as a major advance in pediatric psycho-oncology. More generally, our findings also support the use of parent proxy-reports to assess parent's perceptions of their child's HRQoL. Parent proxy-reports may be especially helpful to assess their child's HRQoL when children are extremely ill or have cognitive delays not allowing them to complete their self-report [31, 32]. However, using parent proxy-reports to replace their child's HRQoL assessment or to lead pediatric health care decisions should be done with caution, since some significant differences were reported between parent proxy-reports and child self-reports.

In this study, PBT patients had a relatively good HRQoL in regard to the parameters of cognitive problems, pain and hurt, movement and balance, and nausea. However, we

Table 4 Pearson correlation coefficient test between the PedsQL brain tumor module, the PedsQL generic core scales and the PROMIS for child self-report by subscale over a 1-week interval

	PedsQL brain tumor module						PedsQL generic core escales				PROMIS questionnaire				
	Cognitive problems	Pain and hurt	Movement and Balance	Procedural Anxiety	Nausea	Worry	Physical functioning	Emotional functioning	Social functioning	School functioning	Pain interference	Peer relation	Depression and sadness	Fatigue	Anxiety and Fear
PedsQL brain tumor module															
Pain and hurt	0.38*														
Movement and balance	0.29	0.26													
Procedural anxiety	0.29	0.28	0.33*												
Nausea	0.19	0.35*	0.17	0.36*											
Worry	0.01	0.21	0.03	−0.02	0.25										
PedsQL generic core escales															
Physical functioning	0.17	0.08	0.54**	0.40**	0.29*	0.04									
Emotional functioning	0.52**	0.38**	0.26	0.35*	0.14	0.10	0.48**								
Social functioning	0.54**	0.21	0.45**	0.33*	0.19	0.10	0.59**	0.42**							
School functioning	0.70**	0.18	0.23	0.30*	0.07	−0.16	0.29*	0.30*	0.30*						
PROMIS questionnaire															
Pain interference	0.17	0.08	0.54**	0.40**	0.29*	0.04	1.00**	0.48**	0.59**	0.29*					
Peer relation	0.82**	0.33*	0.40**	0.44**	0.15	−0.01	0.61**	0.75**	0.75**	0.80**	0.61**				

Table 4 (continued)

	PedsQL brain tumor module						PedsQL generic core escales				PROMIS questionnaire			
	Cognitive problems	Pain and hurt	Movement and Balance	Procedural Anxiety	Nausea	Worry	Physical functioning	Emotional functioning	Social functioning	School functioning	Pain interference	Peer relation	Depression and sadness	Fatigue	Anxiety and Fear
Depression and sadness	−0.52**	−0.44**	−0.49**	−0.54**	−0.54**	0.06	−0.36*	−0.33	−0.46**	−0.45**	−0.36*	−0.57**			
Fatigue	0.09	−0.05	0.06	−0.25	0.03	0.25	0.01	−0.16	0.43**	−0.03	0.01	0.11	−0.13		
Anxiety and fear	−0.41*	−0.36*	−0.36*	−0.37*	−0.26	−0.15	−0.41*	−0.54**	−0.40*	−0.21	−0.41*	−0.50**	0.51**	−0.09	
Mobility	−0.48**	−0.36*	−0.42*	−0.37*	−0.43**	−0.15	−0.63**	−0.38*	−0.55**	−0.33*	−0.63**	−0.56**	0.63**	−0.17	0.69**

*$p < 0.05$; **$p < 0.01$

observed moderate HRQoL in regard to the procedural anxiety and worry parameters. This was consistent with the original study published by Palmer et al. [7]. Indeed, a moderate HRQoL has been reported for procedural anxiety and worry in children's self-report, while the other HRQoL parameters have been found to be good. It has also been observed that cancer and treatment intensity can be associated with posttraumatic stress disorder [33], while Sato et al., assume that intensive related symptoms measured by the PedsQL and treatments might increase anxiety in PBT patients [34]. When assessing parents' perceptions of their child's HRQOL, we observed a relatively good HRQoL for the parameters of cognitive problems, pain and hurt, movement and balance, as well as nausea and worry. As observed in children, parents reported a moderate HRQoL for the procedural anxiety parameter. In fact, when using parents' perceptions of their child's HRQOL to assess child's anxiety, Sato et al., observed that parents reported more procedural and treatment anxiety than other parents of children with cancer [34]. Convergent validity analyses between parent proxy-reports and child self-reports highlighted positive significant correlations for cognitive problems, pain and hurt, movement and balance, procedural anxiety and nausea, whether at time 1 or time 2. However, we found significant differences between parent proxy-report and child self-report for the parameters of cognitive problems, movement and balance, and worry, which suggests a lower concordance. These findings are consistent with current research in oncology that has reported a moderate to strong concordance between parent proxy-report and child self-report [15]. This can be mainly explained by the fact that parents experience anxiety and distress in regard to their child's health, which has the consequence of an overestimation or an underestimation of their child's HRQoL [35–37], as observed in our results. Moreover, it has also been reported that parents of children diagnosed with cancer experience elevated levels of anxiety and depression [38, 39].

Temporal stability was found to be excellent by age and subscale for the parent proxy-report (average ICC = 0.98) and the child self-report (average ICC = 0.98) at 1-week intervals for each subscale. Moreover, repeatability analyses exceeded the minimum recommended ICC standard of 0.75 since we observed an excellent accuracy supported by a significant high correlation over a 1-week interval and an excellent stability for each scale of the PedsQL brain tumor module in both parent proxy-reports [Kendall's $\tau > 0.90$ ($p < 0.01$)] and child self-reports [Kendall's $\tau > 0.89$ ($p < 0.01$)]. These findings were consistent with the original version of the PedsQL [7] and its translated Japanese version [40], which are currently the only published validation articles for the PedsQL brain tumor module. Convergent validity analyses were reported to be excellent and were

Table 5 Pearson correlation coefficient and differences between parent proxy-report and child self-report for the PedsQL brain tumor module by subscale

Scale	*T*1				*T*2			
	Parent proxy-report ($n=48$)	Child self-report ($n=36$)	*p*-value	ICC	Parent proxy-report ($n=48$)	Child self-report ($n=36$)	*p*-value	ICC
Cognitive problems	70.3 ± 23.3	79.5 ± 15.7	0.02	0.30*	69.9 ± 24.3	78.5 ± 17.0	0.02	0.39**
Pain and hurt	80.6 ± 20.3	77.3 ± 25.8	0.82	0.49***	80.2 ± 21.9	76.2 ± 26.2	0.87	0.51***
Movement and Balance	75.5 ± 25.9	86.3 ± 18.7	< 0.001	0.62***	75.7 ± 26.1	85.2 ± 19.7	< 0.001	0.60***
Procedural Anxiety	62.5 ± 34.6	67.4 ± 36.1	0.25	0.50***	62.0 ± 35.2	67.4 ± 35.0	0.20	0.54***
Nausea	87.5 ± 19.0	82.8 ± 18.5	0.52	0.39**	87.3 ± 19.7	83.1 ± 19.8	0.58	0.42**
Worry	87.0 ± 16.4	72.2 ± 25.0	0.02	0.12	87.7 ± 16.8	72.2 ± 24.5	0.02	0.08

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$

also supported through significant high correlations in the expected direction between the PedsQL brain tumor module, the PedsQL generic core scales and the PROMIS-37 pediatric profile questionnaire.

Strengths of our study included the high enrolment rate (95.3%) of French-speaking PBT patients at Sainte-Justine University Health Center, and that no missing item responses were reported. Indeed, 100% of the items for each questionnaire were completed in the database by parents and children enrolled in the study, which indicated that the questionnaire was easy to complete. In light of our results, the PedsQL brain tumor module has been found to have good acceptability and feasibility with the participants. However, this study was conducted at only one pediatric oncology hospital which could have limited the generalization and the scope of our results. Nevertheless, it should be emphasized that our cohort was representative of the PBT population because of the age distribution, types of cancers and acceptable numbers of children and parents in age groups. Finally, since our study was not designed to explore the effects of treatments on HRQoL, further studies will be required to better understand the adverse effects of treatments in this population at high-risk of a reduced HRQoL [5, 41, 42]. Moreover, additional research is needed to validate psychometric properties with a larger sample size.

In conclusion, this study highlights that the French version of the PedsQL brain tumor module is a validate and reliable questionnaire to measure HRQoL among PBT patients since our findings reported excellent psychometric properties. In this sense, measuring HRQoL in this specific population with the French version of the PedsQL brain tumor module will help health care, clinicians, psychologists and researchers to better understand the evolution of the HRQOL in French-speaking PBT patients, whether during or after treatments. The use of the French version of the PedsQL brain tumor module must be made routinely part of patient's follow-up care.

Supplementary Information The online version contains supplementary material available at https://doi.org/10.1007/s11136-021-02815-3.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no competing interests.

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