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# Factors influencing self- and parent-reporting health-related quality of life in children with brain tumors

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**Abstract**
*Purpose* Health-related quality of life (HRQOL) is not only a degree of health but also reflects patient perceptions and expectations of health. For children with brain tumors, better understanding of HRQOL requires the use of complementary reports from parents and interviewer-administered reports for children. Here, we aimed to test whether or not the trait anxiety of children and the psychological distress of their parents influence children's and parents' responses to HRQOL questionnaires, and whether or not the report-administration method for children influences children's responses to HRQOL questionnaires.
*Methods* One hundred and thirty-four children aged 5–18 with brain tumors and one of their parents completed the Pediatric Quality of Life Inventory™ (PedsQL™) Brain Tumor Module questionnaires. In addition, the children also completed the State-Trait Anxiety Inventory for Children (STAIC), and the parents also completed the

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Kessler-10 (K10) and health and sociodemographic characteristics questionnaires. The child questionnaires were administered either by the child (self-administered) or an interviewer. Rater-dependent perceptions about HRQOL were derived from the subscales scores of the PedsQL™ Brain Tumor Module using structural equation modeling based on a multitrait-multimethod model. The STAIC trait-anxiety score, K10 score, report-administration method, and other health and sociodemographic factors related to each child's or parent's perceptions were identified through multiple linear regression analyses of the questionnaire responses. We used a path analysis to estimate the change in a PedsQL™ child-reported score that occurs when interviewer-administration changes the child's perception about HRQOL.

*Results* Surveys for 89 children were self-administered while those for 45 were interviewer-administered. The perceptions of the children and parents were calculated by fitting data to the model (chi-squared $P = 0.087$, normed fit index = 0.932, comparative fit index = 0.978, standardized root mean squared residual = 0.053, and root mean square error of approximation = 0.054). The children's perception of HRQOL was affected by their STAIC trait-anxiety score ($b = -0.43$, 95% CI [−0.60, −0.25]). The parent's perception was affected by their child's treatment status ($b = 0.26$, 95% CI [0.09, 0.43]), the parent's K10 score ($b = -0.21$, 95% CI [−0.37, −0.04]), and by education level ($b = 0.17$, 95% CI [0.00, 0.34]). The change in the child-reported PedsQL™ score in relation to the method of administration ranged from −1.1 (95% CI: −3.5, 1.3) on the procedural anxiety subscale to −2.5 (95% CI: −7.6, 2.6) on the movement and balance subscale.

*Conclusion* Child-reporting of HRQOL is little influenced by the method of administration. Children's perception about HRQOL tended to be influenced by their trait anxiety, while parents' perception was influenced by their psychological distress, academic background, and their child's treatment status.

**Keywords** Brain neoplasms · Child · Observer variation · Parents · Quality of life · Questionnaires

**Abbreviations**

| | |
|---|---|
| AMOS | Analysis of moment structures |
| CCAJ | The Children's Cancer Association of Japan |
| CFI | Comparative fit index |
| CHQ | Child Health Questionnaire |
| CI | Confidence interval |
| HRQOL | Health-related quality of life |
| K10 | Kessler-10 |
| MID | Minimum clinically significant difference |
| MTMM | Multitrait-multimethod |
| NFI | Normed fit index |
| PedsQL™ | Pediatric Quality of Life Inventory™ |
| RMSEA | Root mean square error of approximation |
| SD | Standard deviation |
| SEM | Structural equation modeling |
| SPSS | Statistical package for social sciences |
| SRMR | Standardized root mean squared residual |
| STAIC | State-Trait Anxiety Inventory for Children |
| TACQOL | TNO/AZL Child Quality of Life |

## Introduction

Children with brain tumors often show symptoms, such as pain, nausea, and lack of energy [1]. Even after treatment has ended, they may experience neurological, endocrinological, and cognitive problems and difficulties with psychosocial adjustment [2–6]. Appropriate care of children with brain tumors can be enhanced by assessing the child's health-related quality of life (HRQOL).

HRQOL is a patient-based outcome measured as a continuum of the quality of health experienced by a patient in a variety of aspects, including physical, emotional, social, and cognitive domains. Each of these domains can be measured in two dimensions: by an objective assessment of function or health status and by a subjective perception of health [7]. As such, HRQOL is not only a degree of health but also reflects a patient's personal perception and expectations.

HRQOL questionnaires for children often use both child- and parent-reports, respectively, reflecting the child's and parent's perception of the child's HRQOL; as a result, scores on these reports may differ. Child- and parent-reports provide complementary interpretations of HRQOL [8, 9], and neither is clearly superior to the other [10].

Several standard HRQOL questionnaires have been established for use with children, including the Pediatric Quality of Life Inventory™ (PedsQL™) [11], the TNO/AZL Child Quality of Life (TACQOL) [12], and the Child Health Questionnaire (CHQ) [13]. Several factors need to be considered when choosing a questionnaire, but clinical practice requires that the HRQOL instrument chosen for children with brain tumors reflects the impact of the disease and treatment.

We chose the PedsQL™ because this questionnaire includes generic core and disease-specific modules suitable for use in assessing pediatric chronic health conditions. Further, the PedsQL™ can be administered by an interviewer, a particularly essential factor, as child-reporting by children with brain tumors may occasionally be constrained by complications, such as visual impairment, motor dysfunction, or cognitive deficit. In addition, the

PedsQL™ is the only questionnaire presently available in Japanese and has been used before for children with brain tumors.

Having selected an HRQOL instrument, we then addressed two further questions affecting the feasibility and interpretation of the HRQOL scores: First, what are the causes of any differences between child- and parent-reported scores derived from standard questionnaires? Second, are there any significant differences between self- and interviewer-administered child-reports?

Previous studies have found that questionnaire responses may vary with the personality of the child [14] or their parent's mental health [15]. Jurbergs et al. [14] indicated that children with lowered trait anxiety and elevated defensiveness reported a higher CHQ score for themselves than did their parents. In effect, the personality of the child influences his/her perception about HRQOL, such that the score for the child differs from that perceived by the parent. With regard to parents' reports, Davis et al. indicated that increased maternal psychological distress, as measured by the Kessler-6 questionnaire, lowered the mother-proxy reported PedsQL™ score. These authors further indicated that reduced income of the caregiver resulted in a lowered mother-proxy reported, but not father-proxy reported score [15]. Although these reports suggest that the gender and income of parents may also influence parent-reports on the child-HRQOL, these authors did not compare the parent and child self-reports, and no studies have been conducted on differences between child- and parent-reports for children with brain tumors.

Studies in other medical fields have also confirmed that perceptions of HRQOL are dependent on the reporter. For example, Tamim et al. [16] used a visual analog scale to compare agreement between the HRQOL reported by older people discharging from emergency departments with that reported by their caregivers. The agreement between reported HRQOL was significantly lower for caregivers who had less contact with their patients than for those who lived with or were in daily contact with older people. Similarly, Hays et al. [17] found that the degree of agreement between HRQOL self-assessed by adult epilepsy patients and proxy-reports (by a relative, friend, or other significant person) was related to educational attainment of the patients and the reporters.

HRQOL is also influenced by several factors. Predictors of HRQOL in children with brain tumors include the child's age, age at diagnosis, gender, tumor location, tumor malignancy, relapse, treatment intensity, treatment status, and time since diagnosis [18–22]. Several demographic characteristics (child's age, age at diagnosis, gender) may affect the child's personal perception and expectation about HRQOL but not their HRQOL directly. Similarly, current life status (treatment status, time since diagnosis) may affect the child's or parents' personal perception and expectation about HRQOL but not the child's HRQOL directly.

These studies indicate that reported HRQOL can be influenced by physical, psychological, and sociodemographic characteristics, which may be unrelated to the condition. Further, rater-dependent (of each child's and parent's) perceptions of HRQOL can be influenced by health and sociodemographic characteristics.

We define "children's or parents' perception about the child's HRQOL" as each child's or parent's reporting bias, which is measured as a rater-dependent variance of reported HRQOL scores. Children's or parents' perception is their personal tendency to score an HRQOL questionnaire higher or lower than their parents or child, irrespective of objective measures of the child health. As a result, a child or a parent may score the child's HRQOL differently, even though the child's health condition is the same.

However, which predictors influence the child's or the parent's perception about HRQOL in children with brain tumors remains unclear. A better understanding of the influence of perception would enable more relevant interpretation of the HRQOL score reported by children and parents.

At present, little data are available on the differences between self- or interviewer-administered child-reports for children with brain tumors. Ideally, a person surveying children should be able to choose freely between either method of administration: while self-administered child-reporting may be less expensive, interviewer-administered child-reporting may be useful for children with complications from brain tumors. If these methods can be shown not to differ, then either can be selected for use in measuring HRQOL.

In a previous study using the PedsQL™ Brain Tumor Module, Palmer et al. [23] found no statistically significant difference between self- and interviewer-administered PedsQL™ scores or between parent scores of self-administered children and interviewer-administered children. However, whether or not this finding was clinically significant remains unclear, as Palmer's study was not primarily aimed to compare self- and interviewer-administered scores. It is important to describe the difference between the PedsQL™ self- and interviewer-administered reports.

Here, we investigated the influence of child and parent health, parent socio-demographic characteristics, and report-administration method on the child and parent perceptions about HRQOL (Fig. 1). We hypothesized that a child's perception about their own HRQOL was related to trait anxiety, a parent's perception about their child's HRQOL was related to psychological distress, and a child's perception was not related to the report-administration method (child self- or interviewer administered-reporting).

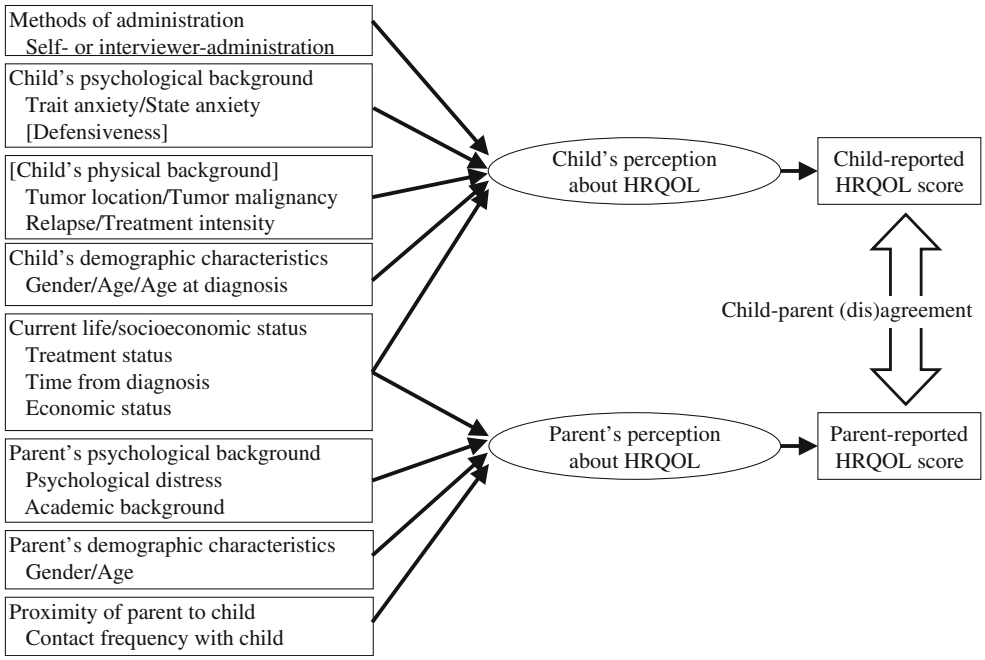


**Fig. 1** Conceptual framework for organizing the factors that influence child and parent agreement. [Bracketed factors] were not measured in this study. *HRQOL* health-related quality of life

The following variables were considered as covariate to the above relationships: child's interviewer, state anxiety, age, gender, age at diagnosis, time from diagnosis, treatment status, and parent's age, gender, academic background, time with child per day, and subjective opinion regarding their economic status.

## Methods

This study was conducted as part of the development of the Japanese version of the PedsQL™ Brain Tumor Module [24].

### Study population

Children with brain tumors and their parents were recruited from six hospitals across Japan and from the Children's Cancer Association of Japan (CCAJ), a non-profit organization established in 1968, which supports children with cancer and their families, between September and December 2008. A child and one parent were included if the child was aged 5–18 years (age range covered by PedsQL™). Families were included if at least 1 month had passed since the child's brain tumor diagnosis and excluded if hospital doctors or social workers of the CCAJ determined that the family found the subject of the child's condition too uncomfortable to discuss.

### Procedure

Researchers presented information about the study to 101 families in participating hospitals orally and in writing. Of these, 98 families elected to participate. At the CCAJ, a written description of the study was given to all families invited to a meeting regarding brain tumors, to which 45 families responded. In total, questionnaires were accordingly distributed to 143 families.

Parents were asked to determine, when providing informed consent, whether their child was able to self-administer the questionnaire. In accordance with the PedsQL™ administration guidelines [11], children aged 5–7 years and those determined to be incapable of self-administration were given the questionnaire by an interviewer, who was either a researcher or, if the child wanted the questionnaire to be administered at home, one of their parents. The parent-report questionnaires were self-administered by one of the parents, but we asked parents and children not to report in concert. If a child was administered the questionnaire by the parent, we asked the parent to complete the parent-report and then administer the child-report.

After distribution, 138 of the 143 families returned questionnaires. The background of the five families who did not respond is unknown. We excluded questionnaires from four families (four children and one parent) who answered less than 50% of items in one or more subscales.

The missing subscales were as follows: cognitive problems subscale for one child, pain and hurt for two children, movement and balance for two children, procedural anxiety for two children, nausea for two children and one parent, and worry for two children and one parent. Therefore, answers from a total of 134 families were analyzed. The children from the four excluded families were 3 boys and 1 girl aged 6–8 years who had been off treatment for 12-53 months.

### Ethical considerations

This study was approved by the review boards of all seven participating institutions. For children aged 13 or over, informed consent from both the child and the parent was required prior to participation. For children aged 12 or under, informed verbal assent from the child and informed written consent from the parent was required.

### Measurements

Child HRQOL was measured by the PedsQL™ Brain Tumor Module. The PedsQL™ Brain Tumor Module [23, 24] measures disease-specific HRQOL and comprises 24 items in six subscales: cognitive problems, pain and hurt, movement and balance, procedural anxiety, nausea, and worry. Children and parents were asked, on separate questionnaires, to describe the extent to which each item had troubled the child over the previous 7 days. For example: Item 1 of the child questionnaire stated "It is hard for me to figure out what to do when something bothers me," with the possible responses of 0 = never, 1 = almost never, 2 = sometimes, 3 = often, 4 = almost always. All subscale scores were calculated in reverse and linearly transformed so that the minimum score was 0 and maximum score was 100, with higher scores indicating a higher HRQOL. Cronbach's alpha coefficients [25] for the subscales for child- and parent-reports in the current study were 0.83 and 0.92 (cognitive problems), 0.52 and 0.78 (pain and hurt), 0.77 and 0.91 (movement and balance), 0.82 and 0.95 (procedural anxiety), 0.84 and 0.94 (nausea), and 0.75 and 0.86 (worry), respectively. Internal consistency in most subscales was considered sufficient, as Cronbach's coefficient alpha values exceeded 0.70 [25].

Global HRQOL was measured by the PedsQL™ Generic Core Scales [11, 26]. The instructions and scoring method are identical to the PedsQL™ Brain Tumor Module. Cronbach's alpha coefficients for the child- and parent-reports were 0.91 and 0.93, respectively.

State- and trait-anxiety of children were measured using the State-Trait Anxiety Inventory for Children (STAIC) [27, 28]. Children aged 8 years or over were asked to complete the questionnaire, with a higher score indicating increased anxiety. Cronbach's alpha coefficients for state- and trait-anxiety scales were 0.89 and 0.89, respectively.

Psychological distress of a parent was measured by the Kessler-10 (K10) questionnaire [29, 30]. The parent was asked to describe the frequency with which they experienced mood or anxiety symptoms over the past 30 days, with higher scores indicating higher psychological distress in relation to depression and anxiety. Cronbach's alpha coefficient for this questionnaire was 0.92.

The parent was also asked to describe their child's age, gender, tumor pathology, age at diagnosis, experience with treatment, their economic status, age, relationship to the child, academic background, and time spent with the child per day.

### Statistical analyses: model for analysis

In the first step of the analysis, each child's perception, and each parent's perception about the child's HRQOL, was calculated by a multitrait-multimethod (MTMM) model [31].

MTMM models are used for quality of life research [32, 33] to test the validity of measures of multiple traits assessed by multiple raters. Here, we used a MTMM model to identify how child- and parent-reported scores of all six PedsQL™ Brain Tumor Module subscales differed. The MTMM model is known to be capable of separating variation in child- and parent-reported HRQOL scores into variation derived from the method and that derived from a trait [32]. The MTMM model also enables the division of HRQOL scores into rater-dependent perception and rater-independent condition. For example, a previous study of HRQOL using the TACQOL questionnaire with seven subscales found that children and parent scores were determined by rater-independent (38–73%) and rater-dependent (0–30%) latent factors [32].

In the present study, the HRQOL of each child was assessed by two raters: the child and one parent. The score for each HRQOL subscale was determined by two elements (Fig. 2) based on the perception of the child or the parent as well as the child's condition. Given that perceptions can differ between the child and parent, the child's perception is one element determining the child-reported scores of the six HRQOL subscales, while the parent's perception is one determining the parent-reported scores for the HRQOL subscales. The other element that determines both child-reported and parent-reported scores is the rater-independent condition, that is, a part of the child's function or health status that is recognized by both the child and the parent. These two elements—each rater's perception about HRQOL and the rater-independent condition of each aspect of HRQOL (for example, pain and hurt)—determine the rater reported score for each of the six subscales (Fig. 2).

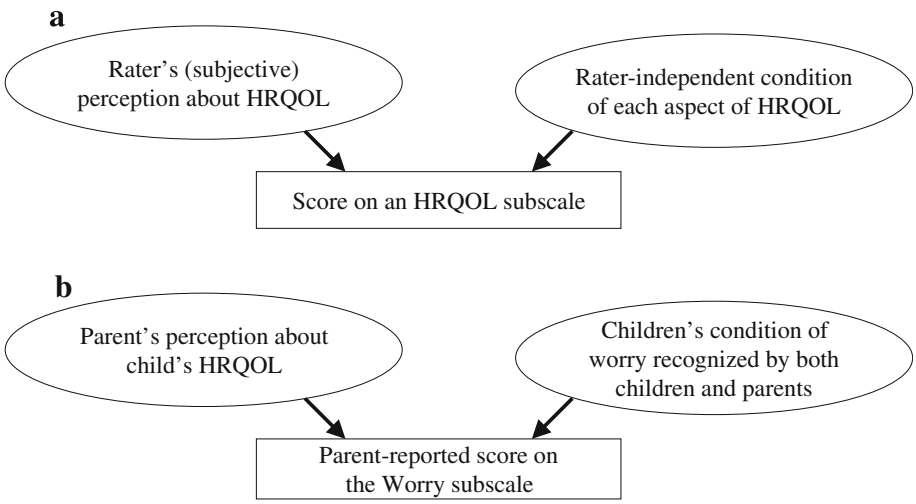


**Fig. 2** **a** Two latent variables that determine the score on a health-related quality of life (HRQOL) subscale. **b** Example of two latent variables that determine parent-reported score on the Worry subscale in the Pediatric Quality of Life Inventory Brain Tumor Module

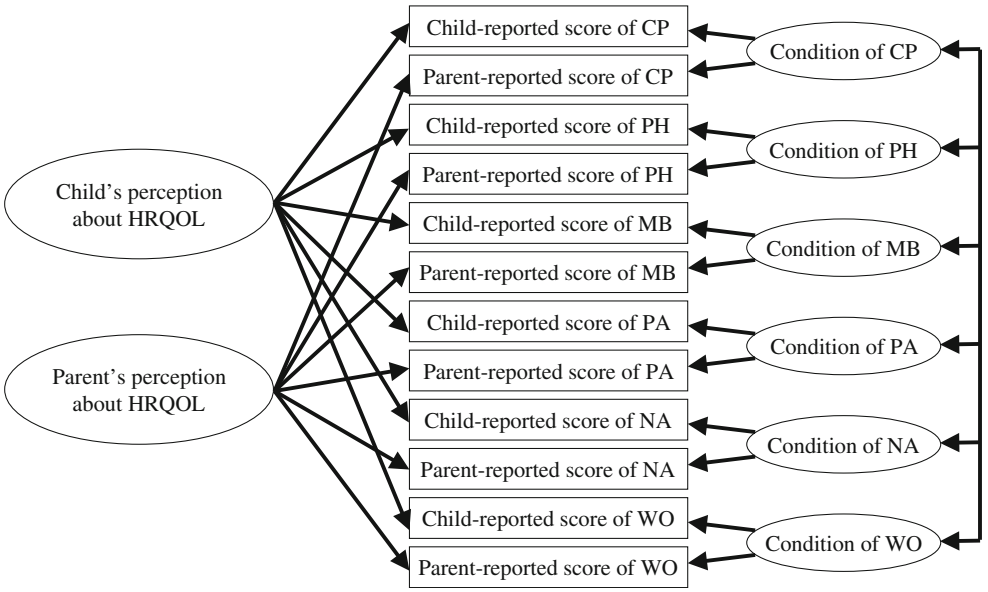


**Fig. 3** Multitrait-multimethod model for Pediatric Quality of Life Inventory (PedsQL) Brain Tumor Module. Unique factors are not displayed. Pediatric Quality of Life Inventory (PedsQL) Brain Tumor Module has six subscales: *CP* cognitive problems, *PH* pain and hurt, *MB* movement and balance, *PA* procedural anxiety, *NA* nausea, *WO* worry

The MTMM model combines each subscale score (Fig. 3) into an independent element as either child's or parent's perception, thereby enabling calculation of perception from either child- or parent-reported scores. The MTMM model was tested via structural equation modeling (SEM) using a maximum-likelihood approach to derive parent and child perceptions from all six subscales in PedsQL™ Brain Tumor Module.

In previous research using an HRQOL measurement with seven subscales (the TACQOL), SEM confirmed that the MTMM model adequately explained child- and parent-reported scores [32]. We believe that SEM can also be used to validate the MTMM model for child- and parent-reported HRQOL scores and to calculate child- and parent-perception scores derived from the PedsQL™ Brain Tumor Module. Here, we tested the validity of the MTMM model via goodness-of-fit indices: model chi-squared $P > 0.05$, normed fit index (NFI) $> 0.90$, comparative fit index (CFI) $> 0.90$, standardized root mean squared residual (SRMR) $< 0.06$, and root mean square error of approximation (RMSEA) $< 0.06$ [34].

The latent scores of the child's and parent's perception about HRQOL were then estimated from the reported scores of each subscale and the factor score weight derived from the SEM. We decided to calculate the perception scores using PedsQL™ Brain Tumor Module. An exploratory factor analysis found that HRQOL derived from the PedsQL™ Brain Tumor Module may be separated into six

factors corresponding to the six subscales [24], and the total score of the brain-tumor subscales cannot be calculated. It follows then that the calculated perception scores indicate whether parents or children tend to score HRQOL high or low rather than the absolute value of children's HRQOL resulting from brain-tumor symptoms. In other words, the calculated perception scores are measuring perception, not HRQOL.

To confirm that the model effectively discriminates perception and condition, we assessed convergent and discriminant validity using the global HRQOL score of the PedsQL™ Generic Core Scales. Both the child- and parent-reported global HRQOL will be correlated with the children's HRQOL resulting from brain-tumor symptoms. The child-reported global HRQOL will also be correlated with child's reporting tendency, but uncorrelated with parent's tendency. Parent-reported global HRQOL will be correlated with parent's reporting tendency about their child's HRQOL, although uncorrelated with their child's tendency.

In the present study, the correlation of the calculated perception scores with the PedsQL™ Generic Core Scales (child's perception and self-reported global HRQOL; parent's perception and the parent-reported global HRQOL) was assessed using Spearman's rank correlation coefficient. We expected a correlation between the child's perception and the child-reported global HRQOL and a correlation between the parent's perception and the parent-reported global HRQOL, but did not expect a correlation between the parent's perception and the child-reported global HRQOL, or between the child's perception and the parent-reported global HRQOL. If there is a correlation between either reporter's (child or parent) calculated perception and the other reporter's (child or parent) reported HRQOL, we should conclude that the calculation cannot be estimating perception because the calculated scores may depend on the absolute value of the HRQOL.

### Statistical analyses: regressions of perceptions about HRQOL

In the second step of the analysis, the factors that influence each child's or parent's perceptions were analyzed by multiple linear regression. Factors related to each child's perception about HRQOL and the parent's perception about their child's HRQOL were then identified by bivariate and multivariate correlation. The bivariate correlations were tested by Spearman's rank correlation coefficient, and the multivariate correlations were tested by the standardized partial regression coefficient from multiple linear regression analysis. A child's perception was treated as a dependent variable, and the following variables were treated as independent: method of administration, interviewer; child's trait anxiety, state anxiety, age, gender, age at diagnosis, time from diagnosis, and treatment status; and parent's subjective opinion regarding economic status and life. Given that we did not measure trait- or state-anxiety of children under 8 years of age, these data were not included in the multiple regression analysis, and regression for perception about children aged 5–7 years was recalculated excluding method of administration, child's trait anxiety, and state anxiety from independent variables.

In a second regression analysis, parents' perception was treated as a dependent variable, and the following variables as independent: parent's psychological distress, age, gender, academic background, time with child per day, subjective opinion regarding economic status and life, and child's treatment status. Missing values in the regression analyses were considered by list-wise case deletion, and independent variables were selected by a step-down procedure, mounted in SPSS software. This procedure was considered necessary, as when all independent variables were selected, the variables were multi-collinear and therefore regression could not be feasibly interpreted. Multi-collinearity was eliminated by removing causative variables one at a time. Regression analysis was then iterated, and after each successive calculation, the variable with the largest probability-of-$F$ value was removed, until the probability-of-$F$ value of all remaining variables was $\leq 0.1$.

As a complementary step, we conducted a sensitivity analysis for the selected variables (related to child's or parent's perception) to assess the difference between child- and parent-reported HRQOL scores. Descriptive statistics (mean and standard deviation [SD]) of the differences between and Pearson's correlation coefficient for child- and parent-reported HRQOL were calculated for mean score of the six subscales of PedsQL™ Brain Tumor Module. We also conducted a multiple linear regression to confirm that the selected variables were related to the difference between child- and parent-reported HRQOL.

### Statistical analyses: differences between self- and interviewer-administered child-reports

In the third step of the analysis, we used path analysis [35] to estimate the points difference between self- and interviewer-administered PedsQL™ child-reported scores. While ideally both types of administrations would be compared via a randomized sequence of administration, we considered this an excessive burden on the children with brain tumors. However, a simple comparison of self- and interviewer-administered HRQOL scores is likely to be biased; in that, interviewer-administered scores tend to be lower than self-administered scores because parents ask for interviewer-administration when their child presents with difficulties, such as visual impairment, motor dysfunction, or cognitive deficit.

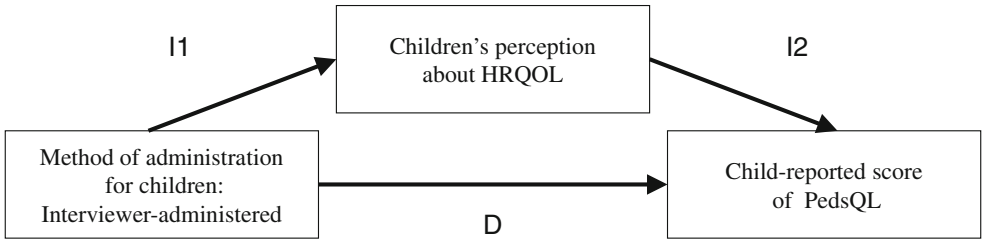


**Fig. 4** Path analytic model to split the effect of the method of administration to child-reported HRQOL in two ways. Unique factors are not displayed. *D* direct effect; *I1*, *I2* subset of indirect effect

Bearing the above constraints in mind, we tested the direct and indirect effect of administration method on the children's perception about their own HRQOL (Fig. 4). An "indirect effect" was defined as a change in a child-reported HRQOL score that occurs when interviewer-administration changes the child's perception about HRQOL. A large indirect effect indicates a specific reporting bias by interviewer-administration that increases or decreases child-reported HRQOL. A "direct effect" was defined as a difference in child-reported HRQOL between self- and interviewer-administered scores, regardless of the perception. A larger direct effect indicates larger between-group differences in HRQOL condition, regardless of difference in perception.

For each PedsQL™ Brain Tumor Module subscale, we estimated three path coefficients and their standard error using path analysis [35]. The direct effect is the path from the method of administration to the child-reported scores of PedsQL™ (D in Fig. 4), and the indirect effect is the path from the method of administration to the children's perception about HRQOL (I1 in Fig. 4) times the path from the children's perception about HRQOL to the child-reported scores of PedsQL™ (I2 in Fig. 4). We also calculated 95% confidence intervals (CIs) for the direct and indirect effects [36].

All analyses were performed using SPSS software, version 12.0 J (SPSS, Inc., Chicago, Illinois, USA) and AMOS software, version 5.0 (SPSS, Inc., Chicago, Illinois, USA), and the level of significance was set at 0.05.

## Results

### Sample characteristics

The median age of the children was 11.0 years (Table 1). The sample was heterogeneous with respect to tumor pathology and treatment experience: the largest groups were embryonal tumors, germ cell tumors, and low-grade gliomas. Median time from diagnosis was 37 months, and 53 children (39.6%) were still under treatment. The other 81 children (61.8%) had completed treatment, and the interval from completion of treatment to the survey was 0.1–13.3 years. Of the responses from 106 children aged 8–18 years, 89 (84.0%) surveys were self-administered, and 17 (16.0%) were interviewer-administered (two with difficulty understanding the questionnaire, one with difficulty sustaining attention, two with difficulty reading, seven with optical impairment, two with difficulty writing by hand, one with both optical impairment and difficulty writing by hand, and two experiencing fatigue). All 28 children aged 5–7 years received interviewer-administered surveys.

Most parents were mothers ($n = 126$, 94.0%), with a median age of 41.0 years; 51 (38.9%) were high school graduates, and 80 (61.1%) were college or university graduates, while 84 (63.6%) considered their economic status to be affluent.

### Measurement of HRQOL

The MTMM model for the PedsQL™ Brain Tumor Module was tested by the chi-squared $P = 0.087$ ($\chi^2 = 36.43$, degrees of freedom = 27), NFI = 0.932, CFI = 0.978, SRMR = 0.053, and RMSEA = 0.054, showing that the model was valid and enabling calculation of latent scores of children's and parent's perception about HRQOL. The child and parent scores were determined based on each child's or parent's perception (2–45%) and rater-independent condition (7–98%) (Table 2). A significant correlation was noted between the calculated scores of the children's perception about HRQOL and the child-reported—but not the parent-reported—global HRQOL ($r = 0.55$, $P < 0.001$ vs. $r = 0.07$, $P = 0.404$) (Table 3). Similarly, parents' perception about HRQOL was correlated with the parent-reported—but not the child-reported—global HRQOL ($r = 0.49$, $P < 0.001$ vs. $r = 0.10$, $P = 0.251$).

### Factors related to children's and parent's perception

The difference in children's perception between self- and interviewer-administered reports was not significant ($P > 0.05$) (Table 4). In the multivariate analysis, the step-

**Table 1** Subject characteristics ($N = 134$)

| | Number of respondents ($n$) | % of total | Mean | SD | Median | Range |
|---|---|---|---|---|---|---|
| Age of children at survey (years) | 134 | | 11.1 | 3.7 | 11.0 | 5–18 |
| Age at diagnosis (years) | 134 | | 7.3 | 4.5 | 7.0 | 0–18 |
| Time from diagnosis (months) | 134 | | 45.8 | 41.6 | 37.0 | 1–202 |
| Gender | | | | | | |
| Male | 73 | 54.9 | | | | |
| Female | 60 | 45.1 | | | | |
| Tumor pathology | | | | | | |
| Embryonal tumors | 39 | 29.5 | | | | |
| Germ cell tumors | 35 | 26.5 | | | | |
| Low-grade glioma | 31 | 23.5 | | | | |
| High-grade glioma | 15 | 11.4 | | | | |
| Other | 12 | 9.1 | | | | |
| Treatment status | | | | | | |
| On treatment | 53 | 39.6 | | | | |
| Off treatment | 81 | 60.4 | | | | |
| Time from treatment end (months) | 79 | | 44.7 | 37.1 | 34.0 | 1–160 |
| Treatment received | | | | | | |
| None | 2 | 1.5 | | | | |
| Surgery ($S$) | 15 | 11.2 | | | | |
| Radiation ($R$) | 0 | 0.0 | | | | |
| Chemotherapy ($C$) | 3 | 2.2 | | | | |
| $S + R$ | 13 | 9.7 | | | | |
| $S + C$ | 18 | 13.4 | | | | |
| $R + C$ | 4 | 3.0 | | | | |
| $S + R + C$ | 79 | 59.0 | | | | |
| Relationship of parent to child | | | | | | |
| Mother | 126 | 94.0 | | | | |
| Father | 6 | 4.5 | | | | |
| Grandmother | 1 | 0.7 | | | | |
| Grandfather | 1 | 0.7 | | | | |
| Age of parents at survey (years) | 133 | | 41.0 | 5.5 | 41.0 | 26–63 |
| Academic background of parents | | | | | | |
| High schools | | | | | | |
| Junior high school | 1 | 0.8 | | | | |
| Senior high school | 50 | 38.2 | | | | |
| Colleges and universities | | | | | | |
| Vocational college | 25 | 19.1 | | | | |
| Junior college | 24 | 18.3 | | | | |
| University (undergraduate) | 30 | 22.9 | | | | |
| University (graduate) | 1 | 0.8 | | | | |
| Parents' time with children (hours per a day) | 132 | | 13.1 | 6.5 | 14.0 | 1–24 |
| Subjective opinion regarding parents' own economic status and life | | | | | | |
| Affluent | 84 | 63.6 | | | | |
| Not affluent | 48 | 36.4 | | | | |
| Method of administration for children | | | | | | |
| Self-administered | 89 | 66.4 | | | | |
| Interviewer-administered | | | | | | |
| Interviewed by researcher | 31 | 23.1 | | | | |

**Table 1** continued

| | Number of respondents (*n*) | % of total | Mean | SD | Median | Range |
|---|---|---|---|---|---|---|
| Interviewed by parent | 14 | 10.4 | | | | |
| State anxiety score of STAIC[a] (20–60) | 104 | | 29.9 | 7.8 | 29.0 | 20–52 |
| Trait anxiety score of STAIC[a] (20–60) | 97 | | 34.9 | 8.8 | 36.0 | 20–52 |
| K10[b] score (0–40) | 132 | | 7.7 | 7.0 | 6.0 | 0–31 |
| PedsQL global HRQOL score[c] (0–100) | | | | | | |
| Self-reported | 132 | | 77.7 | 17.2 | 80.4 | 11–100 |
| Parent-reported | 134 | | 73.7 | 17.0 | 75.0 | 20–100 |

Missing data were excluded

*HRQOL* health-related quality of life, *SD* standard deviation

[a] State Trait Anxiety Inventory for Children. A higher score indicates that children have higher anxiety

[b] Kessler-10. A higher score indicates that parents have higher psychological distress

[c] Pediatric Quality of Life Inventory Generic Core Scales. A higher score indicates that children have higher quality of life

**Table 2** Percentage-explained variance in an MTMM model of HRQOL ($N = 134$)

| Subscales of PedsQL brain tumor module | Condition | Perception | Error |
|---|---|---|---|
| Cognitive problems | | | |
| Child | 30 | 27 | 43 |
| Parent | 71 | 6 | 24 |
| Pain and hurt | | | |
| Child | 35 | 8 | 57 |
| Parent | 41 | 12 | 47 |
| Movement and balance | | | |
| Child | 45 | 23 | 32 |
| Parent | 96 | 3 | 1 |
| Procedural anxiety | | | |
| Child | 98 | 2 | 0 |
| Parent | 41 | 5 | 54 |
| Nausea | | | |
| Child | 95 | 5 | 0 |
| Parent | 43 | 19 | 37 |
| Worry | | | |
| Child | 48 | 14 | 38 |
| Parent | 7 | 45 | 48 |

*HRQOL* health-related quality of life, *MTMM* multitrait-multimethod, *PedsQL* Pediatric Quality of Life Inventory

down procedure excluded the method of administration as an independent variable related to the children's perception.

Trait anxiety was the strongest factor related to children's perception ($r = -0.46$, $b = -0.43$). Children with higher trait anxiety had lower perception about HRQOL ($P < 0.05$). Older children or children from less affluent families also had a lower perception, but these results were not statistically significant. Bivariate analysis showed that children with higher state anxiety had a lower perception about HRQOL; however, this result was not confirmed on multivariate analysis and was therefore determined to be a spurious correlation. This indicates that the relationship between state anxiety and a child's perception is superficial. This relationship was clarified by conducting a staged analysis to identify which covariates attenuated the relationship (Table 5), which found that trait anxiety attenuated the relationship.

With regard to children aged 5–7 years, none of the variables tested were found to be significantly correlated with the children's perception; the strongest relationship was "interviewer" ($r = -0.27$, $P = 0.162$, $n = 28$). Children interviewed by a parent tended to have a lower perception about HRQOL than children interviewed by researcher.

The strongest factor influencing a parent's perception was treatment status (Table 6). The parents of children on treatment had a tendency to report that their child had a

**Table 3** Correlation between calculated scores of perception and reported global HRQOL ($N = 134$)

| | Child-reported global HRQOL | | Parent-reported global HRQOL | |
|---|---|---|---|---|
| | *r* | *P* | *r* | *P* |
| Calculated scores of child's perception about HRQOL | 0.55 | <0.001 | 0.07 | 0.404 |
| Calculated scores of parent's perception about HRQOL | 0.10 | 0.251 | 0.49 | <0.001 |

*HRQOL* health-related quality of life, *r* Spearman's rank correlation coefficient

**Table 4** Factors related to calculated scores of children's perception about HRQOL ($N = 134$)

| | *n* | *r* | 95% CI | *b* | 95% CI |
|---|---|---|---|---|---|
| Trait anxiety score of STAIC[a] | 97 | −0.46* | (−0.60, −0.29) | −0.43* | (−0.60, −0.25) |
| State anxiety score of STAIC[a] | 104 | −0.27* | (−0.44, −0.08) | – | |
| Age at survey | 133 | −0.14 | (−0.30, 0.03) | −0.17 | (−0.35, 0.01) |
| Age at diagnosis | 134 | 0.01 | (−0.16, 0.18) | – | |
| Time from diagnosis | 134 | −0.09 | (−0.26, 0.08) | – | |
| Gender (0: Male, 1: Female) | 133 | 0.02 | (−0.15, 0.19) | – | |
| Treatment status (0: on treatment, 1: off treatment) | 134 | −0.06 | (−0.23, 0.11) | – | |
| Subjective opinion regarding parents' own economic status and life (0: not affluent, 1: affluent) | 132 | 0.07 | (−0.10, 0.24) | 0.16 | (−0.01, 0.34) |
| Method of administration for children (0: self-administered, 1: interviewer-administered) | 134 | −0.06 | (−0.23, 0.11) | – | |
| Dummy-coded variable for comparison between researcher interviews and parent interviews | | | | | |
| Researcher interviews[b] | 134 | 0.03 | (−0.14, 0.20) | – | |
| Parent interviews[c] | 134 | −0.13 | (−0.29, 0.04) | – | |

*HRQOL* health-related quality of life, *CI* confidence interval, *r* Spearman's rank correlation coefficient, *b* Standardized partial regression coefficient by multiple linear regression analysis ($n = 96$, $R^2 = 0.264$)

* $P < 0.05$

– variables not selected by step-down procedure

[a] State Trait Anxiety Inventory for Children. A higher score indicates that children have higher anxiety

[b] 0: self-administered or parent-administered, 1: researcher-administered

[c] 0: self-administered or researcher-administered, 1: parent-administered

**Table 5** Factors that attenuate the relationship between children's state anxiety and lower perception about HRQOL ($N = 96$)

| | *b* | *b* | *b* | *b* | *b* |
|---|---|---|---|---|---|
| State anxiety score of STAIC[a] | −0.29* | −0.12 | −0.24* | −0.26* | −0.06 |
| Trait anxiety score of STAIC[a] | | −0.40* | | | −0.39* |
| Age at survey | | | −0.17 | | −0.17 |
| Subjective opinion regarding parents' own economic status and life (0: not affluent, 1: affluent) | | | | 0.11 | 0.14 |

*HRQOL* health-related quality of life, *b* Standardized partial regression coefficient by multiple linear regression analysis

* $P < 0.05$

[a] State Trait Anxiety Inventory for Children. A higher score indicates higher anxiety

lower HRQOL than those of children who were off treatment. The parents with higher K10 scores who were high school graduates also had a lower perception about their child's HRQOL lower than those parents with lower K10 scores who were college or university graduates. Other variables (age, gender, time with the child per day, and subjective opinion regarding economic status and life) had no influence on a parent's perception about HRQOL.

The sensitivity analysis identified significant differences in the following parameters between child- and parent-reported scores: trait anxiety, parent's psychological distress, treatment status, or academic background of parents (Table 7). Children with elevated trait anxiety rated their HRQOL much lower on average, thereby reducing the difference between child- and parent-reported scores (Fig. 5). Parents with elevated K10 scores, those of children on treatment, and those who were high school graduates also scored their child's HRQOL much lower than did their children themselves, thus increasing the difference between child- and parent-reported scores. Multiple regression analysis also demonstrated that the child's trait anxiety and parent's K10 score were related to the differences between child- and parent-reported HRQOL (Table 8). The relationship between these differences and the child's treatment status and parent's academic background was not statistically significant.

## Differences between self- and interviewer-administered child-reports

The method of administration induced indirect effects, which resulted in a decrease of 1.1–2.5 points in child-

**Table 6** Factors related to calculated scores of parents' perception about child's HRQOL ($N = 134$)

| | *n* | *r* | 95% CI | *b* | 95% CI |
|---|---|---|---|---|---|
| K10 score[a] | 132 | −0.24* | (−0.40, −0.07) | −0.21* | (−0.37, −0.04) |
| Treatment status (0: on treatment, 1: off treatment) | 134 | 0.36* | (0.20, 0.50) | 0.26* | (0.09, 0.43) |
| Gender of parents (0: Male, 1: Female) | 134 | 0.05 | (−0.12, 0.22) | – | |
| Age of parents at survey | 133 | −0.14 | (−0.30, 0.03) | – | |
| Academic background of parents (0: high schools, 1: colleges and universities) | 131 | 0.16 | (−0.01, 0.32) | 0.17* | (0.00, 0.34) |
| Parents' time with children per a day | 132 | −0.04 | (−0.21, 0.13) | – | |
| Subjective opinion regarding parents' own economic status and life (0: not affluent, 1: affluent) | 132 | 0.14 | (−0.03, 0.30) | – | |

Missing data were excluded

*HRQOL* health-related quality of life, *CI* confidence interval, *r* Spearman's rank correlation coefficient, *b* Standardized partial regression coefficient by multiple linear regression analysis

* $P < 0.05$

– variables not selected by step-down procedure

[a] Kessler-10. A higher score indicates that parents have higher psychological distress

**Table 7** Descriptive statistics of the differences and correlation between child- and parent-reported HRQOL ($N = 134$)

| | *n* | HRQOL[a] | | | | Difference[b] | 95% CI | | Pearson's correlation coefficient |
|---|---|---|---|---|---|---|---|---|---|
| | | Child-reported | | Parent-reported | | | | | |
| | | Mean | SD | Mean | SD | | | | |
| Trait anxiety score of STAIC[c] | | | | | | | | | |
| Less than 36 (median) | 48 | 85.8 | 10.2 | 77.1 | 14.9 | 8.7 | 4.3 | 13.2 | 0.30* |
| 36 or over | 49 | 77.3 | 12.9 | 72.2 | 15.7 | 5.2 | 1.9 | 8.5 | 0.69* |
| K10 score[d] | | | | | | | | | |
| Less than 6 (median) | 65 | 83.0 | 12.7 | 79.2 | 12.2 | 3.8 | 0.6 | 6.9 | 0.47* |
| 6 or over | 67 | 75.7 | 15.6 | 65.9 | 15.9 | 9.8 | 6.3 | 13.3 | 0.58* |
| Treatment status | | | | | | | | | |
| On treatment | 53 | 75.5 | 15.4 | 66.2 | 15.2 | 9.4 | 5.5 | 13.3 | 0.57* |
| Off treatment | 81 | 81.5 | 13.6 | 76.9 | 14.6 | 4.6 | 1.5 | 7.7 | 0.52* |
| Academic background of parents | | | | | | | | | |
| High schools | 51 | 79.1 | 13.9 | 70.1 | 14.9 | 9.0 | 2.0 | 13.0 | 0.53* |
| Colleges and universities | 80 | 78.9 | 15.2 | 74.3 | 15.7 | 4.6 | 1.7 | 7.5 | 0.64* |

Missing data were excluded

*HRQOL* health-related quality of life, *CI* confidence interval, *SD* standard deviation

* $P < 0.05$

[a] Mean of six subscale scores of PedsQL Brain Tumor Module

[b] "child-reported mean HRQOL score" minus "parent-reported mean HRQOL score"

[c] State Trait Anxiety Inventory for Children. A higher score indicates higher anxiety

[d] Kessler-10. A higher score indicates that parents have higher psychological distress

reported scores for the PedsQL™ Brain Tumor Module (Table 9). For all subscales, interviewer-administration scores were lower than child-reported scores. However, given that the 95% CIs included values of zero, the method of administration appears to have little effect on children's perception. This result was similar to that obtained on

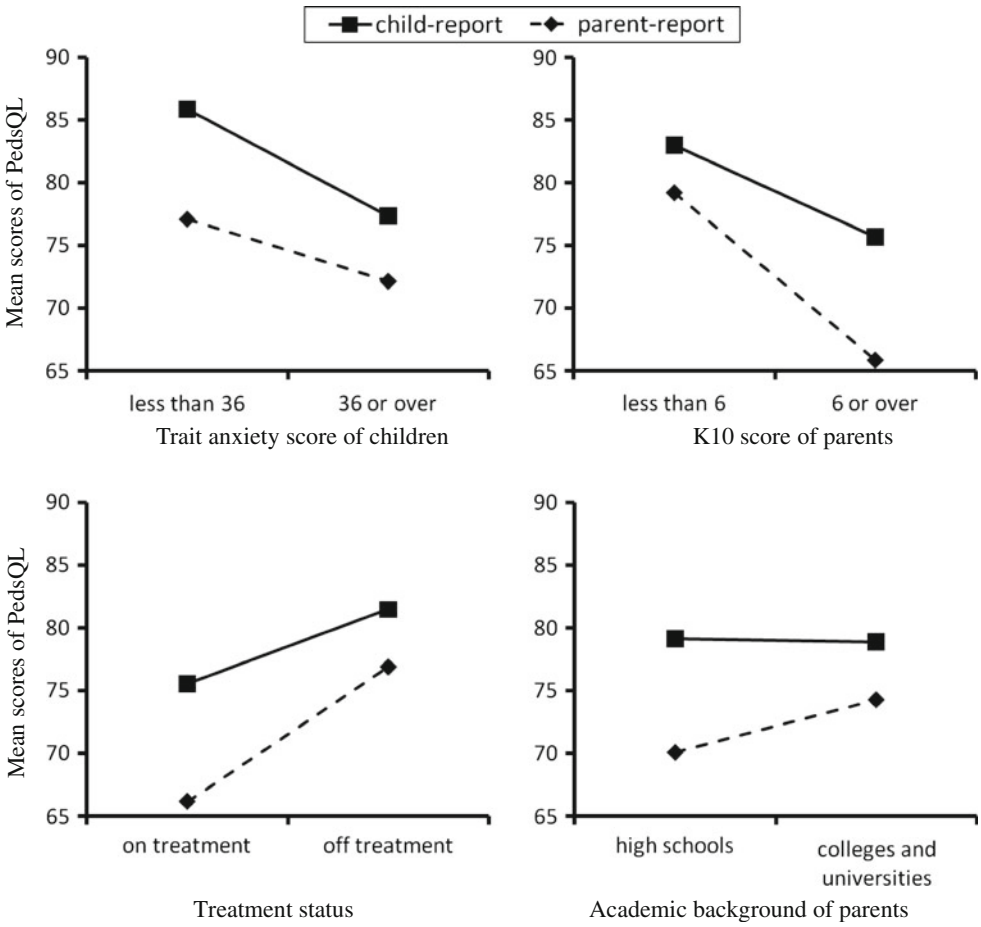


**Fig. 5** Differences between child- and parent-reported mean scores of six subscales of PedsQL Brain Tumor Module by socio-demographic and health characteristics

**Table 8** Regression of the differences[a] between child- and parent-reported HRQOL[b] ($N = 134$)

| | *n* | *r* | 95% CI | *b* | 95% CI |
|---|---|---|---|---|---|
| Trait anxiety score of STAIC[c] | 97 | −0.21* | (−0.39, −0.01) | −0.27* | (−0.47, −0.07) |
| K10 score[d] | 132 | 0.21* | (0.04, 0.37) | 0.29* | (0.09, 0.49) |
| Treatment status (0: on treatment, 1: off treatment) | 134 | −0.15 | (−0.31, 0.02) | −0.13 | (−0.33, 0.06) |
| Academic background of parents (0: high schools, 1: colleges and universities) | 131 | −0.14 | (−0.30, 0.03) | −0.13 | (−0.33, 0.06) |

Missing data were excluded

*CI* confidence interval, *HRQOL* health-related quality of life, *r* Spearman's rank correlation coefficient, *b* Standardized partial regression coefficient by multiple linear regression analysis ($n = 93$, $R^2 = 0.168$)

* $P < 0.05$

[a] "child-reported mean HRQOL score" minus "parent-reported mean HRQOL score"

[b] Mean of six subscale scores of PedsQL Brain Tumor Module

[c] State Trait Anxiety Inventory for Children. A higher score indicates higher anxiety

[d] Kessler-10. A higher score indicates that parents have higher psychological distress

analysis of factors related to children's perception (Table 4).

In contrast, children receiving interviewer-administered surveys had significantly lower scores for cognitive problems, pain and hurt, and movement and balance subscales than those who were self-administered (Table 9).

## Discussion

We show that the response of children aged 5–18 to questions on HRQOL was altered by trait anxiety, while a parent's perception about their child's HRQOL was affected by the child's treatment status and the parent's

**Table 9** Changes in child-reported HRQOL score based on method of administration ($N = 134$)

| | Direct effect | | Indirect effect | | | |
|---|---|---|---|---|---|---|
| | *D* | 95% CI | *I* | 95% CI | I1 | I2 |
| Cognitive problems | −6.4 | (−12.0, −0.8) | −2.5 | (−7.5, 2.5) | −0.14 | 18.1 |
| Pain and hurt | −7.9 | (−13.8, −1.9) | −1.3 | (−3.8, 1.3) | −0.14 | 9.2 |
| Movement and balance | −12.6 | (−19.3, −6.0) | −2.5 | (−7.6, 2.6) | −0.14 | 18.3 |
| Procedural anxiety | −8.8 | (−19.4, 1.8) | −1.1 | (−3.5, 1.3) | −0.14 | 8.1 |
| Nausea | −2.6 | (−9.8, 4.6) | −1.1 | (−3.5, 1.2) | −0.14 | 8.2 |
| Worry | −0.6 | (−8.0, 6.8) | −2.1 | (−6.4, 2.2) | −0.14 | 15.3 |

*CI* confidence interval, *HRQOL* health-related quality of life, *D* path coefficients from the method of administration to child-reported HRQOL, *I* indirect effect from the method of administration to child-reported HRQOL, *I1* path coefficients from the method of administration to children's perception, *I2* path coefficients from the children's perception to child-reported HRQOL

own psychological distress and academic background. Interestingly, children's HRQOL scores from self- and interviewer-administered reports were comparable, showing that the results from bivariate and multivariate analyses were not biased by the method of administration. This important result suggests interviewer measurement of HRQOL for children who are unable to self-administer the questionnaire is valid.

The correlation coefficient between the method of administration and tendency for children to score their own HRQOL highly was −0.06 (95% CI −0.23 to 0.11). Given that correlation coefficients >0.1 are regarded as small, >0.3 as medium and >0.5 as large [37], this finding suggests that the method of questionnaire administration has only a small effect on the assessment of children's perception.

All scales of PedsQL™ were scored from 0 to 100, and the actual difference in child-reported score resulting from administration method ranged from −2.5 to −1.1 points. The US Department of Health suggests methods for inferring minimum clinically significant difference (MID) [38]. Using an empirical rule (e.g., 8% of the theoretical range of scores), the MID in a PedsQL™ score is 8 points. Using a distribution-based approach (e.g., defining the MID as 0.5 times the standard deviation), the MID in the PedsQL™ Brain Tumor Module scores reported a range from 9.2 to 17.2 points [24]. Other authors used a standard error of measurement approach to determine the MID for the PedsQL™ Generic Core Scales child-report was 4.4 [39]. Taken together, these previous findings suggest that the difference in child-reported score resulting from administration method in the present study, while not negligible, is not comparatively significant. As such, we feel confident in adopting an administration method for monitoring HRQOL in clinical settings best adapted to the environment.

Similarly, results for previous comparisons of administration methods show small differences albeit in opposing directions. Huguet and Miro, using a Catalan version of PedsQL™, reported that interviewer-administered scores were 2 points higher than self-administered scores [40]. In their assessment of very low birth weight children aged 14 years by the TACQOL, Verrips et al. [41] found that the interviewer-administered scores were 2 points lower than the self-administered score, whereas Tsakos et al. [42] found no significant difference between self- and interviewer-administered scores for oral HRQOL. Taken together, the findings from the present and previous studies suggest little difference between self- and interviewer-administered scores for child-reporting. Differences between findings for these present and previous studies may be due to differing criteria for HRQOL measured or differences in the children's diseases. To our knowledge, our present study is the first to report that the scores of self- and interviewer-administered questionnaires for HRQOL in children with brain tumors using PedsQL™ are comparable.

Consistent with results for other children with cancer [14], we also found that trait anxiety alters children's own perception about HRQOL. As trait anxiety has a greater effect than the other factors, it should be considered in the interpretation of child-reported scores. Given that trait anxiety is one personality characteristic that does not vary substantially over time [28], if self-reported scores from repeated measurements of a child with a brain tumor are consistently lower than parent-reported scores, the measured result may be attributed to high trait anxiety of the child.

The effect of treatment status on a parent's perception about their child's HRQOL has not been previously investigated. Parents of children on treatment tended to have a lower perception about their child's HRQOL than those of children off treatment, whereas treatment status had no influence on children's perception. As a result, clinical practice or research should use both child- and parent-reports whenever possible, particularly when

HRQOL questionnaires are needed to assess HRQOL variations during the course of treatment, changes in environment, or psychosocial intervention. For example, HRQOL reports from parents and children changed at 1, 6, and 12 months after diagnosis of brain tumor [19]. The pattern of child-reported HRQOL was different from parent-reported HRQOL over time indicating the importance of using use both child- and parent-reports.

Parents may feel a stronger impact of their child's illness than the child himself or herself [43]. In previous studies, parent-reported HRQOL scores were higher than child-reported scores for children without health problems and lower than child-reported scores for children with health problems. Our study also suggests that parents are more aware of their child's treatment through knowledge of tumor symptoms and treatment pain. In other words, the parents may feel a stronger impact of their child's treatment than the child himself or herself and accordingly tend to score the HRQOL of these children lower than the parents of children off treatment.

Vance et al. [44] suggested that parent-reported HRQOL was not influenced by parent's depression. The present study, however, which had a larger sample size than previous studies, found that the parent-reported HRQOL was affected by the parent's own psychological distress. This suggests that the parent's own prospects and cognitive tendency influence their perception about their child's HRQOL.

The present study is the first to use an MTMM model to identify factors that influence child or parent perception about HRQOL. This knowledge will be useful in interpreting the discordance between child- and parent-reports of HRQOL in children with brain tumors. In clinical settings, this finding will allow clinicians to take high trait anxiety in the child or high psychological distress in the parent into account. For example, when the child is off treatment, it will be less surprising that child-reported HRQOL score is low and parent-reported HRQOL score is high if the child has low trait anxiety. Routine measurements in clinical settings thus have the potential to allow the monitoring of both the child's personality and the mental state of his/her parents. This finding will also improve the selection of children for comparison of HRQOL among multiple groups. For example, in non-randomized controlled trials, children may be allocated among groups with consideration to equality of anxiety in children and mental health in parents. Our findings also suggest that single group studies should collect information on parents' academic background as well as other demographic characteristics, such as gender, age, race, etc., that influence selection bias.

Several limitations to our study warrant mention. First, as a cross-sectional study, changes in perception over time were not tested. Accordingly, we cannot conclude that the perception of a parent or child with a brain tumor will change at the end of treatment. Clarification of intrapersonal change in perception or response shift of children with brain tumors and their parents will require a longitudinal study.

Second, we did not conduct an a priori sample size calculation because this study is a part of another study [24] that has a predetermined sample size. The effect of sample size was calculated by G*Power software [45]. If a characteristic that has a medium effect ($f^2 \geq 0.15$ [37]) on either children's or parents' perception is added to a multiple linear regression model with 3 variables, a sample of 55 would enable detection of the characteristic as the 4th independent variable with 80% power and a 5% alpha error. Similarly, a sample of 395 would be required to detect a characteristic that has a small effect ($f^2 \geq 0.02$ [37]) as the 4th independent variable. It follows that the sample size of the present study was sufficient to detect factors having a medium effect. A larger sample might discriminate additional characteristics that were not found to be statistically significant in the present study, such as children's age and economic status.

A larger sample size would also enable simultaneous modeling of responses (MTMM model, Fig. 3) and predictors (predictor model, Tables 4, 6, and Fig. 1), which might then detect any correlation between the predictors and the latent variables of rater-independent assessments of the child's condition. Further, a larger sample size should enable researchers to detect the effect of interviewer type (e.g., parent or researcher interviewer) on a child's perception. Among children aged five-to-seven and eight or more years, those interviewed by a parent tended to have a lower perception about HRQOL than those interviewed by a researcher, although this result was not statistically significant.

Third, we were unable to measure all possible factors that might influence child-parent agreement. We limited the length of our questionnaires to avoid placing further stress on the children, and therefore, measurements of the child's psychological background were limited to anxiety. Other aspects of a child's personality, such as defensiveness [14], might also influence the results, and future research should therefore investigate different personality traits. We also omitted measurements of the child's physical background, such as tumor location, tumor malignancy, relapse history, or treatment intensity [18–22]. All data in the present study were collected not from medical experts but from the children and their parents; as such, obtaining accurate, detailed answers about medical information was somewhat difficult. Additional information derived from patients with specific tumors or under specific treatment regimens will be required to identify residual confounders.

An additional constraint arises from the sample type. The present study collected data from a broad spectrum of children who had experienced brain tumors and included, for example, children diagnosed from 1 month to 17 years before the study. We could cover the broad spectrum to make up the study sample of the two subsamples. The hospitals subsample included more children with short time since diagnosis, young at survey, and on treatment than the CCAJ subsample did. To provide further insight into self- or parent-perceptions about HRQOL, further studies should focus on children at different phases of treatment or follow-up.

Families were excluded if the doctors or social workers determined that the family found the subject of the child's condition too uncomfortable to discuss. Although the number of such excluded families was not recorded, this exclusion may have limited data collection to more well-adjusted families and thereby limited the generalizability of the conclusions as well.

Finally, independent variables identified in this study accounted for 26.4% of the children's perception and 17.3% of the parents' perception. Other independent factors were not identified.

## Conclusion

The method of administration—self- or interviewer-administered—had little influence on child-reporting of HRQOL. Children's perception of their own HRQOL was influenced by their trait anxiety, while parents' perception was influenced by their psychological distress, academic background, and their child's treatment status. These factors underlie the difference between child- and parent-reported HRQOL scores.

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