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Quality of life after brain injury in children and adolescents questionnaire – validation of the proxy version (QOLIBRI-KID/ADO-Proxy)

Nicole von Steinbuechel ^{a*}, Marina Zeldovich ^{a,b*}, Ivana Holloway ^c, Anna C. Mayer ^a, Philine Rojczyk ^{d,e}, Ugne Krenz ^f, Inga K. Koerte ^{d,e}, Michaela Veronika Bonfert ^g, Steffen Berweck ^h, Matthias Kieslich ⁱ, Knut Brockmann ^j, Maike Roediger ^k, Michael Lendt ^I, Michael Staebler ^m, Christian Auer ^{n,o}, Axel Neu ^P, Alexander Kaiser ^P, Joenna Driemeyer ^q, Ulrike Wartemann ^r, Daniel Pinggera ^s, Claudius Thomé ^s, Victoria Schoen ^s, Philipp Geiger ^s, Joachim Suss ^t, Anna Buchheim ^a, Holger Muehlan ^{u,v}, and Katrin Cunitz ^a

^aInstitute of Psychology, University of Innsbruck, Innsbruck, Austria; ^bFaculty of Psychotherapy Science, Sigmund Freud University, Vienna, Austria; Leeds Institute for Data Analytics, School of Medicine, Department of Clinical and Population Sciences, University of Leeds, Leeds, UK; dCBRAIN/ Department of Child and Adolescent Psychiatry, Psychosomatics, and Psychotherapy, LMU University Hospital, Ludwig-Maximilian University, Munich, Germany; ^ePsychiatry Neuroimaging Laboratory, Department of Psychiatry, Mass General Brigham, Boston, Massachusetts, USA; ^fUniversity Medical Center Goettingen (UMG), Goettingen, Germany; ⁹Department of Pediatric Neurology and Developmental Medicine and LMU Center for Development and Children with Medical Complexity, Dr. Von Hauner Children's Hospital, LMU University Hospital, Munich, Germany; hSpecialist Center for Paediatric Neurology, Neurorehabilitation and Epileptology, Schoen Klinik, Vogtareuth, Germany; Department of Paediatric Neurology, Hospital of Goethe University, Frankfurt am Main, Germany; ^jInterdisciplinary Pediatric Center for Children with Developmental Disabilities and Severe Chronic Disorders, Department of Pediatrics and Adolescent Medicine, University Medical Center, Goettingen, Germany; ^kPediatric Cardiology, University Hospital Muenster, Muenster, Germany; Neuropediatrics, Mauritius Therapeutic Clinic, Meerbusch, Germany; "Hegau-Jugendwerk GmbH/ Neurological Rehabilitation Center for Children, Adolescents and Young Adults, Gailingen am Hochrhein, Germany; "Department of Neurosurgery, Kepler University Hospital GmbH, Linz, Austria; °Clinical Research Institute for Neurosciences, Johannes Kepler University Linz, Linz, Austria; PDepartment of Neurology and Neuropediatry, VAMED Klinik Geesthacht GmbH, Geesthacht, Germany; @Department of Pediatrics, University of Hamburg-Eppendorf, Hamburg, Germany; Department of Neuropediatrics, VAMED Klinik Hohenstücken GmbH, Brandenburg an der Havel, Germany; Department of Neurosurgery, Tirol Kliniken GmbH, Medical University Innsbruck, Innsbruck, Austria; Department of Pediatric Surgery, Wilhelmstift Catholic Children's Hospital, Hamburg, Germany: "Department of Health and Prevention, University of Greifswald, Greifswald, Germany: ^vMedical Department, HMU Health and Medical University Erfurt, Erfurt, Germany

ABSTRACT

Background: The QOLIBRI-KID/ADO-Proxy is the first disease-specific health-related quality of life (HRQoL) proxy questionnaire developed for use in the field of pediatric traumatic brain injury (TBI), when children are unable to report their HRQoL themselves.

Methods: Its psychometric properties in a German-speaking context are examined in two samples (development and validation). Dyads of 600 parents and their children (aged 8–17 years) were included. **Results:** The 35-item questionnaire covers six dimensions (Cognition, Self, Daily Life and Autonomy, Social Relationships, Emotions, and Physical Problems). Results showed good to excellent internal consistencies, acceptable test-retest reliability, and low to fair parent-child agreement. Confirmatory factor analyses supported the one-level six-factor structure. In terms of construct validity, there was an overlap between the disease-specific and the generic HRQoL. Lower parent-reported HRQoL in children was associated with lower parental education, lower functional recovery (Study I), more recent TBI, and more severe depressive, anxiety, and post-concussion symptoms. Findings differed between the two studies in terms of age, gender, and TBI severity. Study I found more severe TBI linked to lower HRQoL in adolescents, while Study II indicated lower HRQoL ratings in girls.

Conclusion: The QOLIBRI-KID/ADO-Proxy is recommended when individuals are unable to self-report their HRQoL.

Introduction

Worldwide, pediatric traumatic brain injury (TBI) impacts around 110 per 100,000 children and adolescents annually (1). Some of the children and adolescents affected face serious physical (2), cognitive (3), behavioral (4), and social (2) consequences resulting in long-term disabilities, especially after more severe TBI. Individuals experiencing functional impairment after injury often report a substantial decrease in their quality of life (5). In particular, disease-specific healthrelated quality of life (HRQoL) refers to the interaction between a person's functional status in terms of diseasespecific symptoms (6) and the emotional value that the individual places on being functionally restricted (7).

To address HRQoL specific to impairments following pediatric TBI, the Quality of Life after Brain Injury in

CONTACT Katrin Cunitz katrin.cunitz@uibk.ac.at Institute of Psychology, University of Innsbruck, Universitaetsstraße 15, Innsbruck A-6020, Austria *These authors contributed equally to this work.

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KEYWORDS

Health-related quality of life; traumatic brain injury; proxy; patient-reported outcome measure; child; adolescent Children and Adolescents (QOLIBRI-KID/ADO) instrument was developed as the first self-report disease-specific HRQoL questionnaire for children and adolescents (8–17 years) (8,9). The QOLIBRI-KID/ADO is a 35-item questionnaire covering six domains (i.e., Cognition, Self, Daily Life and Autonomy, Social Relationships, Emotions, and Physical Problems) that has been shown to be a sensitive instrument for assessing HRQoL after TBI (9). However, a proxy version of the QOLIBRI-KID/ADO is important because reliable self-report information on HRQoL may be difficult to obtain in young individuals severely impacted by TBI. In particular, TBIassociated cognitive limitations may affect a patient's ability to comprehend the constructs being measured, requiring a proxy assessment (10).

While proxy reporting is unavoidable for those unable to provide a reliable self-report, it is not necessarily an accurate reflection of the patient's health status. In fact, children's and parents' reports can differ substantially (11). Parent and child ratings of HRQoL have been found to differ, particularly for social or emotional functioning, whereas agreement is generally higher for physical health (12). Interestingly, previous studies with chronically ill children have shown that parents generally tend to rate their children's HRQoL lower than the children themselves (13). Similarly, while the concordance of self-proxy agreement with respect to psychosocial outcomes in adolescents after TBI has been reported to be generally acceptable (11), only fair to poor levels of agreement have been found particularly for covert outcomes (e.g., anxiety, depression, thinking and attention problems) after severe TBI (14). Importantly, however, these few previous studies used generic measures of HRQoL, such as the Pediatric Quality of Life Inventory (PedsQL) (15), which were designed to address a variety of health problems, while neglecting TBI-specific symptoms. Nevertheless, these findings suggest that HRQoL should be assessed by proxies only when children are truly unable to self-report.

Analyses using data from the QOLIBRI-KID/ADO-Proxy instrument may help to identify individuals at risk for significantly reduced HRQoL following pediatric TBI. Previous literature has shown that the experience of TBI is associated with the development of several mental health problems, including depression and anxiety (16). Furthermore, a reduction in HRQoL has been described to be associated with the experience of persistent post-concussion symptoms (PCS) in both self-report and proxy assessments after TBI (17). In addition, lower HRQoL is often associated with female sex (18), older age (6), greater severity (13), poorer functional recovery (19), lower socioeconomic status (20), and single-parent housing (21) in children and adolescents after TBI. Understanding the relationship between neuropsychiatric symptoms, as well as sociodemographic and clinical factors, and HRQoL is crucial for the implementation of personalized clinical interventions aimed at improving the physical recovery and psychological well-being of individuals after pediatric TBI.

To fill the gap in the availability of instruments assessing TBI-specific HRQoL in children and adolescents from a proxy perspective, this paper aims to present the results of the pilot and the final validation study of the QOLIBRI-KID/ADO-Proxy questionnaire developed first in the German language context. Its psychometric properties, reliability, and validity are investigated using a second independent German pediatric TBI sample. In addition, the influence of various sociodemographic and clinical factors on HRQoL in children and adolescents will be examined. Specifically, child and parental sociodemographic data, including age, gender, and education, will be related to proxy ratings of child and adolescent HRQoL and symptoms of anxiety, depression, and post-concussion. By considering these aspects, we aim to provide a comprehensive understanding of the multifaceted factors that influence HRQoL in children and adolescents after TBI.

Both the pilot and the final validation study of the QOLIBRI-KID/ADO as a self-report questionnaire showed good psychometric properties (8,9), suggesting that the instrument is well suited to assessing the impact of TBI on self-reported HRQoL. The QOLIBRI-KID/ADO-Proxy version is therefore expected to have good psychometric characteristics. In addition, significant findings are expected concerning associations between children's characteristics (age, sex, TBI severity, time since injury, parental education) and HRQoL and a lower consensus between parent and child ratings of HRQoL. These findings will further our understanding of the efficacy of proxy reports after TBI.

Materials and methods

Study participants and data collection

The pilot study (Study I) was conducted between January 2019 and January 2022 and the final validation study (Study II) between February 2022 and February 2023. Each of the retrospective multicenter convenience studies included 300 childparent dyads.

Children aged 8–17 years who had been diagnosed with TBI at least three months but no more than 10 years before enrollment were included if their Glasgow Coma Scale (GCS) (22) score or TBI severity was formally reported, if they had outpatient status (or were at the start of resuming inpatient treatment), and if they were able to understand and answer the questions. Children were excluded if they were in a vegetative state at the time of recruitment, had spinal cord damage, severe mental illness (e.g., psychosis, autism, etc.) or epilepsy prior to TBI, a terminal illness, or severe polytrauma. Further clinical details describing the nature of TBI were also collected, such as loss of consciousness, post-traumatic amnesia, need for respiratory support, neurosurgical intervention, presence of lesions on imaging, resuscitation, nausea/vomiting, and posttraumatic epilepsy.

Children/adolescents and their families were recruited through hospital registries in Germany and Austria. Participants were contacted by postal mail, invited to participate in the study, and informed about the research aim and procedures before signing the informed consent and medical records release form. Written consent was obtained from all parents and all children in all age groups. This was done to ensure that all children/adolescents were informed about the study.

Trained medical and psychological staff interviewed and assessed children/adolescents face-to-face at the

recruiting centers or online. Data were collected from parents by post or e-mail. There were two age groups: children aged 8–12 years (KID) and adolescents aged 13–17 years (ADO). The estimated sample size for the intended analyses within the studies was at least 140 subjects per age group (23).

Ethical approval

Both studies were conducted in accordance with all relevant laws of Germany including but not limited to the ICH Harmonized Tripartite Guideline for Good Clinical Practice ('ICH GCP') and the World Medical Association Declaration of Helsinki ('Ethical Principles for Medical Research Involving Human Subjects'). The study (application number 19/4/18) was approved by the Ethics Committee of the University Medical Center in Goettingen. In accordance with the requirements of the International Committee of Medical Journal Editors (ICMJE), the study was registered with the German Register of Clinical Studies (DRKS; https://drks.de/search/ de/trial/DRKS00032854), which works closely with the World Health Organization (WHO).

Sociodemographic and clinical data, instruments, and outcome measures

Parent sociodemographic data (age, education, partnership status) were self-reported. Parents documented the sex of their children. Children's age, TBI severity, time since injury and information concerning recovery as assessed using the Kings Outcome Scale for Childhood Head Injury (KOSCHI; see Appendix A. – Instruments and Measures) (24) were assessed by the clinical or psychological staff at the recruiting centers.

The item pool generation for the newly developed disease-specific HRQoL instrument QOLIBRI-KID/ADO for a pediatric TBI population aged between the ages of 8 and 17 years is described elsewhere (8,25). The proxy version contains the same items and the same number of items as the QOLIBRI-KID/ADO instrument and is worded from a proxy-patient perspective (26), asking proxies to report how they think the patient would respond. The parents report on their child's life satisfaction now and during the past week. The items are rated on a five-point Likert-type scale in terms of satisfaction ('How satisfied do you think your child is with .?' with 1 'Not at all,' 2 'Somewhat,' 3 'Moderately,' 4 'Quite,' 5 'Very') or distress ('How much do you think it bothers your child ... ?' with 1 'Very' to 5 'Not at all'). The questionnaire contains 35 items covering four domains of satisfaction: Cognition, Self, Daily Life and Autonomy and Social Relationships; and two domains of being bothered: Emotions, and Physical Problems. Scores are calculated for each scale and for the Total score. Scores range from 0 to 100, with higher scores reflecting better HROoL.

Parents also completed the proxy-reports of the Pediatric Quality of Life Inventory (PedsQL) generic scale (15), the Patient Health Questionnaire 9 (PHQ-9) (27), the Generalized Anxiety Disorder-7 (GAD-7) (28), and the Postconcussion Symptom Inventory (PCSI-P) (29), which was necessary for the psychometric evaluation of the QOLIBRI-KID/ADO-Proxy.

In this research project, we administered several neuropsychological screening tests to assess verbal memory (digit span of the Wechsler Intelligence Scale for Children (WISC-V) (30) and the Wechsler Adult Intelligence Scale (WAIS-IV) (31) and the Rey Auditory Verbal Learning Test; RAVLT (32)) and matrix reasoning of the WISC-V and WAIS-IV. The learning rate of the RAVLT was selected for this study as a proxy for the actual cognitive functioning to detect differences in performance associated with the parent-reported HRQoL. Learning rates may reflect individual differences in adaptation to novel challenges, whereas a test such as matrix reasoning provides a more static picture of cognitive performance.

The description and scoring of the instruments can be found in Appendix A. – Instruments and Measures.

Missing values

For the QOLIBRI-KID/ADO and QOLIBRI-KID/ADO-Proxy instruments, the prorating method was used if up to one third of the scale responses were missing. For the PedsQL, the mean of the completed items in a scale was calculated, if 50% or more of the items had been completed. For the GAD-7 or PHQ-9, if up to one third of values were missing, these were substituted by the mean score of the non-missing items. For the PCSI-P, the Total score was calculated using prorating if 30% or less of the items were missing; domain scores were calculated if 30% or less of the items were missing in each domain.

Statistical analyses

Proxy and child characteristics, items, scales, and Total scores were summarized using descriptive statistics: mean (M), standard deviation (SD), median, and range for continuous variables; counts and percentages for categorical variables. Skewness (SK) was reported for each item of the QOLIBRI-KID/ADO-Proxy. Data were considered to be symmetrical (for SK values –0.5 to 0.5), moderately skewed (-1 to < -0.5 and > 0.5 to \leq 1), or heavily skewed (values < -1 or > 1) (33). Proportions of responses in the most satisfied/least bothered categories (ceiling effect) and proportions in the least satisfied/most bothered categories (floor effect) were reported (34). Floor and ceiling effects with more than 15% of participants in these categories (35) suggest limited content validity, which consequently affects responsiveness, since changes cannot be measured in those participants.

To assess the psychometric properties of the QOLIBRI-KID /ADO-Proxy, we employed the checklist of measurement properties recommended by the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) initiative (36).

The psychometric evaluation included tests of differential item functioning (DIF) in children and adolescents, reliability (internal consistency, test-retest reliability, and inter-rater reliability), validity (factorial and construct validity), with discriminant validity using well-established supplemental assessment tools, including the PedsQL (15), PHQ-9 (27), GAD-7 (28), and PCSI-P (29) to support the suitability of the proxy version for measuring TBI-associated HRQoL.

To test whether it was appropriate to jointly analyze data from children aged 8–12 years and adolescents aged 13–17 years, we checked for differential item functioning (DIF) using an approach that combines ordinal logistic regression and item response theory (LORDIF). A non-significant difference (p > 0.01) in items between children and adolescents and/or McFadden's pseudo R2 < 0.05, corresponding to a small effect, indicated the absence of DIF (37).

The internal consistency of the item responses was investigated using Cronbach's alpha (α) and McDonald's omega (ω) (38). The calculation of Cronbach's α is based on the assumption that the responses to individual items explain the factor equally and that they are normally distributed (39). In contrast to α , ω is a more robust measure of internal consistency (38). McDonald's ω takes into account the factor structure and the potential variation in the strength of item-factor relationships, which is better suited to assessing the internal consistency of the QOLIBRI-KID/ADO-Proxy. Values of α greater than 0.70 are considered acceptable (39), and the same threshold was used for ω .

To assess the reproducibility (34) of the QOLIBRI-KID /ADO-Proxy, a subsample of proxies re-completed the questionnaire 10 to 20 days after the initial completion. Test-retest reliability was assessed by the intraclass correlation coefficient (ICC) using a two-way mixed model with absolute agreement and a 95% confidence interval (CI). ICCs were calculated for the Total score and for each scale. An ICC above 0.70 is recommended as a minimum standard of reliability (40).

In order to distinguish clinically important changes from measurement errors, the measurement error must be small. Measurement error can be expressed in terms of the standard error of measurement (SEm), which is related to the SD of the first test and the ICC;. Since there are no fixed criteria for acceptable SEm values in the literature, we considered a value of less than 10 to be satisfactory (41), corresponding to 10 points or 10% variation on the QOLIBRI-KID/ADO-Proxy scales and the Total score. The SEm can be further expressed as the minimal detectable change (MDC), i.e., the minimal within-person change in score that can be interpreted as a real change (34). Since we do not yet know what the minimal (clinically) relevant change is, we took a change below 10% to be acceptable (41), corresponding to a change of less than 10 points on the QOLIBRI-KID/ADO-Proxy scales and the Total score.

Cohen's kappa (κ) statistic was calculated for each QOLIBRI-KID/ADO-Proxy item and for each scale as an estimate of the inter-rater observer agreement, considering the expected agreement by chance. Children's self-reported QOLIBRI-KID/ADO scores were used to assess inter-rater reliability, and responses between proxy and child reports were compared. Weighted κ with linear weights was used, assigning equal importance to the differences between any two categories within the response scale. The following ranges were used to describe the relative strength of agreement: poor

< 0, slight (0–0.20), fair (0.21–0.40), moderate (0.41–0.60), substantial (0.61–0.80), (almost) perfect (0.81–1.00); a κ of 0 means there is no difference between the observers and chance alone (42).

Due to the multidimensionality of the QOLIBRI-KID /ADO-Proxy instrument, interpreting its scores requires a thorough examination of the reliability and validity of each of the scores provided, as well as any comparisons between the scores.

Firstly, the scale scores and correlations were reported to assess the relationships between the scales, followed by a confirmatory factor analysis (CFA) investigating the dimensionality of the **QOLIBRI-KID/ADO-Proxy.** A multidimensional model with six correlated latent factors represented by the scales of the QOLIBRI-KID/ADO-Proxy was estimated. The model fit statistics and the loadings of each model were examined. A number of global fit statistics were used to assess the models for the best fit: the ratio of chi-square statistic/degrees of freedom (χ^2/df), the root mean square error of approximation (RMSEA) with 90% confidence limits, the standardized root mean square residual (SRMR), and the comparative fit index (CFI). We considered a model fit to be acceptable if χ^2/df was less than 3.0. The following RMSEA criteria were used for the model fit: poor (RMSEA values above 0.10), mediocre (0.08 to 0.10) and fair (0.055 to less than 0.08). The range of RMSEA confidence limits should be narrow; they are adequate between 0.0001 and 0.090, and limits between 0.0001 and 0.054 are ideal (43). For the SRMR, values less than 0.055 are considered ideal. For the CFI, values above 0.90 are considered acceptable, and values above 0.94 indicate a very good fit (43). A diagonally weighted least square estimator was used in the CFA to account for the ordinal nature of the Likert-type scale of the items. Due to missing endorsements in higher categories corresponding to low HRQoL (i.e., 1-3) for some items, responses were collapsed to perform CFA (1: 1-3, 2: 4, 3: 5).

We assessed the construct validity using Pearson correlation coefficients (r). As no other TBI-specific HRQoL instrument for children and adolescents has been developed yet, we measured the strength of the linear association between the QOLIBRI-KID/ADO-Proxy and the proxy version of the PedsQL Generic Core Scales, which assesses generic HRQoL. We evaluated the strength of association between the following scales of the QOLIBRI-KID/ADO-Proxy vs PedsQL: a) Total score vs Total score, b) Physical Functioning (= Physical Problems) vs Physical Health Summary score, and c) Psychosocial Functioning (sum of Cognition, Self, Social Relationships, Emotions) vs Psychosocial Health Summary score. Absolute values lower than 0.2 were indicative of a very weak correlation (r); values from 0.2 to less than 0.4 weak, values from 0.4 to less than 0.6 were regarded as moderate, and values of 0.60 and higher were considered strong (44).

Discriminant validity was assessed by examining correlations with less related constructs. Pearson correlation coefficients were used to inspect the associations between the QOLIBRI-KID/ADO scores and the PHQ-9, GAD-7, and PCSI-P scores. We expected the GAD-7, PHQ-9, and PCSI-P to show negative correlations of medium effect size (r between -0.30 and -0.50), indicating some overlap and a potential association between lower HRQoL and higher symptom burden.

The relationship between TBI-specific HRQoL and relevant sociodemographic and clinical characteristics was explored using known-group analyses. We investigated the associations between child characteristics, including age (KID vs ADO), sex (male vs female), TBI severity (mild vs moderate/severe), time since injury (<4 vs \geq 4 years ago), functional recovery (KOSCHI categories 3a/b, 4a/b vs categories 5a/b), learning rate (below vs average and above), anxiety, depression, postconcussion symptoms (symptoms vs no symptoms), highest parental education (university vs other) and the QOLIBRI-KID/ADO-Proxy using one-tailed independent t-tests. Based on our assumptions, we expected that older age, being female, more severe pTBI, lower functional recovery, higher symptom burden, and lower educational attainment would be associated with lower QOLIBRI-KID/ADO-Proxy scores.

For those who participated in either Study I or Study II, the QOLIBRI-KID/ADO total score was compared using a t-test. The following Study I and Study II groups were compared using χ^2 tests to ensure comparability for age (KID vs ADO), child gender (male vs female), and TBI severity (mild vs moderate vs severe) as well as parental education (university vs other) and partnership status (living in partnership vs single parent). The significance of the different tests was set at $p \le 0.05$. Cohen's d (t-tests) and $\omega (\chi^2$ -tests) were used to classify the strength of associations and were conventionally considered to represent small (0.10), moderate (0.30), or large (0.50) effects (45).

Analytical software

Data analyses were performed using R version 4.4.0 employing the packages 'psych' (46) for reliability analyses, 'lordif' (37) for DIF analyses, 'lavaan' (47) for CFA and 'semPlot' (48) and 'corrplot' (49) for data visualization.

Results: study I (pilot study)

For the 300 child-parent dyads included in Study I (Online Supplement, Table S1), the mean age of the parents was 46.2 (SD = 5.63) years. In most cases, the mother (79.7%) completed the questionnaire, and most proxies lived in a partnership (87.3%). Two thirds of the parents (76.0%) had a university degree. The mean age of the children/adolescents was 12.4 (SD = 2.69) years (Online Supplement, Table S2). Overall, 59.7% of the sample were boys, and 71.7% had mild, 8.3% moderate, and 20.0% severe TBI. In half of the participants (49.7%) the injury had occurred more than four years ago. Most children and adolescents had recovered well (89.7%).

In Study I, the psychometric properties of the parentreported QOLIBRI-KID/ADO-Proxy values displayed very good internal consistency; Cronbach's α (0.71–0.78) and McDonald's ω (0.73–0.86) exceeded the standard cutoff value of 0.70 for all scales, and the Total score was excellent with α = 0.9 and ω = 0.93 (Online Supplement, Table S3). The testretest reliability was acceptable (Online Supplement, Table S4) with the ICCs at least above 0.6 for the scales (0.614–0.797) and good for the Total score (0.773). Small SEms were observed for four scales (Cognition, Self, Daily Life and Autonomy, Social Relationships) and the Total score, with considerable smallest detectable changes (>15), indicating small measurement errors but the need to consider substantial changes in HRQoL for meaningful detection. The CFA result (Online Supplement, Table S5) supports the interpretation of the QOLIBRI-KID/ADO-Proxy as a six-factor structure that correspond to the self-reported QOLIBRI-KID/ADO (8,9) and the adult QOLIBRI (50,51).

The QOLIBRI-KID/ADO-Proxy and the PedsQL (Online Supplement, Table S6) had mean scale scores above 60, a finding that is in line with other HRQoL studies, particularly those involving children and adolescents (10). The distributions of the QOLIBRI-KID/ADO-Proxy items were left-skewed for all scales except the Emotions scale and for all PedsQL scales, indicating higher HRQoL. Furthermore, the scale scores of the questionnaires assessing post-concussion (PCSI-P), anxiety (GAD-7), and depressive symptoms (PHQ-9) displayed a right-skewed distribution, indicating more proxy-rated symptoms in the children/adolescents.

Inter-rater reliability was fair (Online Supplement, Table S7), with κ values ranging between 0.24 and 0.41 for all scales and with $\kappa = 0.49$ for the Total score.

In terms of construct validity (Online Supplement, Table S8), as expected, the QOLIBRI-KID/ADO-Proxy is comparable in its constructs to the generic HRQoL measure, the PedsQL. Strong correlations were seen between the Total scores (r = 0.72) and between the Psychosocial Functioning score and Psychosocial Health Summary score (r = 0.65). The correlation between Physical Problems and Physical Functioning (r = 0.43) was moderate.

Discriminant validity analyses revealed strong negative associations between the QOLIBRI-KID/ADO-Proxy Total score and depression (r = -0.66), anxiety (r = -0.58), and post-concussion symptoms (r = -0.72).

Known-group analyses (Online Supplement, Table S9) suggest that it is useful in differentiating between parental education (lower proxy-rated HRQoL of children/adolescents with lower parental education; d = -0.51), TBI severities (lower HRQoL with higher severity; d = -0.29), time since injury (lower HRQoL in children/adolescents after a more recent TBI; d = -0.22), functional recovery (lower HRQoL with incomplete recovery; d = -1.01), and the actual symptom burden of the children (lower HRQoL with more depressive (d = -1.40), more anxiety (d = -1.31), and more postconcussion symptoms (d = -1.64)).

Results: study II (final validation study)

The sociodemographic characteristics of the parents are summarized in Table 1. Of the 300 child-parent dyads included in the study, one third (31.3%) had also participated in Study I. The mean age of the proxies was 45.3 (SD = 6.15) years. In most cases, the mother (79.3%) completed the questionnaire, and most proxies lived in a partnership (86.0%). Two thirds (64.3%) of the proxies had a university degree.

Table 1. Study II: Sociodemographic characteristics of the parents.

Proxy characteristics	Category	Statistic	Total (N = 300)
Previous participation in Study I (pilot study)	Yes No	N (%)	94 (31.3) 206 (68.7)
Questionnaire completed by	Mother Father Both Other person Missing	N (%)	238 (79.3) 51 (17.0) 6 (2.0) 3 (1.0) 2 (0.7)
Parent's age	Missing	Mean (<i>SD</i>) Median (Range) N (%)	45.3 (6.15) 44.0 (20.0, 67.0) 3 (1.8)
Partnership status	In relationship/married Single parent Missing	N (%)	258 (86.0) 37 (12.3) 5 (1.7)
Highest education	Primary school Secondary/high school Vocational school College/university Missing	N (%)	1 (0.3) 51 (17.0) 54 (18.0) 193 (64.3) 1 (0.3)

 Table 2. Study II: Children's characteristics.

Child characteristic	Category	Statistic	Total (N = 300)
Age (years)		Mean (SD)	12.2 (2.66)
Sex	Female Male	N (%)	137 (45.7) 163 (54.3)
TBI severity	Mild Moderate Severe	N (%)	240 (80.0) 30 (10.0) 30 (10.0)
Lesions	No Yes	N (%)	227 (75.7) 73 (24.3)
Functional recovery ^a	Lower recovery ^a Good recovery ^a Missing	N (%)	15 (5.0) 282 (94.0) 3 (1.0)
Time since injury (years)	<1 1 to < 2 2 to < 4 4 to 10	N (%)	15 (5.0) 30 (10.0) 55 (18.3) 200 (66.7)

^aKOSCHI values 4b = lower recovery = moderate disability, 5a/b = good recovery.

Of the 300 children included in Study II (Table 2), 167 were in the KID (56%) and 133 in the ADO (44%) group. Overall, 54.3% of the children/adolescents in the sample were male. The majority (80.0%) had a mild TBI, a quarter (24.3%) had lesions, but most of them had recovered well from their injury (94.0%) and were more than four years post-injury (66.7%, M = 5.37 years, SD = 2.71, Md = 5.31 years [0.46, 9.95]).

The QOLIBRI-KID/ADO-Proxy and the PedsQL (Table 3) had mean scale scores above 60. The distributions of the QOLIBRI-KID/ADO-Proxy items were left-skewed in all but the Emotions scale and both summarized scales (Psychosocial Functioning and Total score) and all of the PedsQL scales, indicating higher HRQoL. Additionally, the PHQ-9, GAD-7, and PCSI-P scale scores were right-skewed (higher scores indicating higher intensity of symptoms), suggesting a greater proxy-rated symptom burden in the children and adolescents.

The percentage of missing values was below 2% for all items (Appendix B., Table B1). Most of the items had ceiling effects, above 85% for 10 of the 35 items, indicating that a high

proportion of responses were at the upper end of the scale. Floor effects (>15%) were observed for seven of the 35 items (all of them from the two 'bothered-by' scales, Emotions and Physical Problems).

The values of Cronbach's α and for McDonald's ω are summarized in the Appendix B., Table B1. The results indicate good internal consistency for all scales; the scales' α ranges from 0.77 to 0.84, ω lies between 0.83 and 0.91. The Total score displayed an excellent Cronbach's $\alpha = 0.91$ and McDonald's $\omega = 0.94$.

The test-retest scores for all scales produced reliable ICCs above 0.7 (slightly lower for the Emotions scale). Acceptable SEms below 10 were observed for all scales (except for the Emotions scale). All scales had MDCs above 10 points.

On average, the difference between the test and retest was unidirectional across all scales and the Total score. On average, proxies reported the child's HRQoL as being higher in the retest than in their initial report, Table 4.

The values of the global fit statistics of the six-factor model suggest a fair model fit: SRMR = 0.08, RMSEA = 0.05 [CI_{90%} = 0.04; 0.05], CFI = 0.99, and $\chi^2(545) = 852.87$,

Table 3. Study II: Descriptive statistics of the total score and the scale scores of the QOLIBRI-KID/ADO-Proxy completed and proxy-completed PedsQL, PHQ-9, GAD-7, and PCSI-P.

	Scales	М	SD	Md	Min	Мах	SK	N
QOLIBRI-KID/ADO-Proxy	Cognition	78.83	14.23	82.14	25.00	100.00	-0.81	299
	Self	76.23	15.05	75.00	15.00	100.00	-0.78	298
	Daily Life and Autonomy	86.15	12.26	89.29	42.86	100.00	-0.99	299
	Social Relationships	76.73	14.45	79.17	16.67	100.00	-0.66	298
	Emotions	65.19	24.13	68.75	6.25	100.00	-0.50	298
	Physical Problems	76.37	20.02	83.33	8.33	100.00	-1.09	296
	(= Physical Functioning score)							
	Psychosocial Functioning score	74.23	12.85	74.64	29.03	100.00	-0.34	297
	Total score	76.55	11.91	77.73	32.75	98.12	-0.45	294
PedsQL	Emotional Functioning	71.99	18.39	75.00	0.00	100.00	-0.73	299
	Social Functioning	85.70	15.52	90.00	25.00	100.00	-1.22	299
	School Functioning	77.02	18.01	80.00	0.00	100.00	-0.81	297
	Physical Functioning	89.96	13.28	93.75	25.00	100.00	-2.22	299
	(= Physical Health Summary score)							
	Psychosocial Health Summary score	78.24	13.86	80.00	28.33	100.00	-0.80	297
	Total score	82.33	12.29	84.78	34.09	100.00	-1.24	297
PHQ-9	Total score (depression)	3.77	3.30	3.0	0.00	22.00	5.60	2.3
GAD-7	Total score (anxiety)	3.39	3.19	3.0	0.00	17.00	2.45	2.3
PCSI-P	Total score (post-concussion symptoms)	10.85	14.44	5.00	0.00	81.00	2.17	289

M = Mean, *SD* = standard deviation, *Md* = Median, *Min* = minimum, *Max* = Maximum, *SK* = skewness, *N* = absolute frequencies; QOLIBRI-KID/ADO and PedsQL: range 0 to 100, higher score indicates better HRQoL; PCSI-P: range von 0 to 126; GAD-7: range 0 to 21: PHQ-9: range 0 to 27; higher scores indicate higher intensity of symptoms.

Table 4. Study II: Test-retest reliability.

	Retest	Test	Retest				
QOLIBRI-KID/ADO-Proxy	Ν	M (SD)	M (SD)	ICC	95% Cl _{ICC}	SEm	MDC
Cognition	31	78.83 (14.23)	83.4 (14.2)	0.88	[0.77, 0.94]	4.39	12.18
Self	31	76.23 (15.05)	82.1 (13.0)	0.77	[0.52, 0.89]	5.46	15.13
Daily Life and Autonomy	31	86.15 (12.26)	90.2 (12.5)	0.82	[0.67, 0.91]	5.10	14.14
Social Relationships	31	76.73 (14.45)	80.4 (12.5)	0.74	[0.53, 0.87]	7.55	20.94
Emotions	30	65.19 (24.13)	74.2 (21.8)	0.68	[0.44, 0.83]	13.16	36.48
Physical Problems	30	76.37 (20.02)	84.2 (16.6)	0.86	[0.72, 0.93]	8.69	24.09
Total score	30	76.55 (11.91)	82.2 (11.6)	0.85	[0.67, 0.93]	4.66	12.91

N = number analyzed (parents completing test and retest), M = mean, SD = standard deviation, ICC = intraclass correlation coefficient; CI = 95% confidence interval, SEm = standard error of measurement, MDC = minimal detectable change.



Figure 1. Study II: Six-factor one-level model – items, scales (latent factors), and standardized path coefficients.

Table 5. Study II: Inter-rater reliability (parents vs children/adolescents).

QOLIBRI-KID/ADO	к value [95% С/]
Cognition	0.45 [0.37, 0.54]
Self	0.34 [0.24, 0.44]
Daily Life and Autonomy	0.32 [0.21, 0.43]
Social Relationships	0.31 [0.22, 0.41]
Emotions	0.22 [0.10, 0.34]
Physical Problems	0.27 [0.16, 0.39]
Total	0.41 [0.32, 0.51]

CI = Confidence interval; κ = Cohen's weighted kappa statistic; linear weights were used.

 $df/\chi^2 = 1.56$, p < 0.001. Standardized loadings for individual items and latent factors can be found in Figure 1. Based on the fit statistics, the six-factor solution provides a parsimonious model of the measure.

The strength of agreement (Table 5) between proxies and children on the scale level was fair to moderate with κ values ranging from 0.22 (Emotions) to 0.45 (Cognition).

Analyzing construct validity, the QOLIBRI-KID/ADO-Proxy Total score displayed a strong positive correlation (Figure 2) with the PedsQL's Total score (r = 0.73), indicating that the higher the specific HRQoL, the higher the generic HRQoL. Moderate relationships were observed between the QOLIBRI-KID/ADO-Proxy Physical Problems scale and PedsQL's Physical Health Summary Score (r = 0.49), and the relationship between the QOLIBRI-KID/ADO-Proxy Psychosocial Functioning score and PedsQL's Psychosocial Health Summary Score was strong (r = 0.68). Analyzing discriminant validity (Figure 2), correlations between the Total score of the QOLIBRI-KID/ADO-Proxy and the PHQ-9, GAD-7, and PCSI-P had moderate to strong negative coefficients (r = -0.62, r = -0.56, r = -0.61, respectively), indicating that lower HRQoL is associated with more severe symptoms and vice versa.

There was no evidence of statistically significant differences between the QOLIBRI-KID/ADO-Proxy Total scores and the children's age and TBI severity (Table 6). However, a small but statistically significant difference in the QOLIBRI-KID/ADO-Proxy Total scores was observed between boys and girls (d = -0.02). Parents of girls reported lower HRQoL compared to parents of boys. There was evidence of statistically significant differences between the parents' education and their reporting of their children's HRQoL: parents without a university degree (primary to secondary school) reported lower HRQoL (d = -0.41). The HRQoL was rated significantly lower by single parents compared with parents living in a partnership (d = -0.37). Parents' scores also differed depending on time since injury (d = -0.45): the more recent the TBI, the lower the proxy-rated HRQoL of the children. Moreover, proxies rated the HRQoL of their children significantly lower if the children had depressive (d = -1.23), anxiety (d = -1.17), or post-concussion symptoms (d = -0.78).

Ninety-four (31.3%) participants had also participated in the pilot study; however, prior participation had no effect on the QOLIBRI-KID/ADO-Proxy Total scores in the present study ($M_{\text{repeated}} = 76.71$ vs $M_{\text{naïve}} = 76.22$, t(292) = -0.33, p = 0.745, d = -0.04). Sociodemographic comparisons between



Figure 2. Study II: Construct and discriminant validity, Pearson correlation coefficients between the QOLIBRI-KID/ADO-Proxy and the proxy completed PedsQL, PHQ-9, GAD-7, and PCSI-P.

Table 6. Study II: Results of known-grou	p validity analyses of the	QOLIBRI-KID/ADO-Proxy total score,	, sociodemographic, and clinical	characteristics.
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		QOLIBRI-KID/ADO-Proxy					
Characteristic		Ν	M (SD)	t	df	d	<i>p</i> -value
Age	KID	163	76.35 (12.60)	-0.252	292	-0.03	0.401
	ADO	131	76.71 (11.37)				
Sex	Female	134	75.02 (12.45)	-2.029	292	-0.02	0.022
	Male	160	77.83 (11.32)				
Education of the parents	Other than university	105	73.49 (12.56)	-3.343	292	-0.41	<0.001
	University	189	78.25 (11.22)				
Partnership status	Single parent	36	72.71 (12.50)	-2.071	288	-0.37	0.020
	In relationship/married	254	77.11 (11.82)				
TBI severity	Moderate/Severe	59	74.63 (11.04)	-1.390	292	-0.20	0.083
	Mild	235	77.03 (12.10)				
Time since injury	<4 years	97	73.02 (12.07)	-3.641	292	-0.45	<0.001
	4–10 years	197	78.29 (11.47)				
Functional recovery (KOSCHI)	Incomplete recovery ^a	15	66.11 (14.95)	N/A	N/A	N/A	N/A
	Good recovery ^a	276	77.11 (11.55)				
Learning rate	Below average	57	74.46 (13.42)	-1.452	291	-0.21	0.074
(RAVLT)	Average and above	236	77.01 (11.50)				
Depressive symptoms (PHQ-9)	Mild to severe (≥ 5)	87	67.53 (11.59)	-9.648	292	-1.23	<0.001
	None to minimal (0–4)	207	80.34 (9.85)				
Anxiety symptoms	Mild to severe (≥5)	84	67.75 (11.09)	-9.048	292	-1.17	<0.001
(GAD-7)	None to minimal (0–4)	210	80.07 (10.32)				
Post-concussion symptoms (PCSI-P)	Symptoms present ^b	45	69.21 (11.72)	-4.787	289	-0.78	<0.001
	No symptoms ^b	246	78.07 (11.36)				

One-tailed, independent t-tests were used to evaluate differences between categories (in bold: *p*-values <0.05). For each characteristic, the first line indicates the expected group with lower HRQoL. n = sample size (only groups with n > 30 and only those with available QOLIBRI-KID/ADO-Proxy Total scores included in the analyses); M = mean; SD = standard deviation; scores of those with missing categories are not displayed. ^aincomplete recovery: KOSCHI values of 3a/b. 4a/b, good recovery: 5a/b; ^bPCSI-P: symptoms $\ge M + 1SD$, no symptoms $\le M$.

Study I and II revealed no differences with respect to sex ($\chi^2 = 2.629$, p = 0.105, w = 0.075). There were significant differences for age ($\chi^2 = 5.707$, p = 0.017, w = 0.110), parental education ($\chi^2 = 17.815$, p < 0.001, w = 0.192), and TBI severity ($\chi^2 = 15.838$, p < 0.001, w = 0.177). However, the effect sizes were small.

Discussion

This study presents the German QOLIBRI-KID/ADO-Proxy, the first proxy version of the 35-item QOLIBRI-KID/ADO questionnaire for assessing disease-specific HRQoL after TBI in two German pediatric samples. There is a consensus that parental reports alone are inadequate when characterizing HRQoL in children and adolescents in general (52) and after pediatric TBI in particular (11). In order to improve pediatric health care after injury, integrating child/adolescent and parental views may produce a broad and comprehensive picture of HRQoL in children and adolescents (52).

The results for the newly developed QOLIBRI-KID/ADO-Proxy revealed good to excellent internal consistencies in both studies, with Cronbach's α and McDonald's ω partly far exceeding the cutoff of 0.70 (up to 0.93) for all scales and the Total scores. The test-retest reliability suggests that the questionnaire is stable, valid, and reliable over a test-retest interval, as indicated by the ICC. With the exception of the Emotions scale (Study I and II) and the Physical Problems scale (in Study I), all scale scores had SEm values of less than 10%, indicating considerable variability in the data. Based on the MDC values, a change in TBI-specific HRQoL of more than 12 points in the QOLIBRI-KID/ADO Total and scale scores can be interpreted as a 'true' shift. This indicates that larger changes are needed to exceed the measurement error and to be considered clinically important. These results suggest that the QOLIBRI-KID /ADO-Proxy may have the expected, limited sensitivity to detect small, yet meaningful changes between testing and retesting over an interval of 10 to 20 days. Longitudinal research is recommended, for example on the effects of treatment on HRQoL over a longer period of time.

The model fit statistics for the one-level six-factor model were good. The results are consistent with the findings during the development of the QOLIBRI-KID/ADO questionnaire as a self-report measure in adults (50,51) and children (8,9). By using the scale scores, we gain insights into six specific domains of HRQoL, allowing for a more comprehensive understanding of the impact of TBI on different aspects of well-being: Cognition, Self, Daily Life and Autonomy, Social Relationships, Emotions, Physical Problems.

In both studies, the mean QOLIBRI-KID/ADO-Proxy scores for all scales and the Total scores were around 70 and above (out of 100) and left-skewed (Study I: in all but the Emotions scale); this supports the notion that most parents perceived their children's HRQoL favorably. There could be multiple reasons for these high satisfaction scores. The majority of children in our samples had a mild TBI with good functional recovery, suggesting that parents are not concerned about or do not perceive their children's deficits in these domains. Furthermore, the samples were self-selected in various recruiting centers (and >90% did not respond to the invitation), which may have introduced a selection bias (53). However, it is important to consider the implications of the high mean scale scores and higher ceiling effects of the items. A similar effect was also observed in a study of 13,878 parents of healthy and chronically ill children using the PedsQL (54). The ceiling effect poses a potential challenge (34) when assessing improvements in HRQoL, as once the highest score is reported, further improvement and responsiveness cannot be accurately captured.

Comparing the Total score, the Physical Functioning, and the Psychosocial Functioning scores with the corresponding scales of the generic HRQoL measure (PedsQL), the correlations indicate the expected construct overlap and highlight the ability of the measure to capture important aspects of HRQoL in a TBI population. In line with previous studies (55), the QOLIBRI-KID/ADO-Proxy Total score and post-concussion, anxiety and depression symptoms displayed low to moderate negative correlations. This suggests that higher levels of symptom distress are associated with lower levels of HRQoL and vice versa. One critical aspect of this reduced HRQoL is the symptom burden experienced by children. Anxiety and depression are particularly prevalent, ranging from 11% to 45% among children after TBI (56), leading to delayed recovery and psychosocial outcomes (16) that further exacerbate the impact on their HRQoL (55). Post-concussion symptoms (PCS) can include headaches, dizziness, fatigue, and cognitive impairment, which may persist for weeks or months (57) and are mainly underdiagnosed after complicated and uncomplicated mild TBI (58). Individuals may also experience similar symptoms after moderate and severe TBI, referred to as postconcussion-like symptoms, which require appropriate treatment. Post-concussion symptoms (PCS) are debated in adult research, as they are not specific to head injuries and also occur in non-injured individuals (59) and the general population (60). Various biological, psychological, and social factors contribute to these symptoms (61). The term 'post-concussionlike' symptoms is used, as seen in pediatric studies (62) and adult general population research (60,63,64), to highlight their broader occurrence beyond TBI. Research indicates these symptoms are debilitating and significantly impact HRQoL, even in healthy individuals. In addition to the TBI, other injuries sustained by the children at the same time may also be contributing factors (62). Furthermore, based on the findings after TBI in adults (65) and children (66,67), we recommend that future pediatric studies should also investigate the associations of specific factors (e.g. age, gender, other concurrent injuries, TBI severity, and premorbid problems) with post-concussion-like symptoms. Distinguishing between the occurrence, frequency, and intensity of these symptoms, while controlling for predefined factors, may help to develop more appropriate treatment strategies for individual subgroups with multiple or more intense symptoms. After moderate and severe TBI there is a special need for compensatory strategies to be applied to reduce the burden of long-term consequences. This highlights the need for consistent monitoring of post-concussion and post-concussion-like symptoms, anxiety, and depression as short-term and long-term consequences in the follow-up care of children who have sustained TBI, particularly after mild TBI.

Results from Studies I and II indicate that inter-rater reliability varied from fair (especially for the Emotions and Physical Problems scales) to moderate. This is consistent with findings reported in the literature that parents often underestimate (13) or partly overestimate (68) their children's HRQoL, indicating that there is relatively little concordance between parents and children following TBI (11). For example, the poor inter-rater reliability in the Emotions scale ($\kappa = 0.24$ and 0.22) suggests that there may be specific aspects of the scale that require

further attention in order to improve the inter-rater reliability. Discrepancies may arise from different perspectives on more internalized emotional experiences between the parents and the children themselves (69). The potential limitations of parent-child agreement need to be considered, and researchers and clinicians should not rely solely on proxy reports.

The known-group analyses of Study I and II led to similar results regarding factors that may potentially influence HRQoL. In line with previous studies, we found lower proxyrated HRQoL in relation to lower parental education (6) and more recent TBI (70) in both studies. Furthermore, consistent with previous research on proxy-reported (71) or self-reported HRQoL (55), we observed that more depression, anxiety, and post-concussion symptoms were significantly associated with lower HRQoL in both studies. Also, no difference in HRQoL based on the learning rates of the children/adolescents was identified. Nevertheless, there were some differences between the two studies. In Study II, we discovered a partnership effect (72), with lower HRQoL reported by single parents compared with parents living in a partnership. In Study I, the examination of the scores by children's characteristics demonstrates the ability of the QOLIBRI-KID/ADO-Proxy to distinguish between different levels of TBI severity and functional recovery. In line with other studies, the higher the severity (13) and the lower the functional recovery (19), the lower the HRQoL. However, this finding was not replicated in the final validation Study II, possibly because it included too few individuals after a severe TBI and with severe disability. Discrepancies were also found between the two studies regarding age and sex, which is consistent with equivocal findings in other pediatric TBI research. Study I revealed that younger children had higher proxy-rated HRQoL scores compared to adolescents, as described by Haugland and colleagues (73). In contrast, in the final validation Study II, no significant age effect was observed as also reported by Andruszkow and colleagues (74). Additionally, parents in Study II rated HRQoL lower for girls, which has also been reported in other studies (18).

Strengths & limitations

The QOLIBRI-KID/ADO-Proxy questionnaire is the first proxy-reported questionnaire for assessing TBI-specific HRQoL and covers a range of HRQoL domains that can be assessed separately. In both our studies, completion rates for the HRQoL measures were excellent with a minimal number of missing items, contributing to the robustness of our results.

Further work on the QOLIBRI-KIDDY (for ages 6 to 7 years) and QOLIBRI-KIDDY-Proxy versions is still ongoing. Once completed, we will be able to offer a longitudinal measure of TBI-related HRQoL from early childhood to late adulthood (50,51).

In our studies, children were included up to 10 years postinjury, so TBI may have had a different impact on the children's HRQoL as rated by their parents due to different recovery times. The prevalence of mild TBI is very high, at 90.0% to 97.3% (1), which is also reflected by our studies. This lack of variance in TBI severity could make the results of psychometric testing less generalizable. The potential impact of further factors related to the sociodemographic and clinical characteristics of a proxy completing the measure (e.g., the gender of all parents, parental mental health status, etc.) on their rating behavior needs to be considered in future studies, and the associations between these proxy characteristics and the proxy scores should be explored.

Nevertheless, based on the psychometric analyses conducted in the QOLIBRI-adult development study of the proxy version (75,76), it seems reasonable to conclude that the proxy instrument will also be valid for the assessment of individuals after moderate and severe TBI. As the validation of the questionnaire mainly in mild TBI presents a clear limitation of this study, the validity needs to be increased by assessing individuals with a wider range of symptoms, especially after moderate and severe TBI, who are not able to understand or answer with the proxy instrument. This may provide a more solid basis for the psychometric properties of the QOLIBRI-KID/ADO-Proxy instrument. To date, the validation of QOLIBRI-KID/ADO-Proxy has been limited to the German pediatric/proxy population. Further research extending the use of the measure to non-German populations would contribute to a multinational TBI-specific assessment of HRQoL.

Future research could also consider linking the QOLIBRI-KID/ADO-Proxy longitudinally with the version for younger children (QOLIBRI-KIDDY-Proxy) and with the adult QOLIBRI version, to investigate longitudinal HRQoL trajectories and changes over the lifespan. This would offer valuable insights for clinical practice, research, and interventions targeting long-term well-being. The findings provide valuable support for clinicians and researchers, enhancing their ability to evaluate patients and improve clinical management, care, and rehabilitation following pediatric TBI. The findings indicate that early psychological therapy and, if necessary, medical treatment for depression, anxiety, and post-concussion symptoms may be potential strategies for improving HRQoL after pediatric TBI.

Conclusion

The psychometric evaluation and validation of the TBIspecific HRQoL QOLIBRI-KID/ADO-Proxy questionnaire for children aged 8-17 years in two German samples of parents yielded favorable results. The studies demonstrate that the QOLIBRI-KID/ADO-Proxy is a valid and reliable instrument for assessing HRQoL after pediatric TBI in the German-language context, especially after mild TBI. This multidimensional 35-item measure covering six domains (Cognition, Self, Daily Life and Autonomy, Social Relationships, Emotions, and Physical Problems) provides a comprehensive understanding of HRQoL in children and adolescents after TBI. Due to the limitations of the current study in terms of its validation being restricted to the German language context and mainly among individuals after mild TBI, we strongly recommend validating this questionnaire in other languages and in individuals with a broader range of symptoms and TBI severities. Linguistic translation has already been completed for English, French, and Spanish language contexts. Validation studies in appropriate samples of individuals after pediatric TBI in these language contexts are still needed. Based on the German validation study results, we still recommend the adoption of this measure as a surrogate for self-reported assessments of HRQoL in children and adolescents after TBI when a child lacks the ability to self-report.

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Disclosure statement

No potential conflict of interest was reported by the author(s).

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Data availability statement

The data presented in this study are available on request from the corresponding author. Data are not publicly available for reasons of data protection.

Author contributions

Conceptualization: N.v.S., I.H., S.G., K.C.; methodology: N.v.S., M.Z., I. H., A.C.M., S.G.; software: M.Z., I.H., A.C.M.; validation: N.v.S, M.Z., K. C.; formal analysis: M.Z., I.H., A.C.M.; investigation: U.K., I.K., M.B., S.B., M.K., K.B., M.R., M.L., M.S., C.A., A.N., A.K., J.D., U.W., D.P., C.T., J.S., A.B., H.M., K.C.; resources: N.v.S.; data curation: M.Z., I.H.; writing – original draft preparation: N.v.S., I.H., P.R., K.C.; writing – review and editing: all authors; visualization: M.Z., K.C.; supervision: N.v.S.; project administration: N.v.S., K.C.; funding acquisition: N.v.S. All authors have read and agreed to the published version of the manuscript.

Informed consent statement

Informed consent was obtained from all subjects involved in the study.

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APPENDICES

Appendix A. Instruments and measures

Kings Outcome Scale for Childhood Head Injury (KOSCHI)

The KOSCHI (24) is a clinician-rated outcome instrument documenting a child's recovery from injury and is used for monitoring the burden of disability caused by TBI. In this study, the KOSCHI category membership was assessed by the investigators, and only children with recovery categories three though five were included. The five KOSCHI categories are: 1. Death, 2. Vegetative state, 3. Severe disability, 4. Moderate disability, and 5. Good recovery.

Proxy Pediatric Quality of Life Inventory (PedsQL[™]) version 4.0, Generic Core Scales

The PedsQLTM Generic Core Scales (15) measure generic HRQoL using 23 items on four multidimensional scales (Physical, Emotional, Social, and School Functioning). Three summary scores can be calculated: Physical Health Summary Score (eight items), Psychosocial Health Summary Score (15 items), and a Total score (23 items). Parents are asked to answer questions about the child's physical, emotional, social, and school functioning in the past one month using a five-point Likert-type scale ranging from 0 to 4 ('Never' to 'Almost always'). To obtain scores, item values are reversed and linearly transformed to a 0–100 scale with higher scores indicating better generic HRQoL.

Rey Auditory Verbal Learning Test (RAVLT)

The Rey Auditory Verbal Learning Test (RAVLT) (32) was employed for the purpose of evaluating verbal learning and memory. The examiners read out 15 words, which the children were then required to repeat over the course of eight trials. The learning rate was calculated by subtracting the number of words recalled in Trial I from those recalled in Trial V. This learning rate was then categorized as being above, below, or within the typical range for the child's age group ($M \pm 1$ SD).

Patient Health Questionnaire 9 (PHQ-9)

The PHQ-9 (27) contains nine items assessing symptoms of depression according to the DSM-5 (27). Parents completed the proxy version of the PHQ-9 (27), rating children's symptoms over the past two weeks. The total score is calculated by summing the responses to each item using a four-point Likert-type scale from 0 ('Not at all') to 3 ('Nearly every day'), the range is from 0 to 27; higher scores indicate more depressive symptoms. PHQ-9 Total scores rate severity of depression symptoms as none/minimal (0-4), mild (5-9), moderate (10-14), or severe (score 15 and above) (27).

Generalized Anxiety Disorder-7 (GAD-7)

The GAD-7 (28) is a seven-item instrument used to assess symptoms of anxiety according to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) (28). Total scores are calculated by summing the responses to each item using a four-point Likert-type scale, coded 0 ('Not at all') to 3 ('Nearly every day'). The Total score ranges from 0 to 21; higher values indicate greater disturbance and impairment; none/minimal (scores 0–4), mild (5–9), moderate (10–14), and severe impairment (score 15 and above) (28). Parents completed the proxy version and rated children's symptoms in the last two weeks.

Postconcussion Symptom Inventory – Parent Report (PCSI-P)

The PCSI-P (29) consists of 21 proxy-rated post-concussion symptoms in children and adolescents. These symptoms are rated on a seven-point Guttman scale with three anchor categories: 'Not a problem,' 'Moderate problem,' and 'Severe problem.' Items cover four domains: physical, emotional, cognitive, and sleep/fatigue. The sum of all the items constitutes the Total score. Due to the lack of reference values, the Total scores are categorized as below average, above average, or within the average range ($M \pm 1$ SD).

Appendix B.

,		Descriptive statistics					Internal consistency		-	D anal	IF lyses		
Scale	ltems	м	SD	% Miss-ina	SK	% Floor	% Cei-lina	α	Changes in α if omitted	ω	СІТС	D	R ²
Cognition				J	-		J	0.81		0.86		r	
cognition	Concentration	3.82	0.84	2	-0.46	5	66	0.01	-0.06	0.00	0.78	0.412	
	Talking to Others	4.41	0.74	1	-1.07	2	87		-0.01		0.53	0.097	
	Remembering	4.13	0.89	0	-1.01	6	81		-0.05		0.74	0.070	
	Planning	3.93	0.96	1	-0.83	6	70		-0.03		0.64	0.001	0.02
	Decision between Two Things	3.81	0.91	1	-0.7	7	68		0.01		0.40	0.308	
	Orientation	4.73	0.58	0	-2.39	0	95		-0.01		0.48	0.456	
	Thinking Speed	4.23	0.86	0	-1.12	3	82		-0.04		0.70	0.305	
Self								0.80		0.86			
	Energy	3.78	0.91	0	-0.73	8	68		-0.03		0.62	0.040	
	Accomplish-ment	4.32	0.79	1	-1.19	3	87		-0.03		0.60	0.048	
	Appearance	4.03	0.8	0	-0.98	4	81		-0.03		0.68	0.059	
	Self-Esteem	4.03	0.75	1	-0.72	3	80		-0.07		0.78	0.249	
	Future	4.09	0.77	1	-0.65	3	80		-0.04		0.66	0.437	
Daily Life and Autonomy								0.79		0.86			
	Daily Independence	4.83	0.45	0	-2.84	0	97		-0.03		0.44	0.436	
	Getting Out and About	4.71	0.58	1	-2.16	1	95		-0.02		0.66	0.050	
	Manage at School	4.2	0.85	1	-0.98	3	80		-0.05		0.57	0.114	
	Social Activities	4.41	0.77	0	-1.26	2	88		-0.04		0.69	0.280	
	Decision Making	4.17	0.86	0	-1.02	4	81		-0.04		0.65	0.067	
	Support from Others	4.18	0.79	1	-0.75	2	82		-0.01		0.65	0.143	
	Ability to Move	4.6	0.73	1	-2.17	1	91		-0.03		0.52	0.250	
Social Relation-ships								0.84		0.91			
	Open up to Others	4.05	0.76	1	-0.54	2	78		-0.02		0.64	0.170	
	Family Relationship	4.17	0.75	1	-0.53	2	82		0.01		0.49	0.414	
	Relationship with Friends	4.31	0.69	1	-0.68	1	88		-0.03		0.75	0.536	
	Friendships	4.24	0.79	0	-0.94	2	84		-0.04		0.77	0.749	
	Attitudes of Others	3.96	0.79	1	-0.72	4	77		-0.05		0.81	0.965	
F	Demands from Others	3.68	0.85	1	-0.51	/	61		-0.02		0.67	0.105	
Emotions		2.00	4.95	•	0.07	10	70	0.82		0.85	0.65		
	Loneliness	3.88	1.25	0	-0.87	19	/0		-0.02		0.65	0.554	
	Anxiety	3.63	1.21	1	-0.50	21	59		-0.07		0.76	0.857	
	Sadness	3.44	1.15	1	-0.52	23	56		-0.11		0.86	0.630	
Dhard and Durch Laws a	Anger	3.5	1.18	I	-0.45	23	57	0 77	0.00	0.00	0.60	0.198	
Physical Problems	Chamainana	2 41	1 22	1	0.22	26	50	0.77	0.01	0.83	0.27	0.007	0.011
	Clumsiness Others Indexide	3.41	1.22	1	-0.33	26	52		0.01		0.37	0.007	0.011
	Other injuries	4.42	1.09	2	-1.83	9	81		-0.04		0.62	0.230	
	neadaches	3.62	1.42	1	-0.59	26	60		-0.05		0.6/	0.031	
	Pain Seeing / Leaving	3.99	1.22		-0.96	15	/0		-0.07		0.73	0.328	
	Seeing/Hearing	4.4	1.05	2	-1./3	9	82		-0.04		0.62	0.981	
Tatal Casua		4.49	0.99	2	-2.09	/	85	0.01	-0.03	0.04	0.57	0.190	
Total Score								0.91		0.94			

Table B1. Study II: item and scale statistics of the QOLIBRI-KID/ADO-Proxy questionnaire: descriptive statistics, internal consistency parameters, and DIF analyses.

M = Mean; SD = standard deviation; % = percent; SK = skewness. Negative values indicate left-skewed distributions. R^2 = McFadden's R². *CITC* = corrected item – total correlations. Negative values in 'Changes in a if omitted' indicate a decrease in a scale's Cronbach's a if this item is omitted. *p* refers to a χ^2 -test between LORDIF models, including scale scores for an item only, to models including the scale score, the age category, and the age category and scale score interaction. McFadden's R² is only reported for items with significant differences in model comparison.