

Health-related quality-of-life measures for long-term follow-up in children after major trauma

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Abstract

Objective Our objective was to review measures of health-related quality of life (HRQL) for long-term follow up in children after major trauma and to determine the measures that are suitable for a large age range, reliable and valid, and cover a substantial amount of the domains of functioning using the International Classification of Functioning, Disability, and Health (ICF) of the World Health Organization (WHO).

Methods The Medline and EMBASE databases were searched in all years up to October 2007 for generic HRQL measures suitable for children aged 5–18 years old and validated in English or Dutch. Measures were reviewed with respect to the age range for which the measure was suitable and reliability, validity, and content related to the ICF.

Results The search resulted in 1,235 hits and 21 related articles. Seventy-nine papers met the inclusion criteria, describing in total 14 measures: Child Health and Illness Profile Adolescent and Child Edition (CHIP-AE/CE), Child Health Questionnaire Child and Parent Forms (CHQ-CF87/PF50/PF28), DISABKIDS, Functional Status II (FS II)(R), Health Utilities Index Mark 2 (HUI 2), KIDSCREEN 52/27, KINDL, Pediatric Quality of Life Inventory (PedsQL), TNO Institute of Prevention and Health and the Leiden University Hospital (TNO-AZL), TNO-AZL Children's Quality Of Life (TACQOL), and Youth Quality of Life Instrument—Research Version (YQOL-R). Measures that were suitable for a large age range were CHQ-PF50/PF28, DISABKIDS, FS II(R), HUI 2, KIDSCREEN, PedsQL, and TACQOL. All measures had moderate to good psychometric properties, except for CHQ-PF50/PF28, KINDL, and TACQOL, which had either low internal consistency or bad test–retest reliability. The measures that covered more than six chapters of the ICF domains were CHIP-AE/CE, CHQ-CF87/PF50, DISABKIDS, KIDSCREEN-52, PedsQL, and TACQOL.

Conclusions DISABKIDS, KIDSCREEN 52, and PedsQL are suitable for long-term follow-up measurement of HRQL in children after major trauma. They cover a large age range, have good psychometric properties, and cover the ICF substantially.

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Abbreviations

CHIP-AE Child Health and Illness Profile Adolescent
Edition
CHIP-CE Child Health and Illness Profile Child Edition

CHQ-CF	Child Health Questionnaire Child Form
CHQ-PF	Child Health Questionnaire Parent Form
HRQL	Health Related Quality of Life
HUI 2	Health Utilities Index Mark 2
ICF	International Classification of Functioning, Disability, and Health
PedsQL	Pediatric Quality of Life Inventory
TACQOL	TNO-AZL Children's Quality Of Life
YQOL-R	Youth Quality of Life Instrument—Research Version
WHO	World Health Organization

Introduction

Injuries are a leading cause of death in children of 1–18 years of age [1, 2]. The survival rate of major traumatized children is about 80% [2, 3]. Injuries can cause severe functional impairment and psychosocial problems in the short term and long term [4–9]. Despite the prominent role of major trauma in mortality and morbidity in children, relatively little research has been done in terms of quality of life of children after major trauma. Most studies focus on the consequences of brain injury [10–12], whereas the quality of life in pediatric major trauma remains relatively unexplored. Van der Sluis and colleagues described the long-term outcome in pediatric polytrauma patients in 1997 [13]. Nine years after trauma, the RAND-36 was administered to patients 18 years of age or older. The quality of life enjoyed by the patients did not differ from a healthy reference population. Holbrook et al. recently studied the quality of life in adolescents 3, 6, 12, 18, and 24 months after major trauma with the Quality of Well-being Scale [14]. Significant deficits in quality of well-being were found in adolescents after major trauma compared with US norms for healthy adolescents.

There are many terms used to describe quality of life in health care, for example: health-related quality of life (HRQL), well-being, health status, and functional status. In this review, the definition of HRQL as described by the World Health Organization (WHO) is adopted. The WHO defines HRQL as the individuals' perception of their position in life in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns [15]. To study HRQL in pediatric trauma patients, first a decision has to be made about what measure to use. Currently, many HRQL measures for children are available. Some measures are disease specific, whereas others are generic. Unfortunately, no trauma-specific HRQL measure has been developed for children, leaving generic measures as first choice.

Comparison of the available measures enables a well-considered decision.

The aim for this review is to provide an overview of the available measures of HRQL for long-term follow-up in children after major trauma so that measures can be selected that are suitable for a large age range, valid and reliable, and cover a substantial amount of the content of the International Classification of Functioning, Disability, and Health (ICF) of the WHO [16].

Methods

Literature search

Medline and EMBASE databases were searched in all years up to October 2007 for measures of HRQL in children. The following search was entered: [(child* OR pediatr* OR paediatr* OR adolesc*) AND (quality of life OR health status) AND (psychometr* OR validity OR reliability OR cronbach OR test–retest)]. In Medline the extension (Title/abstract) was added to all terms to specify the search. Inclusion criteria were: (1) validation study of a generic HRQL measure in children in a Western country, (2) the measure is suitable for children in the age range of 5–18 years, (3) the paper is written in English or Dutch, (4) the measure has an English or Dutch version, (5) the measure has both validity and reliability reported.

Measure comparison

The measures were reviewed on four levels: (1) age range, (2) reliability, (3) validity, and (4) the content related to the ICF. The underlying idea for the measure comparison on these four levels is as follows:

Age range

When a measure is suitable for a large age range, fewer measures are needed to study a cohort. Therefore, a better comparison can be made over time and between subjects of different ages. In this review, a large age range is defined as at least 10 years covered. Measures were selected that were suitable for children who were >5 years old, because it is hypothesized that 5 years after trauma the most recovery that can be expected has taken place and that the child is in a relatively stable situation. Some measures have different versions for different age categories. When these versions were similar in content, the age ranges of these different versions were added. When they had a different amount of questions or a different scoring system, the versions were considered as separate measures and the age ranges were not added.

Reliability

On the second level, the internal consistency and the test–retest reliability of the HRQL measures were compared. In this review, a measure was considered reliable when it reached at least group comparison level for internal consistency (Cronbach’s alpha > 0.70), [17] and had a substantial test–retest reliability [kappa, intraclass correlation coefficients (ICC), Spearman or Pearson correlation coefficient > 0.60] [18]. A measure was found reliable when at least 80% of the measurements of reliability exceeded the set levels.

Validity

Comparison of the validity of a measure is a complicated matter, because there are many ways to describe it. Validity can be divided into content and construct validity. A method often used to describe content validity of an HRQL measure is the ability to differentiate between healthy subjects and children with a disease. Construct validity can be described, for example, by factor analysis, by the correlation of a measure with other instruments that aim to measure similar or different constructs, and by the correlation with preknown information or clinical symptoms. In this review, an attempt was made to give an overview of the content and construct validity for all included HRQL measures.

Content related to the ICF

The fourth and final level of comparison included the content of the questionnaires. This comparison was made in light of the ICF [16] (Fig. 1). It is a model in which health condition is defined by three domains: body functions and structures, activities, and participation. These domains are divided into chapters, as listed in Table 5. To compare the content of the questionnaires, all items were placed in one of the ICF chapters. If an item encompassed different constructs, the item was placed in more than one chapter. For example, the fourth item of the Health Utilities Index Mark 2 (HUI 2) “Learns and remembers school work normally for age,” encompassed two constructs: “learn” and “remember.” These two constructs were placed in two different chapters, namely, the first chapter of activities and participation and the first chapter of body functions and structures, respectively. If the content of the item did not fit in one of the chapters, the item was placed in the category “other”.

Placement of items in the chapters of the ICF was done by three researchers independently. One of them (LJ) placed the items of all measures, whereas the other two (MK and MB) placed the items of seven measures. So finally, all items were placed by two researchers. In case of disagreement, a discussion followed, led by a fourth

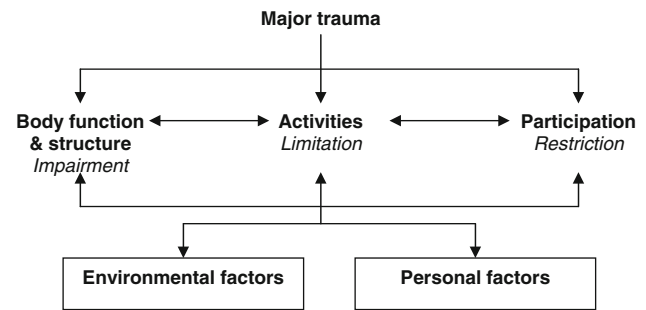


Fig. 1 International Classification of Functioning, Disability and Health (ICF) of the World Health Organization (WHO) [12]

independent person (JWG). This person finally decided in which ICF chapter the item was placed. The number of chapters covered by the items was used as a measure for covering the ICF. In this review, a measure was found to represent the ICF substantially when the items covered more than six chapters.

Results

The search in Medline and EMBASE databases rendered 1,235 hits and 21 related articles. Seventy-nine papers met the inclusion criteria, describing in total 14 measures. The number of references per measure varied between 1 and 26. The included measures are Child Health and Illness Profile Adolescent and Child Edition (CHIP-AE [19–21], CHIP-CE [22, 23]), Child Health Questionnaire Child and Parent Forms (CHQ-CF87 [24–30], CHQ-PF50 [26, 27, 30–53], CHQ-PF28 [54–57]), DISABKIDS [58, 59], Functional Status II (FS II)(R) [60, 61], HUI 2 [32, 52, 62–64]), KIDSCREEN 52 [65, 66] and KIDSCREEN 27 [67, 68], KINDL [25, 69–72], Pediatric Quality of Life Inventory 4.0 (PedsQL [10, 73–91]), TNO-AZL Child Quality of Life questionnaire (TACQOL [92–95]), and Youth Quality of Life Instrument—Research Version (YQOL-R [96]).

Comparison of the age range and other general characteristics

CHIP, CHQ, DISABKIDS, KIDSCREEN, PedsQL, and TACQOL have different versions for different age categories. Besides language adaptations, the age-adapted versions of CHIP and CHQ also have different numbers of items and different scoring systems. Therefore, the child and adolescent edition of CHIP and the child and parent form of CHQ were considered as separate measures. The number of items and the scoring system of the different versions of DISABKIDS, KIDSCREEN, PedsQL, and TACQOL are similar. Therefore, these versions were considered as one measure, and the age ranges are added.

The measures that are suitable for the largest age range are HUI 2 and PedsQL. They are both validated for children between 2 and 18 years old. CHQ-PF50/28 (5–18 years), DISABKIDS (4–16 years), FS II(R) (0–12 years), KIDSCREEN 52/27 (8–18 years), and TACQOL (6–15) are also validated for an age range of 10 years or more. Measures suitable for an age range of less than 10 years are CHIP-AE/CE (11–17/6–11 years), YQOL-R (12–18 years), CHQ-CF (10–18 years), and KINDL (8–16 years). The large age range measures are all proxy reported or clinician administered, except for PedsQL, DISABKIDS, KIDSCREEN, and TACQOL, which also have a self-report version. The minimal age limit used for self-report measures varies between 8 and 11 years. The proxy-report measures and the clinician-administered measures are suitable for children of all ages.

The number of items varies enormously for each measure. HUI 2 contains less than ten items, whereas CHIP-AE and TACQOL contain more than 100 items, resulting in large differences in the time needed to complete the questionnaire. Short measures take only 5 min or less, whereas the larger measures take 10–45 min to complete. Measures that take 20 min or more to complete were CHIP-AE/CE and CHQ-CF87/PF50. Items are placed in a varying number of domains, with a median of six domains. PedsQL and YQOL-R have only four domains, whereas CHQ has 13 domains. General characteristics of all measures are summarized in Tables 1 and 2.

Comparison of reliability

Internal consistency for the total score is reported for FS II(R), KINDL, PedsQL, and YQOL-R. In KINDL, PedsQL proxy-report version, and YQOL-R, all Cronbach alphas

for the total score exceeded the 0.70 level of group comparison. In the PedsQL self-report version and in FS II(R), 95% and 63% of the alphas for the total score were >0.70, respectively. Internal consistency for the domains is reported for all measures except for HUI 2. In CHIP-AE/CE, DISABKIDS, FS II(R), KIDSCREEN 52/27, and YQOL-R, all alphas for the domains exceeded the 0.70 level. Measures with nearly all alphas for the domains >0.70 were CHQ-CF/PF50 (93% and 86%) and the proxy- and self-report version of PedsQL (95% and 84%). Measures with <80% of alphas for domains >0.70 were TACQOL (69%), CHQ-PF28 (53%), and KINDL (33%).

ICC, Pearson correlation coefficients, and kappas were used to report test–retest reliability in the reviewed articles. Test–retest reliability for the total score is reported for FS II(R), HUI 2, PedsQL, and YQOL-R. All measured coefficients for the total score exceeded the 0.60 level. Test–retest reliability for the domains is reported for all measures except for FS II(R), KIDSCREEN 52, KINDL, and PedsQL self-report version. All coefficients for the test–retest reliability of the domains exceeded the 0.60 level for CHIP-AE/CE, DISABKIDS, KIDSCREEN 27, PedsQL proxy-report version, and YQOL-R. HUI 2 has 80% of its reported coefficients >0.60. Measures with <80% of coefficients >0.60 were TACQOL (73%), CHQ-PF50 (65%), CHQ-CF87 (60%), and CHQ-PF28 (50%). Reliability for all measures is summarized in Table 3.

Comparison of validity

Validity was assessed and reported differently in all studies, so a comparison was difficult to make. For most measures, content validity was assessed by the ability to

Table 1 General characteristics of health-related quality of life (HRQL) measures in children: number and titles of the domains

Measure	Number and titles of the domains
CHIP-AE	6 Discomfort, disorders, satisfaction with health, achievement, risks, resilience
CHIP-CE	5 Satisfaction, comfort, risk avoidance, resilience, achievement
CHQ-CF87	13 Physical functioning, role functioning: emotional/behavioral, role functioning: physical, bodily pain, general behavior, mental health, self-esteem, general health perceptions, parental impact: emotional,
CHQ-PF50	parental impact: time, family activities, family cohesion, change in health
CHQ-PF28	
DISABKIDS	6 Independence, physical limitation, emotion, social inclusion, social exclusion, treatment
FS II (R)	8 Communication, mobility, mood, energy, play, sleep, eating, toileting
HUI 2	6 Sensation, mobility, emotion, cognition, self-care, pain
KIDSCR-52	10 Physical well-being, psychological well-being, moods & emotions, self perception, autonomy, parent relation and home life, peers and social support, school environment, bullying, financial resources
KIDSCR-27	5 Physical well-being, psychological well-being, parent relations & autonomy, social support & peers, school environment
KINDL	6 Physical health, general health, family functioning, self-esteem, social functioning, school functioning
PedsQL4.0	4 Physical functioning, emotional functioning, social functioning, school functioning
TACQOL	7 Pain and symptoms, basic motor functioning, social functioning, school functioning
YQOL-R	4 Self, relationships, environment, general quality of life

Table 2 General characteristics of health-related quality of life (HRQL) measures in children: validated age range, how to report, rating scale, number of items, time needed to complete the measure

Measure	Age in years	Report	Rating scale	Number of items	Time in minutes
CHIP-AE	11–17	Self	3 to 5 point Likert scale	107	45
CHIP-CE	6–11	Proxy	3 to 5 point Likert scale	76	20
CHQ-CF87	10–18	Self	4 to 6 point Likert scale	87	20
CHQ-PF50	5–18	Proxy	4 to 6 point Likert scale	50	20
CHQ-PF28	5–18	Proxy	4 to 6 point Likert scale	28	5–10
DISABKIDS	4–16	Proxy or self	5 point Likert scale	37	10
FS II (R)	0–12	Proxy	3 point Likert scale	14	10
HUI 2	2–18	Clinician or proxy	Ordinal classification system	6	<5
KIDSCR-52	8–18	Proxy or self	5 point Likert scale	52	15–20
KIDSCR-27	8–18	Proxy or self	5 point Likert scale	27	10–15
KINDL	8–16	Self	5 point Likert scale	24	5–10
PedsQL4.0	2–18	Proxy or self	3 or 5 point Likert scale	23	5–10
TACQOL	6–15	Proxy or self	3 and 4 point Likert scale	108	10
YQOL-R	12–18	Self	11 point Likert scale	41	10–15

differentiate between healthy subjects and children with a disease. All measures were able to do so in a variety of diseases, except for KINDL, which could not differentiate between healthy and chronically ill children. No information about content validity was reported for CHIP-CE and KIDSCREEN 52. Construct validity was assessed by factor

analysis, by correlation with other instruments that aim to measure similar or different constructs, and by correlation with preknown information or clinical symptoms. Factor analysis was performed for CHIP-AE/CE, CHQ-PF50, KIDSCREEN 27, KINDL, PedsQL, and TACQOL and revealed that most items of these measures load most

Table 3 Internal consistency and test–retest reliability for health-related quality of life (HRQL) measures in children

Measure	Total, domain, subdomain	Internal consistency		Test–retest	
		Cronbach α	>0.70 (%)	ICC, κ , Pearson	>0.60 (%)
CHIP-AE	Domain	0.79–0.92	100	0.74–0.93	100
CHIP-CE	Domain	0.70–0.88	100	0.63–0.85	100
CHQ-CF87	Domain	0.54–0.97	93	0.06–0.84	60
CHQ-PF50	Domain	0.39–0.97	84	–0.30–1.00	65
CHQ-PF28	Domain	0.07–0.88	53	0.14–0.75	50
DISABKIDS	Domain	0.70–0.90	100	0.71–0.83	100
FS II(R)	Total	0.56–0.91	63	0.60–0.92	100
	Domain	0.83–0.93	100		
HUI 2	Total			0.90	100
	Domain			0.55–1.00	80
KIDSCR-52	Domain	0.76–0.90	100		
KIDSCR-27	Domain	0.78–0.84	100	0.61–0.74	100
KINDL	Total	0.71–0.95	100		
	Domain	–0.19–0.89	33		
PedsQL4.0 proxy-report	Total	0.74–0.94	10	0.78–0.88	100
	Domain	0.59–0.93	95	0.75–0.91	100
PedsQL4.0 self-report	Total	0.66–0.92	97	0.86	100
	Domain	0.39–0.90	84		
TACQOL	Domain	0.55–0.95	69	0.30–0.91	73
YQOL-R	Total	0.94–0.96	100	0.78	100
	Domain	0.77–0.99	100	0.74–0.85	100

highly on their conceptually derived scale. A summary of the information on content and construct validity for all measures is reported in Table 4.

Covering the ICF

Measures that covered more than six chapters of the ICF domains were CHIP-AE/CE, CHQ-CF87/PF50, DISABKIDS, KIDSCREEN 52, PedsQL, and TACQOL. CHQ-PF, HUI 2, and KIDSCREEN-27 covered six chapters; YQOL-R covered five chapters; KINDL covered four chapters, and FS II(R) covered three chapters. CHIP-AE covered the ICF domain body functions & structures best, with all chapters represented in the measure. Only one to four of the chapters of body functions & structures were covered by the other measures. CHIP-AE/CE, CHQ-CF87, and TACQOL covered ICF domains activities and participation best, with seven of nine chapters represented in the measures. Measures with less than half of the chapters of activities and participation covered were CHQ-PF28, FS II(R), HUI 2, KINDL, and YQOL-R (see Table 5).

Discussion

The 14 measures that resulted from the literature search performed differently on all four aspects that were looked at in this review. Measures that performed best on one level were outperformed on other levels and vice versa. For the purpose of this review, a measure should meet the criteria on all four aspects to be found suitable in measuring HRQL in children after major trauma. Most measures met the first criterion: “suitable for an age range of at least 10 years.” Measures that did not meet this criterion were CHIP-AE/CE, CHQ-CF87, KINDL, and YQOL-R. The second criterion was group comparison level for the internal consistency ($\alpha > 0.70$) and substantial test–retest reliability (kappa, ICC, Spearman or Pearson correlation coefficient >0.60) in at least 80% of the measurements of reliability. Measures that did not meet this criterion were CHQ-CF87/PF50/PF28, FS II(R), KINDL, and TACQOL. The third aspect looked at was the content and construct validity of the measures, which was confirmed for all measures. The fourth and final criterion was that the items covered more than six chapters of ICF domains. This criterion was met by all measures except for CHQ-PF28, FS II(R), HUI 2, KIDSCREEN-27, KINDL, and YQOL-R. So the measures that met all four criteria were DISABKIDS, KIDSCREEN 52, and PedsQL4.0.

Two earlier reviews also came to a recommendation after comparing the general characteristics and psychometric properties of pediatric HRQL measures. Willis et al. assessed outcome measures in pediatric trauma populations

[97]. They recommended PedsQL 4.0 for children >2 years of age because it captured both functional and QOL information, was quick to administer, covered a large age range, and had a self- and parent-proxy-report version. Eiser et al. reviewed generic and disease-specific measures of QOL in 2001 [98]. They recommended PedsQL for brief assessment during a regular clinic visit and CHQ where the goal is to improve family functioning or school integration. Other measures that performed well in current review: DISABKIDS and KIDSCREEN 52, were unfortunately not included in these two earlier reviews. In 2007, the European Consumer Safety Association (ECSA) developed guidelines for the conduction of follow-up studies measuring injury-related disability [99]. They chose EuroQoL-5D (EQ-5D) in combination with HUI 3 as the preferred common core to measure functional outcome after injury in patients aged 5 years or older. The ECSA assessed the content of the measures related to ICF domains. However, the psychometric properties of the measures were not considered. EQ-5D and HUI 3 were not included in this review because the measures were developed for adults and have not yet been sufficiently validated in children.

Strengths and limitations

The two largest biomedical databases (Medline and EMBASE) were searched for validation studies of HRQL measures for children. Despite the extensive search strategy, some relevant related articles were not found initially. Perhaps the addition of more synonyms for quality of life could have overcome this limitation. Another option is to search more databases, for example, the psychological database PsycINFO. However, it seems that no measures were missed. The pediatric HRQL measures included in the most recent review articles corresponded mostly with the measures that were included in this review [97, 100–102]. The How are You (HAY) was excluded because it also contained disease-specific questions. The Exeter HRQL and the Generic Child Questionnaire (GCQ) were excluded because psychometric properties were reported insufficiently. No measures were included that had not been reviewed previously.

The articles were screened for meeting the inclusion criteria. Because no trauma-specific HRQL measure is available for children, generic measures were selected. To make comparison of psychometric properties possible, only measures were included for which validity and reliability was reported. Results were limited to validation studies performed in Western countries, because culture is hypothesized to have a great impact on the psychometric properties of the measure. Only measures that have an English or Dutch version were included, because the English language is most used in Western society, and

Table 4 Content and construct validity for health-related quality of life (HRQL) measures in children

Measure	Content validity Differentiates health & disease	Construct validity Factor analysis, correlation with instruments, preknown information, clinical symptoms, etc.
CHIP-AE	Healthy \neq illness School population \neq illness	Most items correlate most highly with the sub-domain in which they had originally been placed (factor analysis). Differentiates in predicted direction between four groups of teenagers known to differ in their current health status
CHIP-CE	Healthy \neq major chronic illness	Basic conceptual framework is supported by factor analysis. Emotional discomfort correlates (r 0.63) with Baltimore How I Feel scale. Self-esteem correlated with CHQ satisfaction (r 0.58). Limitation of activity correlates (r 0.53) with CHQ physical functioning scale
CHQ-CF87	Healthy \neq illness Norm \neq diabetes Healthy \neq chronic health condition	Presence of diabetes symptoms and concerns correlated with lower physical and psychosocial functioning of CHQ. In asthma 7 of 9 dimensions of the CHQ correlate with the Child Health Assessment Questionnaire. The CHQ correlated with the KINDL on the domains: physical, emotional, and self esteem
CHQ-PF50	Norm \neq diabetes Norm \neq diabetes Healthy \neq chronic health condition	CHQ scales loaded highest on their hypothesized vector (factor analysis). Strong correlations between CHQ bodily pain and HUI 2/HUI 3 pain scales (r 0.51–0.60), and between CHQ mental health and HUI 2/HUI 3 emotion (r 0.53–0.64). CHQ is correlated with symptom severity in Juvenile Chronic Arthritis (JCA) and symptom activity in asthma
CHQ-PF28	Healthy \neq HIV Healthy \neq chronic health condition	Severity of sickle cell disease correlates with mean physical summary score. All correlation coefficients between CHQ domains and the visual analog scale rating of the child's health are positive and significant
DISABKIDS	Healthy \neq severe health condition	Differentiates between levels of severity of asthma and arthritis. Correlations were highest with dimensions of HRQL measures evaluating similar concepts
FS II(R)	Healthy \neq medical problems/ complaints	Moderate correlation with clinical rating. Negatively correlated with days hospitalized, days absent from school, and days in bed
HUI 2	Off treatment \neq on treatment	HUI 2/3 pain correlates with CHQ bodily pain (r 0.51–0.60). HUI 2 mobility correlates with CHQ physical functioning (r 0.45–0.58). HUI 2/3 emotion correlates with CHQ mental health (r 0.53–0.64). Important differences in HRQL scores between patients, parents, and physicians
KIDSCR-52	?	Strong correlation with KIDSCREEN-27 (r 0.63–0.96). High correlation with KINDL for dimensions assessing similar constructs (r 0.51–0.68)
KIDSCR-27	Healthy \neq physically ill Healthy \neq mentally ill	Strong correlation with KIDSCREEN-52 (r 0.63–0.96). Moderate to high correlation with other HRQL measures assessing similar constructs (r 0.36–0.63). Correlation with psychosomatic complaints (r 0.52)
KINDL	Healthy \neq DM Healthy = chronically ill	KINDL physical correlates with CHQ physical scales (r -.38–0.55). KINDL emotional and self esteem correlates with CHQ mental health and self esteem (r 0.41–0.62). Factor solution in line with the original subscales. Strong correlation with the Short Form-36 for mental health and physical functioning (r 0.53–0.86)
PedsQL4.0	Healthy \neq chronic health condition (CP, ADHD, headache, asthma, DM, cancer, rheumatic disease) On \neq off treatment	Most PedsQL items load most highly on their conceptually derived scale (factor analysis). Significant correlations in the expected direction with the PedsMIDAS total score (headache-specific measure of disability). Negatively correlated with the GMFCS score. Discriminates between children with extremity fractures and children with traumatic brain injury. Related to indicators of morbidity and illness burden. Change over time as a result of clinical intervention
TACQOL	Healthy \neq chronic diseases, medical treatment	Almost all items (93%) loaded higher on their own factors than on other factors. Correlation between TACQOL and KINDL (r 0.24–0.60). Mean correlation between contextual similar domains of the EuroQoL and the TACQOL was –0.55)
YQOL-R	Healthy \neq chronic health condition	All scales correlate highly with the scales of the KINDL. Low correlation with two measures assessing different constructs: the Functional Disability Inventory and the Children's Depression Inventory

Table 5 Number of items on the chapters of International Classification of Functioning, Disability and Health (ICF) of pediatric health-related quality of life (HRQL) measures

	CHIP-AE	CHIP-CE	CHIP-CF87	CHQ-PF50	CHQ-PF28	CHQ-DISABKIDS	FS (R)	HUI 2	KIDSCR-27	KIDSCR-27	KINDL	PedsQL	TACQOL	YQOL-R
Body functions & structures														
BS 1 Structures of the nervous system and mental functions	17	10	16	7	4	8	11	2	22	10	12	8	20	13
BS 2 The eye, ear and related structures, sensory functions and pain	10	5	3	2	1			2			1	1	5	
BS 3 Voice and speech and the structures involved	3		1					1						
BS 4 F&S of the cardiovascular, immunological, and respiratory systems	11	2												
BS 5 F&S of the digestive, metabolic, and endocrine systems	7													
BS 6 F&S of the genitourinary and reproductive systems	6													
BS 7 Neuromusculoskeletal and movement-related F&S	6													
BS 8 F&S of the skin and related structures	6	1												
Activities & participation														
D 1 Learning and applying knowledge	1	4		2		1		1					4	2
D 2 General tasks and demands	3	3				1			1					4
D 3 Communication			1						1				3	
D 4 Mobility	11	5	7	5	3	1		1	2			4	6	
D 5 Self-care	30	3	1	1				1				1	4	
D 6 Domestic life			1					1				1		
D 7 Interpersonal interactions and relationships	25	27	18	8	4	9	1	16	8		6	3	9	14
D 8 Major life areas	14	4	1	1	1	1		4	3		1	3	2	1
D 9 Community, social, and civic life	4	2	4	3	2	2		3	1		1	1	3	
Other	59	11	34	21	13	14	1	0	4	3	4	2	8	6
F&S functions and structures														

Dutch is the language of interest of the research group. Another reason was that for comparison of the content of the measures the researcher should fully understand the items. Two French questionnaires, the Vecú de Santé Perçué Adolescent (VSP-A) and the Duke Health Profile (DUKE HP), were therefore excluded.

The number of available references for each measure is quite variable in this review. Some measures were assessed on the basis of only one reference, whereas other measures have 26 references for assessment. More references lead to a more reliable assessment of the psychometric properties of the measure. Unfortunately, internal consistency was not reported for HUI 2, no test–retest was reported for KINDL, and no content validity was reported for KIDSCREEN 52. It is questionable whether the reported information on content validity—the ability to discriminate between health and disease—is really that interesting in a trauma population. It seems much more important for an HRQL measure to distinguish between subjects with injuries of different severity levels. Unfortunately, this information is lacking in current literature for all the included HRQL measures. In fact, PedsQL 4.0 is the only HRQL measure validated in children after trauma at all [10]. Comparison of general characteristics and covering ICF chapters of activities and participation are not influenced by the number of references.

Strength of this review is comparison of HRQL measures on four levels: age range, reliability, validity, and content related to ICF. Earlier reviews on generic HRQL measures in children report general characteristics and psychometric properties [97, 98, 100–104]. The age range for which the measure is suitable, domain titles, number of items, and time needed to complete the questionnaire is often described. Internal consistency of the measures is reported by Ravens-Sieberer et al., Willis et al., Rajmil et al., and Connolly et al., and the last two also reported test–retest reliability [97, 101–103]. Only Rajmil et al. report on the content of the measures [102]. They placed the dimensions of the questionnaires in one of three domains: physical, psychological, or social. No previous review compares HRQL measures for children on all four levels looked at in our review. An interesting concept that was considered as fifth level in this review was the responsiveness of the measure. Terwee et al. divided responsiveness of HRQL instruments into three categories: (1) the ability to detect change in general, (2) the ability to detect clinically important change, and (3) the ability to detect real changes in the concept being measured [105]. They also eliminated 31 measures of responsiveness after an extensive literature search.

All items of HRQL measures were placed into the chapters of ICF domains. This provided a clear overview of the content of the measures related to ICF. Most

measures covered the chapters of activities and participation much better than the chapters of body functions & structures. This implies that in children, activities and participation are considered of more importance for HRQL than are body functions & structures. Sometimes placement of an item was difficult, because multiple interpretations of the item were possible. Especially when it came to cognitive functions, distinction between body functions and activities was often not very clear. Furthermore, many items could not be placed in one of the ICF chapters. The constructs measured by these items were often too broad to be placed in one chapter. Also, items about personal or environmental factors, feelings, and emotions could not be placed in the chapters of the three ICF domains. The fact that many items could not be placed in ICF implies that HRQL is a broader concept than health status as defined by ICF.

Conclusion

Based on the results of this review, DISABKIDS, KIDSCREEN 52, and PedsQL4.0 seem to be most suitable to measure HRQL of children over the long term after major trauma. They cover a large age range, have good psychometric properties, and cover the ICF content substantially.

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